

# Community-wide End-of-life /Palliative Care Initiative



## Community Conversations on Compassionate Care

# Advance Care Planning

**Know your choices, share your wishes:**

**Maintain control, achieve peace of mind,  
and assure your wishes are honored.**



**Compassion and Support**  
at the End of Life

[CompassionAndSupport.org](http://CompassionAndSupport.org)





Dear Fellow Citizens,

What would happen if you experienced a sudden illness that prevented you from making your own medical decisions? How would you ensure that you receive the kind of care that you wanted? Would your family or loved ones know enough about what you value and believe to feel comfortable about making decisions about your care?

According to the 2008 End-of-life Care Survey of Upstate New Yorkers, nearly nine of ten local adults said it is important to have someone close to them making medical decisions for them if they were to have an irreversible terminal condition and were unable to make these decisions. Yet less than half have designated a spokesperson (a "Health Care Agent", known as a "Durable Power of Attorney for Health Care" in other states) to assure their wishes are carried out.

With the input of more than 150 community volunteers, the Community-wide End-of-life/Palliative Care Initiative developed a two-step approach to advance care planning that is outlined in this comprehensive Advance Care Planning booklet. A Spanish version of the booklet is available. Section One outlines the Community Conversations on Compassionate Care (CCCC) Program that encourages all adults 18 and older to start a conversation and use **Five Easy Steps** to complete an advance directive:

1. Learn about Advance Directives
  - New York State Health Care Proxy and Living Will
  - Advance Directives from other States
2. Remove Barriers
3. Motivate Yourself - View the CCCC videos
4. Complete Your Health Care Proxy and Living Will
  - Have a conversation with your family and health care provider
  - Choose the right Health Care Agent
  - Discuss your values, beliefs and what is important to you
  - Understand life-sustaining treatment
  - Share copies of your completed advance directives
5. Review and Update

Section Two describes the Medical Orders for Life-Sustaining Treatment (MOLST) Program that was developed for those who are seriously ill or near the end of their lives to ensure a person's end-of-life wishes are followed whether the person is at home, in a nursing home, in a hospital or in any community setting. In July 2008, Gov. David A. Paterson signed into law a bill that makes MOLST a permanent, statewide program. The New York State Department of Health's (DOH) revised MOLST form (DOH-5003) is included in this booklet, easy to understand and aligns with the Family Health Care Decisions Act (FHCDA). Both became effective on June 1, 2010. The FHCDA **DOES NOT** eliminate the need for open and honest conversations with loved ones about your wishes and desires for medical care and completion of advance directives.

We are pleased to produce this revised Advance Care Planning booklet on behalf of the Community-wide End-of-life/Palliative Care Initiative to help individuals "Know Your Choices and Share Your Wishes." While advance directives may differ from state to state, the advance care planning process outlined in this booklet is the same. Additional information to assist in medical decision-making is available at the community website [CompassionAndSupport.org](http://CompassionAndSupport.org). Complete your advance directive today!

Sincerely yours,

*Patricia A. Bomba MD*

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Leader, Community-wide End-of-life/Palliative Care Initiative  
Chair, MOLST Statewide Implementation Team



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## Step 1: Learn about Advance Directives

### Advance Care Planning: What is it?

Advance Care Planning (ACP) is a process of planning for future medical care in case you are unable to make your own medical decisions. It is a continual process and not merely a document or isolated event. Advance Care Planning assists you in preparing for a sudden unexpected illness, from which you expect to recover, as well as the dying process and ultimately death.



Advance Care Planning is a gift to you and your family. It allows you to maintain control over how you are treated and to ensure that you experience the type of care and the type of death that you desire.

The Advance Care Planning process involves the following:

- Becoming educated about the topic
- Removing barriers or reasons for not completing the process
- Motivating yourself to “Know Your Choices and Share Your Wishes” with your loved ones and health care providers
- Exploring, clarifying, and documenting your values, beliefs and goals
- Choosing a spokesperson (the “Health Care Agent” identified in the Health Care Proxy, known as a “Durable Power of Attorney for Health Care” in other states) and an alternate spokesperson (the “alternate Health Care Agent” identified in the Health Care Proxy) to work with doctors to make medical decisions on your behalf in case you are unable to speak for yourself
- Reviewing your wishes and desires about death and dying as well as organ donation with your spokesperson, alternate spokesperson, and the people you trust and/or those whose decisions will impact the manner in which you die (e.g. family, close friends, spiritual advisor, doctors, lawyers)
- Completing the New York Health Care Proxy and Living Will forms (also known as Advance Care Directives, or Directives) or Advance Directives from other States that identify your spokesperson and alternate spokesperson and specify your desires and wishes. Put it in Writing!
- Reviewing and updating these forms periodically or after major life-altering events
- Conducting *ongoing* discussions and updates about your wishes and desires about death with your spokesperson, alternate spokesperson, those you trust and/or those who may care for you when you are approaching death

Advance Care Planning begins with conversations among families and other trusted individuals, such as close friends, doctors, etc. The process builds trust and establishes relationships among family, close friends, health care professionals and others who will care for you or be with you as you approach death. **Advance Care Planning permits peace of mind for you and your family by reducing uncertainty and helping to avoid confusion and conflict over your care.**

**Remember:** Directives apply **only** when the need arises and you are unable to make your own medical decisions.

Learn more about **Advance Care Planning** at [CompassionAndSupport.org](http://CompassionAndSupport.org).

## Information about the Forms

This booklet contains two types of **Advance Directives** that protect your right to request treatments *you want* and to refuse medical treatments *you do not want* in case you lose the ability to make medical decisions yourself:

1. The **New York Health Care Proxy** is a legal document that lets you name someone to make decisions about your medical care, including decisions about life-sustaining treatment. The Health Care Proxy form appoints someone to speak for you *any time you are unable to make your own medical decisions, not only at the end of life*.
2. The **New York Living Will** lets you state your wishes about medical care in the event that you develop an *irreversible* condition that prevents you from making your own medical decisions. The Living Will becomes effective if you become terminally ill, permanently unconscious or minimally conscious due to brain damage and will never regain the ability to make decisions. Persons who want to indicate under what set of circumstances they favor or object to receiving any specific treatments use the New York Living Will.



You do not need to notarize your New York Health Care Proxy form or New York Living Will.

You do not need a lawyer to fill out these forms.

These documents will be legally binding only if the person completing them is a competent adult (at least 18 years of age); the documents are properly signed, witnessed and dated; and the documents are available when needed.

## Frequently Asked Questions

### **1) Do I need to complete both of these documents?**

Completing both documents helps to ensure that you receive the medical care you desire. However, you should continue to have ongoing discussions with your spokesperson to assure that that person knows your values and wishes and can speak on your behalf regardless of what your circumstances may be.

In addition, it is beneficial to have completed both documents in case you suffer an injury or acute medical episode while traveling and are unable to make medical decisions for yourself. Completing both documents increases the likelihood that at least one of the documents will be legally recognized in another state.

### **2) How can I be sure that my New York Health Care Proxy will be honored?**

To be legally valid, you must sign and date your Health Care Proxy form in the presence of **two** adult witnesses. The witnesses must sign a statement in your Health Care Proxy to confirm that you signed the document willingly and free from duress. Your spokesperson and alternate spokesperson cannot act as witnesses.

### **3) How do I make sure that my New York Living Will is going to be honored?**

Unlike most states, New York does not have a specific law recognizing living wills but relies upon "clear and convincing evidence" of your wishes. Documenting your wishes in a Living Will may help to show the required level of "clear and convincing evidence." You should follow the witnessing procedures established in the Health Care Proxy Act and sign your Living Will in the presence of two adult witnesses.



**4) Can I list more than one alternate spokesperson?**

Yes, you may list as many as you would like. However, each alternate spokesperson must meet the criteria listed on page 7 (see "What to Keep in Mind When Choosing a Spokesperson").

**5) Do I need to add personal instructions to my New York Health Care Proxy?**

You do not need to add personal instructions to your Health Care Proxy except regarding artificially administered fluids and nutrition. One of the strongest reasons for naming a spokesperson is to have someone who can respond *flexibly* to changes in your medical situation. Adding personal instructions to the New York Health Care Proxy may unintentionally restrict your spokesperson's power to act in your best interest.

**6) Can I add personal instructions to my Living Will?**

Yes. Personal instructions may be added to the section titled "Other Directions." If there are specific treatments you wish to refuse that are not already listed on the document, you may list them here. Also, instructions such as "I want maximal pain medications, even if it hastens my death," "I do not want to be placed in a nursing home," or "I want to die at home" can be added to this section. If you have appointed a spokesperson, it is a good idea to include a statement such as, "Any questions about how to interpret or when to apply my Living Will are to be decided by my spokesperson."

**7) What are life-sustaining treatment such as cardiopulmonary resuscitation (CPR), intubation and mechanical ventilation, and artificially administered fluids and nutrition?**

See page 9 and 10 of this booklet for a detailed explanation of life-sustaining treatment.

**8) What if I change my mind about my New York Health Care Proxy or Living Will?**

You may revoke your New York Health Care Proxy or Living Will by notifying your health care provider or spokesperson orally or in writing of your revocation, or by any other act that clearly shows your intent to revoke the document. Once informed, your physician must record the revocation in your medical record and notify your spokesperson and any medical staff responsible for your care. Additionally, an updated form voids any previous forms.

**9) If I live in another state or spend extended periods of time in another state, will my New York or other state-specific advance directives be honored in that state?**

Each state has its own laws governing Advance Care Planning and the use of Health Care Proxy forms, Living Wills, MOLST and DNR Orders. Therefore, it is important that you investigate that state's laws on Advance Care Planning. You may want to begin by checking out the state's Department of Health website or going to [caringinfo.org](http://caringinfo.org) where you can find Advance Directives from other States.

**10) Are there any restrictions on who can be my spokesperson?**

Your spokesperson **cannot** be:

- a. An operator, administrator or employee of a health care facility in which you are a resident or patient, or to which you have applied for admission, at the time you sign your proxy, unless that person is a relative by blood, marriage or adoption;
- b. A physician, if that person also acts as your attending physician.

**11) What do I do if I am a resident in a facility licensed or operated by the Office of Mental Health or the Office for People with Developmental Disabilities?**

Special witnessing requirements exist for residents of facilities operated or licensed by the Office of Mental Health or the Office for People with Developmental Disabilities (OPWDD). For more information, in NYS, contact OPWDD at <http://www.omr.state.ny.us/>, or call 1 (866) 946-9733 or contact the National Hospice & Palliative Care Organization, a non-profit organization dedicated to ensuring excellent end-of-life care, at [caringinfo.org](http://caringinfo.org), or call 1 (800) 989-9455.

## Step 2: Remove Barriers

Common reasons given for not completing a Health Care Proxy form in the 2008 [End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions](#)\* include:

- **Don't need it/don't think it's important:** Acute illness or injury can occur unexpectedly at any time.
- **Don't know enough about it:** You have begun by reading this ACP booklet. For more information, visit [CompassionAndSupport.org](#).
- **Too young to be concerned about it:** Acute illness or injury can occur unexpectedly at any time and knows no age boundary.
- **Not having the time/haven't gotten around to it:** ACP is an important aspect of planning, similar to creating a financial plan and legal planning like writing a will.
- **Not knowing where to get the forms:** All the necessary forms are contained in this ACP booklet and also on the website [CompassionAndSupport.org](#).
- **Don't know whom to designate as my Health Care Agent:** Read more about how to choose your spokesperson.
- **Uncomfortable thinking about such things:** If you are uncomfortable, you are not alone. Talking about death can be difficult but conversation does not make death happen.

## Step 3: Motivate Yourself

If you are having difficulty beginning the conversation, start with stories that show how advance care planning helps to maintain control, achieve peace of mind and is an important step in assuring that personal wishes are honored. Knowing what is important to an individual can reduce the burden of decision-making and avoid potential conflict and confusion for loved ones. Ten personal stories and the Five Easy Steps are highlighted in the [Community Conversations on Compassionate Care](#) videos that are available on-line in the Compassion And Support Video Library\*\* at the [CompassionAndSupport.org](#) website.

## Step 4: Complete Your Health Care Proxy and Living Will

### Have a Conversation with Your Family and Health Care Provider: Avoid Problems

Problems may arise if you fail to plan or fail to share your wishes with your health care spokesperson, your family or your doctor. Problems may arise if your goals for care or treatment change but these wishes are not reflected in your documented forms. At times, an individual's preferences may be unclear or the focus may be too narrow. As a spokesperson, it is important to avoid making assumptions and to clarify wishes ahead of time.



Be sure to talk to your health care spokesperson, alternate spokesperson(s), doctor(s), spiritual advisor, family and close friends about your wishes concerning medical treatment. Discuss your wishes with them often, particularly if your medical condition changes.

Be aware that your New York documents will not be effective in the event of a medical emergency. Ambulance personnel are required to provide cardiopulmonary resuscitation (CPR) unless they are given a separate order that is called a Do Not Resuscitate Order (DNR). Read more on DNR and the Medical Orders for Life-Sustaining Treatment (DOH-5003 MOLST) in this booklet and at [CompassionAndSupport.org](#). Information on programs in other states can be found at [POLST.org](#).

\*<https://www.excellusbcbcs.com/wps/wcm/resources/file/eb856805385613f/End%20of%20Life%20survey-EX.pdf>

\*\*[http://www.compassionandsupport.org/index.php/resource\\_directory/compassion\\_and\\_support\\_video\\_library/public\\_service\\_announcements\\_videos](http://www.compassionandsupport.org/index.php/resource_directory/compassion_and_support_video_library/public_service_announcements_videos)

## Choose the Right Health Care Agent or “Spokesperson”

It is important to choose the right health care spokesperson (identified in the Health Care Proxy, or Advance Directives from other States) because **this person will assure that your wishes are carried out based on your previously expressed and discussed values and beliefs.** In addition, you should also choose the right alternate spokesperson (identified in the Health Care Proxy, or Advance Directives from other States) to substitute if your primary spokesperson is unable or unavailable. In some states, a Health Care Agent is known as a “Durable Power of Attorney for Health Care.”



You indicate your spokesperson and alternate spokesperson using a legal document called the New York Health Care Proxy, or Advance Directives from other States. This form identifies your spokesperson – the individual you have designated to make decisions about your medical care – including decisions about life-sustaining treatment – if you can no longer decide for yourself.

## What to Keep in Mind When Choosing a Spokesperson

This person must:

- Meet legal criteria (competent adult, at least 18 years old)
- Be willing to speak on your behalf
- Be willing to act on your wishes
- Be able to separate his/her own feelings from yours
- Live close by or be willing to come
- Know you well
- Understand what is important to you
- Be willing to talk with you now about sensitive wishes
- Be willing to listen to your wishes
- Be able to work with those providing your care to carry out your wishes
- Be available in the future
- Be able to handle potential conflicts between your family, close friends
- Be able to handle responsibility

## Questions for the Person That You Might Designate as Your Spokesperson

Your spokesperson may be required to speak for you in a variety of circumstances. These situations might include those in which your desires may not mesh with the opinions and beliefs of either your spokesperson or others concerned about your welfare. **Below are questions to discuss with the individual(s) you may be considering choosing as your spokesperson.** Discussing these questions with a potential spokesperson beforehand will help you feel confident that the person chosen for this function is the best one to decide for you when you cannot do so.

1. Will you respect my wants and needs, even if they are different from what they used to be, or if you think they are unusual or foolish?
2. If I cannot communicate for myself, will you make sure that what I have asked is done, even if you would make different choices yourself?
3. Will you talk with me openly and lovingly about any unfinished business between us and listen if I need to apologize or ask for forgiveness for anything that has hurt you in the past?
4. Will you talk with me about my coming death – my fears, my sorrows, my joys and gratitude?
5. Will you care for yourself so that you are not drained by my illness?
6. Will you stay with me even if the going gets rough?
7. Will you seek out information about my disease and what to expect as I get sicker and near the end of life?

## Discuss Your Values, Beliefs and What is Important to You



Many people have strong opinions about what would be important to them at the very end of their lives. Others want to make sure that certain things they dislike or fear will be avoided. Therefore, it is important for you to take some time to explore your own values and beliefs.

After investigating your values and beliefs, it is important that your spokesperson and alternate spokesperson, family, close friends, spiritual advisor, physicians, and lawyer understand your specific values and beliefs. Below are some questions for you to think about and discuss with your spokesperson and alternate spokesperson in order to make sure that he/she understands you and can act on your behalf.

### Exploratory Questions: Your Feelings about End-of-Life Care

What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

What are your biggest hopes about the end of your life?

What are your biggest fears about the end of life?

*Instructions: For each row, check one answer to express how important these issues would be to you if you were dying.*

	Not Important	Moderately Important	Very Important	Extremely Important
<b>a.</b> Avoiding pain/suffering, even if it means that I might not live as long				
<b>b.</b> Being alert, even if it means I might be in pain				
<b>c.</b> Being around my family and close friends				
<b>d.</b> Being able to feel someone touching me				
<b>e.</b> Having religious or spiritual advisors at my side when I die				
<b>f.</b> Being able to tell my life story and leave good memories for others				
<b>g.</b> Reconciling differences and saying "good-bye" to my family and close friends				
<b>h.</b> Being at home when I die				
<b>i.</b> Being in a hospital when I die				
<b>j.</b> Being kept alive long enough for my family to get to my bedside to see me before I die, even if I'm unconscious				

The information contained within this page is from the ©EPEC Project, The Robert Wood Johnson Foundation, 1999.

## Understand Life-Sustaining Treatment

Note: In New York State, it is essential for your spokesperson to know your wishes about artificially administered fluids and nutrition. Documentation of these wishes is vital.

According to New York State Public Health Law, if you fail to include your wishes on artificially administered fluids and nutrition, your spokesperson **cannot** make these decisions.

The statement “My agent does know my wishes regarding artificial nutrition and hydration” as noted in the New York Health Care Proxy form included in this booklet is sufficient to allow your spokesperson to make these decisions.

Life-sustaining treatment or life support replaces or supports ailing bodily function. When patients have curable or treatable conditions, life support is used temporarily until the illness or disease can be stabilized and the body can resume normal functioning. At times, the body never regains the ability to function without life-sustaining treatment.

When making decisions about specific forms of life-sustaining treatment, gather the facts you need to make informed medical decisions. In particular, understand the benefit as well as the burdens that the treatment will offer you or your loved one. A treatment may be beneficial if it relieves suffering, restores functioning, or enhances the quality of life. The same treatment can be considered burdensome if it causes pain, prolongs the dying process without offering benefit, or detracts from a person's quality of life. When gathering information about specific treatments, understand why the treatment is being offered and how it will benefit your care.

Given the rapid advances in medicine and technology, it is difficult to know all of the possible treatment choices in advance. This is why taking the time to clarify values and beliefs and to discuss personal goals of medical care is so important.

## Understand How to Make Medical Decisions

When making decisions about life-sustaining treatment, it is important to consider the following questions:

- Will the treatment make a difference?
- Do the burdens of treatment outweigh the benefits?
- Is there hope for recovery? If so, what will life be like afterward?
- What do I value? What is important? What is the goal for my medical care?

Difficulty in decision-making arises when recovery cannot be predicted. In this case, a short-term trial of life-sustaining treatment may be desired. These trials must begin with clarifying the patient's goals of care and require active discussions between your doctor and your spokesperson about the most appropriate course of treatment. The patient's goals for medical care should drive the choice of interventions.

Additional information to help make decisions regarding life-sustaining treatment can be found at [CompassionAndSupport.org](http://www.compassionandsupport.org)\*.

\* [http://www.compassionandsupport.org/index.php/for\\_patients\\_families/life-sustaining\\_treatment](http://www.compassionandsupport.org/index.php/for_patients_families/life-sustaining_treatment)

## Commonly Used Life-Sustaining Treatment:

- **Cardiopulmonary resuscitation:** Cardiopulmonary resuscitation (CPR) involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving. However, the success rate is extremely low for people who are at the end of a terminal disease process. Critically ill patients who receive CPR have a small chance of recovering. Patients who choose a DNR order indicate that they do not wish to have medical personnel attempt resuscitation in an emergency and prefer to allow natural death.
- **Intubation and mechanical ventilation:** Intubation and mechanical ventilation involves placing a tube down the patient's throat that is connected to a breathing machine (a ventilator or respirator) that pumps air into and out of the lungs. Mechanical ventilation is used to support or replace the function of the lungs. Mechanical ventilation is often used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists. Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important for them. For the dying patient, however, mechanical ventilation often merely prolongs the dying process until some other body system fails. It may supply oxygen but it cannot improve the underlying condition. If a patient chooses not to be intubated and placed on a breathing machine, treatments are available for shortness of breath, such as oxygen and morphine.
- **Artificially administered fluids and nutrition (also referred to as, "artificial hydration and nutrition"):** When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. Artificially administered fluids and hydration can save lives when used until the body heals. Long-term artificially administered fluids and nutrition may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them. Long-term use of feeding tubes is frequently given to people with irreversible and end-stage conditions. For these patients, the treatment will not reverse the course of the disease itself or improve the quality of life and very often causes more harm than good.

The distinction often is made between not starting treatment and stopping treatment. **However, no legal or ethical difference exists between withholding and withdrawing a medical treatment in accordance with a patient's wishes.** If such a distinction existed in the clinical setting, a patient might refuse treatment that could be beneficial out of fear that once started it could not be stopped.

It is legally and ethically appropriate to discontinue medical treatments that are no longer beneficial. It is the underlying disease, not the act of withdrawing treatment, which causes death.

Additional information to help make decisions regarding life-sustaining treatment can be found at [CompassionAndSupport.org](http://CompassionAndSupport.org)\*.

The booklet "Hard Choices" is an excellent reference and can be found at [hardchoices.com](http://hardchoices.com). A Spanish version of this booklet is also available.

\* [http://www.compassionandsupport.org/index.php/for\\_patients\\_families/life-sustaining\\_treatment](http://www.compassionandsupport.org/index.php/for_patients_families/life-sustaining_treatment)

## Practical Issues to Consider after Completing Your Documents

### Share Copies of Your Completed Advance Directives: Assure Accessibility

Guarantee accessibility to your New York Health Care Proxy and Living Will or Advance Directives from other States.

- Keep a copy for yourself in a secure place. Do not put the documents in a safe deposit box or any other security box that would keep others from having access to them.
- Give a copy to your spokesperson and alternate spokesperson, your primary care physician, all specialist physicians who participate in your care and the primary hospital where you receive care. You may wish to give a copy to your spiritual advisor.
- A copy should be shared with an electronic registry, if one exists in the community.
- If you enter a nursing home or hospital, have photocopies of your documents placed in your medical records.

### Talk to Your Doctor

Your doctor and the other health care professionals caring for you when you are seriously ill or dying may play an important part in assuring that your wishes are understood and met. Work with your physician and consider asking your physician to fill out a Medical Orders for Life-Sustaining Treatment (MOLST) form. It is important to speak to your doctor and other health care professionals ahead of time about what is important to you. At that time, ask them questions about the kind of support you think you may need and whether they think that they could provide this support to you.

You have a right to participate in the planning of your health care even if you lose the capacity to make medical decisions. An advance directive gives you the ability to exercise this right. Physicians have a legal, moral, and professional responsibility to assure this right is honored.

Questions individuals have asked their doctors and other health care professionals:

1. Will you acquaint yourself with the social norms of my culture and religion and respect these?
2. Will you talk openly with me and/or my family about my illness?
3. What will you do if I have a lot of pain or other uncomfortable symptoms?
4. Will you let me know if treatment stops working so that my family and I can make appropriate medical decisions?
5. Will you support me in having my pain properly managed and in getting hospice care?
6. What will you do to make sure that you always listen to me and/or my family?
7. If I reach a point where I am too sick to speak for myself, how will you make decisions about my care?
8. Will you still be available to me even when I'm sick and close to the end of my life?

### Step 5: Review and Update

Review and update your forms periodically.

- Review after major life events like divorce, birth of a child or death of a spouse, as you may wish or need to choose a new spokesperson
- Reevaluate your wishes if new life-threatening or chronic illnesses develop, as these chronic illnesses progress, and after complicated life-sustaining treatment. Your wishes and desires may change after these events
- If your wishes change after your documents have been completed, an entirely new set of documents reflecting your new wishes must be written, signed, dated and witnessed. Give a new set of the documents to your health care spokesperson and alternate spokesperson, your primary care physician, all specialist physicians who participate in your care and the primary hospital where you receive care. These will replace the old version.

## Medical Orders for Life-Sustaining Treatment (MOLST)

Surveys have shown that people are not dying in the setting of their choice, most do not have advance directives in place, the majority of those being referred to hospice arrive too late to fully benefit, and most fear dying in pain and without dignity or control.



### **What is the MOLST Program?**

The MOLST program is designed to improve the quality of care people receive at the end of life. The MOLST program is based on the belief that individuals have the right to make their own medical decisions, including decisions about life-sustaining treatment, to describe these wishes to health care providers, and to receive comfort care while wishes are being honored. MOLST is based on effective communication of patient wishes, documentation of medical orders on a bright pink form and a promise by health care professionals to honor these wishes.

### **What is the MOLST form?**

The MOLST form is a bright pink medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form, based on the patient's current medical condition, values, wishes and MOLST Instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the Health Care Agent or Surrogate.

MOLST includes medical orders based on patient preferences regarding cardiopulmonary resuscitation, intubation and mechanical ventilation, artificially administered fluids and nutrition, future hospitalization and transfer, antibiotics, treatment guidelines and other instructions. The MOLST is approved by the New York State Department of Health for use in all settings statewide.

### **Must all health care professionals follow the medical orders on the MOLST form?**

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

### **Who should have a MOLST form?**

MOLST is generally for patients with serious health conditions (advanced progressive chronic illness or terminal illness) and others who are interested in further defining their care wishes as they are facing the end of life. The patient or other decision-maker should work with the physician and consider asking the physician to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment
- Wants to allow natural death and avoid efforts to attempt cardiopulmonary resuscitation (CPR) when the heart stops or breathing stops
- Resides in a long-term care facility or requires long-term care services
- Might die within the next year

### **How is the MOLST form completed?**

Completion of the MOLST begins with a conversation or a series of conversations between the patient, the Health Care Agent or the Surrogate and health care professionals that defines the patient's goals for care, reviews possible treatment options on the MOLST form, and ensures the decision-maker understands the decisions made about life-sustaining treatment. If a patient is not ready to discuss or make a decision regarding a specific life-sustaining treatment, full treatment will be provided.



### **Who signs the MOLST form?**

A licensed physician must always sign the MOLST form. If the physician is licensed in a border state, the physician must insert the abbreviation for the state in which he/she is licensed, along with the license number.

### **Who makes medical decisions on the MOLST form?**

Patients are presumed to have the ability to make medical decisions about life-sustaining treatment unless a physician and another health or social service practitioner determines the patient is unable to make such decisions, in accordance with the Family Health Care Decisions Act (FHCDA).

If the patient has the ability to make medical decisions, the patient makes the decision. If the patient loses the ability to make medical decisions and has a health care proxy, the Health Care Agent makes medical decisions. If the patient does not have a health care proxy, a Public Health Law Surrogate makes medical decisions. The FHCDA defines the Surrogate list and their authority. Surrogates under the FHCDA must meet higher standards in making these medical decisions because the patient did not have a prior discussion. Thus, completing a health care proxy and having a discussion with your family and health care provider is very important. For further information on the FHCDA, visit [CompassionAndSupport.org](http://CompassionAndSupport.org) and [health.state.ny.us](http://health.state.ny.us).

### **Can the MOLST be used for patients with mental illness or developmental disabilities?**

The MOLST is approved by the Office of Mental Health and the Office for People with Developmental Disabilities (OPWDD). Thus, the MOLST can be used for patients with mental illness and patients with developmental disabilities. If the patient has a developmental disability and does not have the ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist. Learn more at [CompassionAndSupport.org](http://CompassionAndSupport.org).

### **What is the difference between a Health Care Proxy/Living Will and the MOLST?**

A Health Care Proxy and a Living Will are traditional advance directives for all adults 18 years of age and older. These advance directives are completed ahead of time and only apply when decision-making capacity is lost. A properly completed MOLST form contains valid medical orders. MOLST is **not** intended to replace traditional advance directives like the Health Care Proxy and Living Will. In contrast to a Health Care Proxy, the MOLST applies right now and is **not** conditional on the patient losing the capacity to make complex medical decisions.

### **What are the benefits of the MOLST Program?**

MOLST orders are followed by EMS personnel in the pre-hospital setting. Medical orders carry more weight in the field because they are precise and can be easily interpreted in an emergency. MOLST expands on the DNR order and provides additional orders for life-sustaining treatment and future hospitalization. The MOLST can be used in the community instead of the New York State Nonhospital Do Not Resuscitate (DNR) form.

For more information regarding MOLST in New York State, please visit [CompassionAndSupport.org](http://CompassionAndSupport.org) and [health.state.ny.us](http://health.state.ny.us).

### **Can MOLST be used in other states? What is POLST?**

MOLST is New York State's approved Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program. For further information on other states with approved or developing programs, please visit [POLST.org](http://POLST.org).

## Checklist for Action

Using the simple checklist provided below will ensure that you do not miss a step while creating a comprehensive Advance Care Plan.

- I have thought about what is important to me and shared that with my family
- I have chosen my spokesperson and alternate spokesperson
- I have discussed my wishes with my:
  - Spokesperson (Health Care Agent)
  - Alternate Spokesperson (Alternate Health Care Agent)
  - Family members, close friends
  - Doctors
  - Spiritual Advisor
  - Attorney
- I have discussed my wishes regarding artificially administered fluids and nutrition with my Spokesperson and alternate spokesperson
- I have completed my New York Health Care Proxy or my state's Advance Directive
- I have documented on my Health Care Proxy or my state's Advance Directive, that my spokesperson knows my wishes regarding artificially administered fluids and nutrition
- I have documented my wishes about organ donation on my Health Care Proxy, New York State driver's license (or other New York State issued identification), and/or official organ donor card.
- I have registered my intent to be an organ donor and enrolled in the [New York State Donate Life Registry](#) (on-line registration is available), \* [or other state-specific registry, if available.](#)
- I have completed my New York Living Will
- I have given copies of both my New York Health Care Proxy and Living Will to my:
  - Spokesperson (Health Care Agent)
  - Alternate Spokesperson (Alternate Health Care Agent)
  - Family members, close friends
  - Doctors
  - Hospital
  - Attorney
- I have filled out the wallet card enclosed in this booklet according to the directions, and I carry the wallet card with my state-issued identification and insurance card
- I have added my Health Care Proxy and Living Will, or my state's Advance Directive to the electronic registry, if available.
- I have reviewed and updated my advance directives, as needed
- I have thought about the MOLST or similar approved or developing program in my state.
- I have worked with my physician and asked the physician to fill out a MOLST form.

\*<https://apps.nyhealth.gov/professionals/patients/donation/organ/DonorRegistration.action>

## Appendix

- New York State Health Care Proxy Form
- New York State Living Will Form
- Medical Orders for Life-Sustaining Treatment (MOLST) DOH-5003 Form
- Nonhospital Do Not Resuscitate (DNR) Form

Portions of this booklet have been adapted with permission from materials originally published by Partnership for Caring, Inc., 1620 Eye Street, NW, Suite 202, Washington, DC 20006, 1 (800) 989-9455  
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**ORGAN  
DONATION  
(OPTIONAL)  
CONTINUED**

(a) Any needed organs, tissues, or parts; **OR**

(b) The following organs, tissues, or parts

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(c) My gift is for the following purposes:  
(put a line through any of the following you do not want)

- (i) Transplant
- (ii) Therapy
- (iii) Research
- (iv) Education

(5) Unless I revoke it, this proxy shall remain in effect indefinitely, or until the date or condition I have stated below. This proxy shall expire (specific date or conditions, if desired):

---

---

**ENTER A  
DURATION OR A  
CONDITION  
(IF ANY)**

**SIGN AND DATE  
THE DOCUMENT  
AND PRINT  
YOUR ADDRESS**

(6) Signature \_\_\_\_\_ Date \_\_\_\_\_

Address \_\_\_\_\_

**WITNESSING  
PROCEDURE**

**Statement by Witnesses (must be 18 or older)**

I declare that the person who signed this document appeared to execute the proxy willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence. I am not the person appointed as proxy by this document

Witness 1 \_\_\_\_\_

Address \_\_\_\_\_

Witness 2 \_\_\_\_\_

Address \_\_\_\_\_

**YOUR  
WITNESSES  
MUST SIGN AND  
PRINT THEIR  
ADDRESSES**

# NEW YORK LIVING WILL



*This Living Will has been prepared to conform to the law in the State of New York, as set forth in the case In re Westchester County Medical Center, 72 N.Y.2d 517 (1988). In that case the Court established the need for "clear and convincing" evidence of a patient's wishes and stated that the "ideal situation is one in which the patient's wishes were expressed in some form of writing, perhaps a 'living will.'"*

**PRINT YOUR  
NAME**

I, \_\_\_\_\_, being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below:

I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying, if I should be in an **incurable or irreversible mental or physical condition with no reasonable expectation of recovery**, including but not limited to: (a) **a terminal condition**; (b) **a permanently unconscious condition**; or (c) **a minimally conscious condition in which I am permanently unable to make decisions or express my wishes**.

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment.

While I understand that I am not legally required to be specific about future treatments **if I am in the condition(s) described above I feel especially strongly about the following forms of treatment:**

- I do not want cardiac resuscitation.
- I do not want mechanical respiration.
- I do not want artificial nutrition and hydration.
- I do not want antibiotics.

However, I **do want** maximum pain relief, even if it may hasten my death.

**CROSS OUT  
ANY  
STATEMENTS  
THAT DO NOT  
REFLECT YOUR  
WISHES**

**ADD PERSONAL  
INSTRUCTIONS  
(IF ANY)**

Other directions:

These directions express my legal right to refuse treatment, under the law of New York. I intend my instructions to be carried out, unless I have rescinded them in a new writing or by clearly indicating that I have changed my mind.

**SIGN AND DATE  
THE DOCUMENT  
AND PRINT  
YOUR ADDRESS**

Signed \_\_\_\_\_ Date \_\_\_\_\_

Address \_\_\_\_\_

**WITNESSING  
PROCEDURE**

I declare that the person who signed this document appeared to execute the living will willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence.

**YOUR  
WITNESSES  
MUST SIGN AND  
PRINT THEIR  
ADDRESSES**

Witness 1 \_\_\_\_\_

Address \_\_\_\_\_

Witness 2 \_\_\_\_\_

Address \_\_\_\_\_

**THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.**

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/STATE/ZIP \_\_\_\_\_

DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_

Male  Female

eMOLST NUMBER (THIS IS NOT AN eMOLST FORM) \_\_\_\_\_

**Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)**

This is a medical order form that tells others the patient’s wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form, based on the patient’s current medical condition, values, wishes and MOLST Instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the orders and changes them.

**MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician and consider asking the physician to fill out a MOLST form if the patient:**

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

**If the patient has a developmental disability and does not have ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.**

**SECTION A Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing**

Check *one*:

**CPR Order: Attempt Cardio-Pulmonary Resuscitation**

CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

**DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**

This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

**SECTION B Consent for Resuscitation Instructions (Section A)**

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law.

\_\_\_\_\_  
SIGNATURE  Check if verbal consent (Leave signature line blank) \_\_\_\_\_  
DATE/TIME

\_\_\_\_\_  
PRINT NAME OF DECISION-MAKER

\_\_\_\_\_  
PRINT FIRST WITNESS NAME

\_\_\_\_\_  
PRINT SECOND WITNESS NAME

**Who made the decision?**  Patient  Health Care Agent  Public Health Law Surrogate  Minor’s Parent/Guardian  §1750-b Surrogate

**SECTION C Physician Signature for Sections A and B**

\_\_\_\_\_  
PHYSICIAN SIGNATURE PRINT PHYSICIAN NAME DATE/TIME

\_\_\_\_\_  
PHYSICIAN LICENSE NUMBER PHYSICIAN PHONE/PAGER NUMBER

**SECTION D Advance Directives**

Check all advance directives known to have been completed:

- Health Care Proxy  Living Will  Organ Donation  Documentation of Oral Advance Directive

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT \_\_\_\_\_

DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_

**SECTION E**

**Orders For Other Life-Sustaining Treatment and Future Hospitalization  
When the Patient has a Pulse and the Patient is Breathing**

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped.

**Treatment Guidelines** No matter what else is chosen, the patient will be treated with dignity and respect, and health care providers will offer comfort measures. *Check one:*

- Comfort measures only** Comfort measures are medical care and treatment provided with the primary goal of relieving pain and other symptoms and reducing suffering. Reasonable measures will be made to offer food and fluids by mouth. Medication, turning in bed, wound care and other measures will be used to relieve pain and suffering. Oxygen, suctioning and manual treatment of airway obstruction will be used as needed for comfort.
- Limited medical interventions** The patient will receive medication by mouth or through a vein, heart monitoring and all other necessary treatment, based on MOLST orders.
- No limitations on medical interventions** The patient will receive all needed treatments.

**Instructions for Intubation and Mechanical Ventilation** *Check one:*

- Do not intubate (DNI)** Do not place a tube down the patient’s throat or connect to a breathing machine that pumps air into and out of lungs. Treatments are available for symptoms of shortness of breath, such as oxygen and morphine. (This box should **not** be checked if full CPR is checked in Section A.)
- A trial period** *Check one or both:*
  - Intubation and mechanical ventilation**
  - Noninvasive ventilation (e.g. BIPAP), if the health care professional agrees that it is appropriate**
- Intubation and long-term mechanical ventilation, if needed** Place a tube down the patient’s throat and connect to a breathing machine as long as it is medically needed.

**Future Hospitalization/Transfer** *Check one:*

- Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled.**
- Send to the hospital, if necessary, based on MOLST orders.**

**Artificially Administered Fluids and Nutrition** When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have either a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. *Check one each for feeding tube and IV fluids:*

- No feeding tube**
- A trial period of feeding tube**
- Long-term feeding tube, if needed**
- No IV fluids**
- A trial period of IV fluids**

**Antibiotics** *Check one:*

- Do not use antibiotics.** Use other comfort measures to relieve symptoms.
- Determine use or limitation of antibiotics when infection occurs.**
- Use antibiotics** to treat infections, if medically indicated.

**Other Instructions** about starting or stopping treatments discussed with the doctor or about other treatments not listed above (dialysis, transfusions, etc.).

**Consent for Life-Sustaining Treatment Orders (Section E)** (Same as Section B, which is the consent for Section A)

\_\_\_\_\_  
SIGNATURE  Check if verbal consent (Leave signature line blank) \_\_\_\_\_  
DATE/TIME

\_\_\_\_\_  
PRINT NAME OF DECISION-MAKER

\_\_\_\_\_  
PRINT FIRST WITNESS NAME

\_\_\_\_\_  
PRINT SECOND WITNESS NAME

- Who made the decision?**  Patient  Health Care Agent  Based on clear and convincing evidence of patient’s wishes  
 Public Health Law Surrogate  Minor’s Parent/Guardian  §1750-b Surrogate

**Physician Signature for Section E**

\_\_\_\_\_  
PHYSICIAN SIGNATURE

\_\_\_\_\_  
PRINT PHYSICIAN NAME

\_\_\_\_\_  
DATE/TIME



State of New York  
Department of Health  
Nonhospital Order Not to Resuscitate  
(DNR Order)

Person's Name: \_\_\_\_\_

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Do not resuscitate the person named above.

Physician's Signature \_\_\_\_\_

Print Name \_\_\_\_\_

License Number \_\_\_\_\_

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart.

The issuance of a new form is **NOT** required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90-day period.



**HEALTH CARE PROXY**

I, \_\_\_\_\_, of \_\_\_\_\_

STREET CITY STATE

DAYTIME PHONE EVENING PHONE

hereby appoint \_\_\_\_\_ of \_\_\_\_\_

NAME OF AGENT

STREET CITY STATE

DAYTIME PHONE EVENING PHONE

as my health care agent to make all health care decisions for me if I become unable to decide for myself, including decisions about artificial nutrition and hydration.

SIGNATURE (PROXY INITIATOR) DATE

This proxy was signed in my presence. The signer is known to me and appears to be of sound mind and to act of his/her own free will.

WITNESS DATE

WITNESS DATE

**Instructions for Wallet Card:**

In case of emergency, this wallet card alerts medical personnel to the presence of a Health Care Proxy and directs them to your Spokesperson.

To be most effective, the wallet card should be carried on you along with your state-issued identification and insurance card.

**To use this Wallet Card:**

1. Simply remove the card by tearing along the perforations and fold.
2. Fill out the card so that the card includes the identical information contained within your New York Health Care Proxy form.
3. Follow the same witnessing procedures as the New York Health Care Proxy form by having the card properly witnessed by two individuals.
4. Carry this wallet card along with your state issued identification and insurance card.
5. Enjoy the peace of mind knowing that your Spokesperson can be contacted and your wishes discussed even if something happens to you while you are not near any copies of your completed New York Health Care Proxy form.

[CompassionAndSupport.org](http://CompassionAndSupport.org)

Patients, families and professionals view reliable information on:

Advance Care Planning Health Care Proxies  
Medical Orders for Life-Sustaining Treatment (MOLST)

Life-Sustaining Treatment Feeding Tubes  
Pain Management  
Hospice & Palliative Care  
Death & Dying  
Spiritual Information  
Pediatrics  
En Espanol

Visit [CompassionAndSupport.org](http://CompassionAndSupport.org) to view our MOLST video.



Learn how a new program for seriously ill patients improves care at the end-of-life

Created by the Community-wide End-of-life/Palliative Care Initiative



**Compassion and Support**  
at the End of Life

[CompassionAndSupport.org](http://CompassionAndSupport.org)

SPECIAL INSTRUCTIONS

HEALTH CARE PROXY

for

NAME

distributed by:



**Compassion and Support**  
at the End of Life

[CompassionAndSupport.org](http://CompassionAndSupport.org)

FOR MORE INFORMATION, please contact your regional Excellus BlueCross BlueShield office, Lifetime Health Medical Group Center, or visit [CompassionAndSupport.org](http://CompassionAndSupport.org).

Visit [CompassionandSupport](http://CompassionandSupport.org) to view our **Community Conversations on Compassionate Care (CCCC) video**



Learn why healthy individuals should complete their Advance Directive.

**Five Easy Steps**

**1. Learn About Advance Directives**

- NYS Health Care Proxy
- NYS Living Will
- Advance Directives from other States

**2. Remove Barriers**

**3. Motivate Yourself**

- View CCCC Videos

**4. Complete your Health Care Proxy and Living Will**

- Have a conversation with your family
- Choose the right Health Care Agent
- Discuss what is important to you
- Understand life-sustaining treatment
- Share copies of your directives

**5. Review and Update**

[CompassionAndSupport.org](http://CompassionAndSupport.org)

Community Conversations on Compassionate Care (CCCC) Program is an Advance Care Planning Program developed by the Community-wide End-of-life/Palliative Care Initiative. As leader of the initiative, we are pleased to produce this updated Advance Care Planning Booklet to support the CCCC program.

For further information about this initiative, contact Dr. Patricia Bomba at (585) 238-4514 or [Patricia.Bomba@lifethc.com](mailto:Patricia.Bomba@lifethc.com) or visit [CompassionAndSupport.org](http://CompassionAndSupport.org).

For additional copies, contact your Excellus BlueCross BlueShield regional office or download from [CompassionAndSupport.org](http://CompassionAndSupport.org).

September 2010