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.**

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Compassion and Support
at the End of Life

www.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 assure 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 decisions. Yet less than half have designated a spokesperson (a "health care agent") to ensure their wishes are carried out.

With the input of more than 150 community volunteers, the Community-wide End-of-life/Palliative Care Initiative produced a comprehensive Advance Care Planning booklet that outlines **Five Easy Steps** to complete an advance directive:

1. Learn about Advance Directives
2. Remove Barriers
3. Motivate Yourself
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

In July 2008, Gov. David A. Paterson signed into law a bill that helps to ensure a person's end-of-life wishes are followed whether the person is at home, in a nursing home or in any other non-hospital setting. The new law makes permanent and statewide a program piloted in Monroe and Onondaga counties called Medical Orders for Life-Sustaining Treatment (MOLST). This revised booklet includes information on the MOLST Program.

Additional information to assist in medical decision-making is available at the CompassionAndSupport.org Web site, which includes a:

- **Community Conversations on Compassionate Care** video produced to motivate healthy individuals to complete advance directives
- **Writing Your Final Chapter** video produced to educate patients, families and professionals on the MOLST Program.

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."

Sincerely yours,

Patricia A. Bomba MD

Patricia A. Bomba, M.D., F.A.C.P.
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 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) and an alternate spokesperson (the "alternate health care agent" identified in the Health Care Proxy) to work with doctors to make decisions on your behalf in case you are unable to speak for yourself
- Reviewing your wishes and desires about death and dying 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, spiritual advisor, doctors, lawyers)
- Completing the New York Health Care Proxy and Living Will forms (also known as Advance Care Directives, or Directives) 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 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 health care decisions.

Learn more about **Advance Care Planning** at 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 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 support. 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 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. Indicate the presence of your Living Will under Optional Instructions on the New York Health Care Proxy.

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 artificial nutrition and hydration. 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 treatments such as cardiopulmonary resuscitation (CPR), mechanical ventilation, and artificial nutrition and hydration?
See page 9 and 10 of this booklet for a detailed explanation of life-sustaining treatments.

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 spend extended periods of time in another state, will my New York advance care planning forms 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 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 Web site or going to caringinfo.org.

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 of Mental Retardation and Developmental Disabilities?
Special witnessing requirements exist for residents of facilities operated or licensed by the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities. For more information, contact the National Hospice & Palliative Care Organization, a non-profit organization dedicated to ensuring excellent end-of-life care, at caringinfo.org, or call 1 (800) 989-9455.

Step 2: Remove Barriers

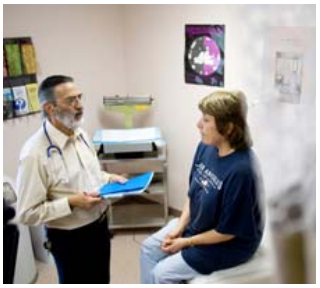
Common reasons given for not completing a Health Care Proxy form in the End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions* include:

- **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 Web site 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 it 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 video that is available on-line at the CompassionAndSupport.org Web site.

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 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 (MOLST) in this booklet and at CompassionAndSupport.org.

*https://www.univerahealthcare.com/wps/wcm/resources/file/eb856b0538eb709/End-of-life%20survey-UN.pdf

Choose the Right Health Care Agent or "Spokesperson"

It is important to choose a health care spokesperson (identified in the Health Care Proxy) 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 an alternate spokesperson (identified in the Health Care Proxy) to substitute if your primary spokesperson is unable or unavailable.

You indicate your spokesperson and alternate spokesperson using a legal document called the New York Health Care Proxy form. This form identifies your spokesperson – the individual you have designated to make decisions about your medical care – including decisions about life support – if you can no longer speak 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, 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 speak 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, 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
a. Avoiding pain/suffering, even if it means that I might not live as long				
b. Being alert, even if it means I might be in pain				
c. Being around my family and close friends				
d. Being able to feel someone touching me				
e. Having religious or spiritual advisors at my side when I die				
f. Being able to tell my life story and leave good memories for others				
g. Reconciling differences and saying "good-bye" to my family and friends				
h. Being at home when I die				
i. Being in a hospital when I die				
j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I'm unconscious				

Understand Life-Sustaining Treatment

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

According to New York State law, if you fail to include your wishes on artificial hydration and nutrition, your spokesperson **cannot** make these decisions.

The statement "My agent does know my wishes regarding artificial hydration and nutrition" 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 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 support.

When making decisions about specific forms of life support, gather the facts you need to make informed 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 support 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.

Commonly Used Life-Sustaining Treatment:

- **Artificial nutrition and hydration:** Artificial nutrition ("tube-feeding") and hydration (fluid replacement) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein. Artificial nutrition and hydration can save lives when used until the body heals. Long-term artificial nutrition and hydration 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 tube feeding is frequently given to people with irreversible and end-stage conditions. Often, the treatment will not reverse the course of the disease itself or improve the quality of life.

- **Cardiopulmonary resuscitation:** Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing cease. CPR attempts to restart the heart and breathing. It may consist of mouth-to-mouth breathing, pressing on the chest to circulate the blood, electric shock and/or drugs to stimulate the heart. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving. The success rate, however, 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.

- **Mechanical ventilation:** Mechanical ventilation is used to support or replace the function of the lungs. A ventilator (or respirator), a machine that is attached to a tube inserted through the nose or mouth and into the windpipe, forces air into 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.

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.

The booklet "Hard Choices" is an excellent reference and can be found at hardchoices.com. A Spanish version of this booklet is also available.

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.

- 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. 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 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 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 treatments. 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.

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
- ☐ Doctors
- ☐ Spiritual Advisor
- ☐ Attorney

☐ I have discussed my wishes regarding artificial nutrition and hydration with my spokesperson and alternate spokesperson

☐ I have completed my New York Health Care Proxy form

☐ I have documented on my Health Care Proxy form that my spokesperson knows my wishes regarding artificial nutrition and hydration

☐ 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.*

☐ 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
- ☐ 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 to the electronic registry, if available.

☐ I have reviewed and updated my forms as needed

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

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 health care decisions, including decisions about life-sustaining treatments, 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 signed by a New York State licensed physician that communicates patient wishes regarding life-sustaining treatment to health care providers. These valid medical orders must be followed by all health care professionals in all sites of care, including the community.

The form includes medical orders and patient preferences regarding:

- CPR (cardiopulmonary resuscitation) vs. Do Not Resuscitate
- Intubation and mechanical ventilation
- Artificial hydration and nutrition
- Future hospitalization and transfer
- Antibiotics

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 documents are completed ahead of time and only apply when decision-making capacity is lost. A properly completed MOLST form contains valid medical orders signed by a licensed New York State physician. It 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?

The MOLST program was created to facilitate the communication of medical orders impacting end-of-life care for patients with advanced chronic or serious illness. The MOLST contains actionable medical orders for seriously ill patients near the end of life that 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. The MOLST program is based on a proven national model.

Who should have a MOLST form?

Individuals who have advanced progressive chronic illness, are terminally ill or are interested in further defining their care wishes should discuss MOLST with their physician and other health care providers. **An individual should also discuss MOLST if he/she:**

- Wants *all* appropriate treatments including cardiopulmonary resuscitation (CPR)
- Wants to avoid *all* life-sustaining treatments
- Chooses to *limit* life-sustaining treatments
- Wants to avoid cardiopulmonary resuscitation (CPR) by requesting a "Do Not Resuscitate Order" (DNR order)
- Might die within the next year
- Resides in a long-term care facility
- Resides in the community and is eligible for long-term care

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.

In signing the legislation that permits statewide community use of the MOLST form, Governor Paterson said, "People should be allowed as much say in their end-of-life care as they would have at any other time. This bill will allow many people who are critically ill to make enduring decisions on the care they will receive. These will be difficult decisions for every person to make, but they should have the freedom to make them."

New York State Health Commissioner Richard F. Daines, M.D. noted "I congratulate Governor Paterson on signing this bill. This will give patients more choices for end-of-life care. It expands patients' instructions beyond a do-not-resuscitate order into areas of intubation and medication, which many end-stage patients would like to control for themselves as much as possible."

For more information regarding DNR and MOLST Orders in New York State, please visit CompassionAndSupport.org and health.state.ny.us.

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

MOLST is an approved Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program. For further information and/or if you live outside New York State, please visit POLST.org.

Appendix

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

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INSTRUCTIONS

NEW YORK
HEALTH CARE PROXY

PRINT YOUR NAME

(1) I, _____, hereby appoint:
(name)

PRINT NAME, HOME ADDRESS AND TELEPHONE NUMBER OF YOUR AGENT

_____
(name, home address and telephone number of agent)

_____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. **My agent does know my wishes regarding artificial nutrition and hydration.**

This Health Care Proxy shall take effect in the event I become unable to make my own health care decisions.

ADD PERSONAL INSTRUCTIONS (If Any)

(2) Optional instructions: I direct my agent to make health care decisions in accord with my wishes and limitations as stated below, or as he or she otherwise knows.

PRINT NAME, AND TELEPHONE NUMBER OF YOUR ALTERNATE AGENT

(3) Name of substitute or fill-in agent if the person I appoint above is unable, unwilling or unavailable to act as my health care agent.

_____
(name, home address and telephone number of alternate agent)

_____

ORGAN DONATION (OPTIONAL)

(4) Donation of Organs at Death: Upon my death:

[ ] I **do not** wish to donate my organs, tissues or parts.
[ ] I **do** wish to be an organ donor and upon my death I wish to donate:

ORGAN DONATION (OPTIONAL) *CONTINUED*

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

[ ] (b) The following organs, tissues, or parts

_____

_____

[ ] (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

ENTER A DURATION OR A CONDITION (IF ANY)

(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):

_____

_____

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

YOUR WITNESSES MUST SIGN AND PRINT THEIR ADDRESSES

Witness 1 _____

Address_____

Witness 2 _____

Address _____

INSTRUCTIONS

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.

CROSS OUT ANY STATEMENTS THAT DO NOT REFLECT YOUR WISHES

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.

ADD PERSONAL INSTRUCTIONS (IF ANY)

Other directions:

SIGN AND DATE THE DOCUMENT AND PRINT YOUR ADDRESS

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.

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 _____

SEND FORM WITH PATIENT/RESIDENT WHENEVER TRANSFERRED OR DISCHARGED

MOLST

Medical Orders for Life-Sustaining Treatment

Do-Not-Resuscitate (DNR) and other Life-Sustaining Treatments (LST)

This is a Physician's Order Sheet based on this patient/resident's current medical condition and wishes. It summarizes any Advance Directive. If Section A is not completed, there are no restrictions for this section. When the need occurs, *first follow* these orders, then contact physician. Review the entire form with the patient. Any section not completed implies full treatment for that section. ***WARNING**: If patient lacks medical decision-making capacity as a result of mental retardation or developmental disability or has a legal guardian, specific, mandatory procedures need to be followed. Review information and seek legal counsel.*

Last Name/First/Middle Initial of Patient/Resident
Address
City/State/Zip
Patient/Resident Date of Birth (mm/dd/yyyy)
Gender ☐ M ☐ F
Unique Patient Identifier (Last 4 SSN)

This form should be reviewed and renewed periodically, as required by New York State and Federal law or regulations, and/or if:

- The patient/resident is transferred from one care setting or care level to another, or
- There is a substantial change in patient/resident health status (improvement or deterioration), or
- The patient/resident treatment preferences change

Section A

Check One Box Only

RESUSCITATION INSTRUCTIONS (ONLY for Patients in Cardiopulmonary Arrest):

(If patient/resident has no blood pressure, no pulse and no respiration) This form can be used in all settings, including community.

☐ **Do Not Resuscitate (DNR)*/Allow Natural Death** ***[DNR = No CPR, endotracheal intubation or mechanical ventilation]**

☐ **Full Cardio-Pulmonary Resuscitation (CPR)** **[No Limitations; accepts intubation and mechanical ventilation]**

* For incapacitated adults; and/or for therapeutic or medical futility exceptions; and/or for residents of OMH, OMRDD or correctional facilities, also complete relevant sections of Supplemental DNR Documentation Form for Adults. For residents of OMRDD without capacity in the community, also complete NYSDOH Nonhospital DNR form. For minor patients, also complete Supplemental DNR Documentation Form for Minors.

Section B

Patient/ Resident/ Health Care Agent or Surrogate Decision-Maker Consent for Section A

Complete one of the subsections of Section B

DNR (CPR) CONSENT OF PATIENT/RESIDENT WITH DECISION-MAKING CAPACITY:

Section A reflects my treatment preferences.

Patient/Resident Signature ☐ Check if verbal consent *	Print Patient/Resident Name	Date
Witness of Patient/Resident Signature or Verbal Consent	Print Witness Name	Date
Witness of Patient/Resident Signature or Verbal Consent	Print Witness Name	Date

*Patient with capacity can provide verbal consent in the presence of two adult witnesses. Written consent requires only one witness signature. If verbal consent, one witness must be a physician. In facility, physician must be affiliated with the facility, e.g. resident physician qualifies.

DNR (CPR) CONSENT OF HEALTH CARE AGENT (HCA) OR SURROGATE DECISION-MAKER FOR PATIENT / RESIDENT WITHOUT DECISION-MAKING CAPACITY: This document reflects what is known about the patient/resident's treatment preferences. For Patient/Resident without decision-making capacity, or when medical futility or therapeutic exception is used, Supplemental MOLST Documentation Form MUST be completed and should always accompany this MOLST Form. If patient/resident has a legal and valid DNR previously completed while patient/resident had capacity, attach to MOLST. ☐ **Prior DNR form attached** ☐ **Supplemental Documentation Form completed**

HCA/Surrogate Signature ☐ Check if verbal consent	Print Name	Date

Relationship to Patient/Resident: _____

Witness Signature	Print Witness Name	Date

(Must witness HCA/surrogate signature or verbal/telephone consent)

Section C

Physician Signature for Section A and B

Physician Signature for Sections A and B:

Physician Signature	Print Physician Name	Date

*(Must Witness Patient/Resident Signature **or** obtain Verbal Consent. Resident physician signature must be co-signed by licensed physician.)*

Physician License #: _____ **Physician Phone/Pager #:** _____

It is the responsibility of the physician to determine, within the appropriate period, (see below) 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 appropriate time period. The **physician must review these orders** as follows: **Hospital: at least every 7 Days; Nursing Home/Skilled Nursing Facility: at least every 60 Days; Nonhospital/Community Setting: at least every 90 Days**

Section D

ADVANCE DIRECTIVES: Patient/Resident has completed an additional document that provides guidance for treatment measures if he/she loses medical decision-making capacity:

☐ **Health Care Proxy** ☐ **Living Will** ☐ **Other Written Documentation or Oral Advance Directive**

Section E

HIPAA Permits Disclosure of MOLST to Other Health Care Professionals & Electronic Registry as necessary for treatment.

ORDERS FOR OTHER LIFE-SUSTAINING TREATMENT AND FUTURE HOSPITALIZATION: (If patient/resident has pulse and/or is breathing)

Review patient's goals and patient's choice of interventions and then complete orders for appropriate subsections. Blank subsections can be completed at a later date. If patient has decision-making capacity, patient should be consulted prior to treatment or withholding thereof. *After confirming consent of appropriate decision-maker, obtain signature or verbal consent and complete the consent section of Section E, at the bottom of this page.* Physician must sign and date each subsection at the time of completion.

Physician may complete form with patient who has capacity or with Health Care Agent. Include Section E consent.

ADDITIONAL TREATMENT GUIDELINES: (Comfort measures are always provided.)

☐ **Comfort Measures Only –** The patient is treated with dignity and respect. Reasonable measures are made to offer food and fluids by mouth. Medication, positioning, wound care, and other measures are used to relieve pain and suffering. Oxygen, suction and manual treatment of airway obstruction are used as needed for comfort. *Do Not Transfer to hospital for life-sustaining treatment. Transfer if comfort care needs cannot be met in current location.*

☐ **Limited Medical Interventions** - Oral or intravenous medications, cardiac monitoring, and other indicated treatments are provided except as specified in Sections A or E. Guidance about acceptable/unacceptable interventions relevant to this patient/resident may be written under "Other Instructions" below. May consider less invasive airway support (e.g. CPAP, BIPAP). *Transfer to the hospital as indicated.*

☐ **No Limitations on Medical Interventions -** All indicated treatments are provided except as specified in Sections A. *Transfer to the hospital is indicated, including intensive care.*

MD Signature: ***Date:***

Physician may complete form for incapacitated patients without Health Care Agent only with clear and convincing evidence. Include Section E consent.

ADDITIONAL INTUBATION AND MECHANICAL VENTILATION INSTRUCTIONS: If patient/resident chooses DNR, review all options if patient/resident has progressive or impending pulmonary failure without acute cardiopulmonary arrest. If patient chooses full CPR, review options of trial and long-term intubation & mechanical ventilation:

☐ **Do Not Intubate (DNI)**
(Review available symptomatic treatment of dyspnea: oxygen, morphine, etc.)

☐ **A trial period of intubation and ventilation** ☐ **A trial of BIPAP** ☐ **A trial of CPAP**
(Discuss duration of trial and document in other instructions.)

☐ **Intubation and long-term mechanical ventilation, if needed**

MD Signature: ***Date:***

FUTURE HOSPITALIZATION / TRANSFER: (For long-term care residents and home patients)

☐ **No hospitalization unless pain or severe symptoms cannot be otherwise controlled.**

☐ **Hospitalization with restrictions outlined in Sections A and E.**

MD Signature: ***Date:***

Physician should consult legal counsel for MR/DD patients without capacity. See Surrogate's Court Procedure Act §1750-b.

ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION: (If Health Care Agent makes decision, it must be based on reasonable knowledge of patient/resident's wishes.)

☐ **No feeding tube** (offer food/fluids as tolerated) ☐ **No IV Fluids** (offer food/fluids as tolerated)

☐ **A trial period of feeding tube** ☐ **A trial of IV fluids**

☐ **Long-term feeding tube, if needed**

MD Signature: ***Date:***

ANTIBIOTICS:

☐ **No antibiotics** (except for comfort) ☐ **Antibiotics**

MD Signature: ***Date:***

OTHER INSTRUCTIONS: (May include additional guidelines for starting or stopping treatments in sections above or other directions not addressed elsewhere.)

_____

_____

_____

MD Signature: ***Date:***

Section E Consent

CONSENT FOR SECTION E OF PERSON NAMED IN SECTION B: Significant thought has been given to life-sustaining treatment. Patient/resident preferences have been expressed to the physician and this document reflects those treatment preferences. As the medical decision-maker, I confirm that the orders documented above in Section E reflect patient/resident's treatment preferences.

_____ _____ _____

Signature ☐ **Check if verbal consent** **Print Name** **Date**

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.

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.

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

SPECIAL INSTRUCTIONS

HEALTH CARE PROXY
for

_____
NAME

distributed by:

FOR MORE INFORMATION, please contact the Univera Healthcare office, Lifetime Health Medical Group Center, or visit www.CompassionAndSupport.org.

Visit CompassionandSupport 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

2. Remove Barriers

3. Motivate Yourself
- View Full CCCC Video

4. Complete your documents
- 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

www.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 or visit www.CompassionAndSupport.org.

For additional copies, contact the Univera Healthcare office or download from www.CompassionAndSupport.org.

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