

Health Care Planning Q&A

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How to use this guide

Senior Law Day Collaborative Q&As are intended to guide older adults and caregivers as they address issues related to aging and planning for the future. We suggest you review this information in the full before seeking out an elder law attorney or other professional, so that you are familiar with the terms and can be ready to ask questions specific to your needs.

At our website – **seniorlawday.info** – you will find:

- additional Q&As for review and download
- a library of recorded webinars on topics relevant to elders and caregivers
- an opportunity to get your specific questions answered via email or during our quarterly consultation events
- notice up upcoming educational programs

All services of the Collaborative are offered at no charge. Our goal is to help you get the answers you need so you can plan and move forward with confidence.

This Q&A is an excerpt from the 22nd edition of the **Elder Law Q&A: An Introduction to Aging Issues and Planning for the Future** written by Steven A. Schurkman Esq. and members of the Senior Law Day Collaborative.

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Health Care Planning

Health Care Proxies and Living Wills

I am healthy now but want to make sure that if I ever become severely incapacitated, no artificial lifesustaining treatments will be imposed. How can I ensure that my wishes will be carried out?

There are three (3) documents which you should consider signing to make sure your health care wishes are followed.

1. A **Health Care Proxy** is a legal document that can be used to protect your health care wishes in the event of your incapacity. A health care proxy allows you (the principal) to appoint someone else (the health care agent) to make health care decisions for you if you become incompetent. A successor health care agent, to act if the primary agent cannot act, may also be appointed. Routine decisions and decisions regarding life-sustaining treatment may be made using a health care proxy. However, your health care agent will not be able to withhold artificial nutrition or hydration unless your intention to do so has been clearly expressed in the health care proxy itself, or in more detail in a separate living will or medical order for life-sustaining treatment. In addition, pursuant to legislation passed on October 4, 2000, you can now also state your wishes concerning organ donorship in your health care proxy.

A copy of the most current New York State Statutory Power of Attorney Form is provided in Q&A Appendices as Appendix A (seniorlawday.info/qa-appendices/) and can also be found at health.ny.gov/publications/1430.pdf

2. A **Living Will** is a document that sets forth your intentions concerning health care, particularly with respect to artificial life-sustaining procedures. In a Living Will, you can establish your intention to forgo certain measures, such as artificial nutrition or hydration (which may be imposed if you are unable to eat or drink on your own) or mechanical respiration (which may be imposed if you cannot breathe on your own).

Other types of treatments that you may decide to forgo include, but are not limited to, cardiopulmonary resuscitation (if your heart stops beating), antibiotic treatment, saline injections (to prevent dehydration), and pain relief (beyond a stated maximum amount). The Living Will sets forth your intentions concerning these important issues in the event that you, at some future point, become unable to make these decisions for yourself.

A copy of the most current New York State Statutory Power of Attorney Form is provided in Q&A Appendices as Appendix B (seniorlawday.info/qa-appendices/) as well as here: ag.ny.gov/sites/default/files/livingwill-template-fillin.pdf

3. A Medical Order for Life-Sustaining Treatment ("MOLST") is an alternative form to a living will in that it allows individuals, working together with their physicians, to document their end-of-life care preferences and to assure that those preferences are made known to health care providers across the health care delivery system. The MOLST document is a physician order form (DOH-5003) on bright pink paper approved by the New York State Department of Health to be used statewide by health care providers and facilities. The MOLST form can be used to issue any orders for life-sustaining treatment for general hospital inpatients and nursing home residents. In the community, the form can be used to issue a non-hospital Do Not Resuscitate (DNR) or Do Not Intubate (DNI) order, and in certain circumstances, orders concerning other life-sustaining treatment.

A copy of a MOLST form with supporting checklists is provded in Q&A Appendices as Appendix C (seniorlawday.info/qa-appendices/) and can be downloaded here: health.ny.gov/professionals/patients/patient_rights/molst/

When should I create a health care proxy?

Every person eighteen (18) years and older should have a health care proxy.

When should I create a Living Will?

A Living Will should be created if you do not want to be kept alive artificially by medical devices if you were to be in a persistent vegetative state. Every person eighteen (18) years and older should have a living will.

When should I ask my doctor for a MOLST?

Consider completing a MOLST with your physician if you reside in a long term care facility, reside in the community and need long term care services such as home health aides, have a serious illness, have a limited life expectancy, or if you want to avoid or receive all or some life sustaining treatment.

What do the medical terms on the MOLST form mean?

- CPR is cardiopulmonary resuscitation, a combination of techniques including chest compressions and rescue breathing. CPR is designed to pump the heart to get blood circulating and deliver oxygen to the brain, until definitive treatment can stimulate the heart to start working again.
- Cardiac arrest is a condition when the heart stops beating.
- Intubation is the insertion of a tube into the windpipe to breath for you when you cannot.
- Mechanical ventilation is a machine that delivers oxygen and eliminates carbon dioxide from the body.
- Feeding tubes are inserted into the body through the nose or in the abdomen.
- Antibiotics are for the treatment of bacterial infections.

What are the differences and similarities between the standard one-page non-hospital DNR order and the MOLST form?

Both the Non-hospital Order Not to Resuscitate form (DOH-3474) and the MOLST form (DOH-5003) are New York State Department of Health forms. Both forms are intended for individuals living at home, but the MOLST can also be used in a health care setting. The MOLST is an alternative form for patients to document their end-of- life care preferences and to assure that those preferences are made known to health care providers across the health care delivery system.

The MOLST form **DOH-5003** is a bright pink multi-page form; however, a photocopy or facsimile of the original form is acceptable and legal. A Non-hospital Order Not to Resuscitate form **DOH-3474** is a single page form on white paper with black ink and available in both English and Spanish. **Please see Appendix D in Q&A Appendices** (seniorlawday.info/qa-appendices/) or health.ny.gov/forms/doh-3474.

MOLST provides for end-of-life orders concerning resuscitation and intubation for emergency medical technicians (EMT) when the patient is in full cardio-pulmonary arrest or has pulmonary failure without acute cardiopulmonary arrest. The Non-hospital Order Not to Resuscitate form only applies to patients in full cardio or pulmonary arrest. Both forms, the MOLST form and the Non-hospital Order Not to Resuscitate form, must be completed by a physician.

Unlike the Non-hospital Order Not to Resuscitate form, there are multiple patient orders contained on the MOLST form that are intended for other health care providers to follow in other health care settings such as the hospital or nursing home. The MOLST form gives pre-hospital care providers and agencies direction regarding the patient's end-of-life treatment orders, while the Non-hospital Order Not to Resuscitate only contains a single direction regarding resuscitation. If an individual does not have either form and 911 is called, the individual will be resuscitated and care will be provided.

What do I do if the patient has both a Non-hospital DNR order and a MOLST form? Which do I honor?

If the forms have different orders, you should follow the form that has the most recently dated authorization. In all instances you should follow the DNI instructions on the MOLST form if the form is signed by a physician, as the Non-hospital DNR order does not provide this advice.

Does the MOLST law allow Emergency Medical Services (EMS) to honor other advance directives?

The MOLST law does not expand the ability of EMS personnel to honor advance directives such as a Health Care Proxy or Living Will. Without a Do Not Resuscitate order from a physician, EMS must resuscitate a patient when responding to an emergency even if the patient has a health care proxy and/or living will, as they are not medical orders.

What procedures are, and are not, performed if the patient presents a DNR?

Do Not Resuscitate ("DNR") means, for the patient in cardiac or respiratory arrest (i.e., when the patient has no pulse and/or is not breathing), no chest compressions, ventilation, defibrillation, endotracheal intubation, or medications. If the patient is not in cardiac or respiratory arrest, full treatment for all injuries, pain, difficult or insufficient breathing, hemorrhage and/or other medical conditions must be provided, unless different instructions are provided on a MOLST form by the physician documenting the patient's wishes. Relief of choking caused by a foreign object will be provided; however, if breathing has stopped, ventilation will not be assisted. CPR must be initiated if no Out of Hospital, MOLST or facility DNR is presented. If a DNR order is presented after CPR has been started, CPR can then be stopped.

At what point does a health care proxy, living will or MOLST form become effective?

A health care proxy becomes effective when your attending physician determines, to a reasonable degree of medical certainty, that you (as the principal) lack capacity to make your

own health care decisions. If a decision to withhold life-sustaining treatment is involved, the attending physician must consult with a second physician to confirm that you lack capacity.

If you are using a living will to decide in advance that certain life-sustaining treatments should not be used, you should also decide when and how a determination should be made that you are in a condition in which artificial life-sustaining methods should be withheld. For example, your living will might provide that artificial life-sustaining methods should be withheld if your attending physician determines that you have suffered a substantial and irreversible loss of mental or physical capacity, and that there is no reasonable expectation of recovery. Other standards can be specified as well.

If using a MOLST document instead of a living will, its effectiveness will be immediate in that a MOLST document has the strength and benefit of having your end-of-life preferences being contained in an enforceable physician's order.

Who can I appoint as my health care agent?

You can appoint almost any adult to serve as your health care agent. Often, health care agents are the spouse, children, brothers, sisters, or other relatives or close friends of the principal. It is important to choose someone you trust, someone who understands your health care concerns, and someone you believe will actively and effectively carry out your health care wishes.

State law does impose some limitations on individuals serving as health care agents. For example, if you live in a residential health care facility or hospital, the operator, administrator, or employee of that facility or hospital cannot serve as your health care agent (unless that operator, administrator or employee is related to you by blood, marriage or adoption). Also, absent a relationship to you by blood, marriage or adoption, any doctor affiliated with your residential health care facility or hospital cannot serve as your health care agent. In addition, an individual who is already serving as a health care agent for ten or more principals cannot be your health care agent unless such person is your spouse, child, parent, brother, sister or grandparent.

How can I be certain that my wishes, whether contained in a health care proxy, living will or MOLST form, will be respected?

Both a health care proxy and a living will serve as substantial evidence in a court of law of your intentions concerning health care decision making. However, general instructions about refusing treatment, even if written, may not be effective. Therefore, although it is often difficult to anticipate future medical needs, it is best to be as specific as possible about the kinds of treatment you do not want and the medical conditions under which you would refuse those treatments.

If you do not wish to be kept alive by artificial means, it is important to state your intention in both your health care proxy and your living will documents.

The law states that unless your agent is aware of your wishes about artificial nutrition or hydration, she or he will not be allowed to refuse or consent to these matters for you. Therefore, if you are sure that you do not want to be artificially fed or hydrated, you should put specific language concerning the withholding of these interventions in your health care proxy. The following language might be used to express such an intention:

> My agent knows my wishes concerning artificial hydration and nutrition and is authorized to make such decisions.

Your living will is the document in which you can set forth in further detail under what circumstances life support can be withheld or withdrawn (specifically as relates to artificial nutrition or hydration), as well as to discuss other types of health care treatment, including:

- Administration of anti-psychotic medication
- Antibiotic treatments
- Artificial respiration
- Blood transfusions
- Cardiopulmonary resuscitation (CPR)
- Dialysis
- Electric shock therapy
- Palliative care

- Psycho-surgery
- Organ transplants
- Sterilization

To assist in making sure your wishes concerning health care are enforced, you should sign multiple originals of the health care proxy and living will forms. You should then furnish duplicate originals of both your living will and health care proxy to the primary and successor agents you designated in the proxy, as well as to your primary care physician for immediate placement in your medical file. Your attorney should also retain a copy of your health care proxy and living will. You may also want a member of your clergy to hold original copies of these documents for you.

Since 2008, in legislation signed by then New York Governor David Paterson, the use of Medical Orders for Life-Sustaining Treatment (MOLST) primarily intended for persons facing endof-life decisions. The MOLST form gives specific instructions to medical personnel regarding treatment. A MOLST form is enforceable as it is a medical order, signed by a physician.

Can anyone make health care decisions for me if I do not have a Health Care Proxy or Living Will?

The Family Health Care Decision Act, passed in New York in 2010, allows the appointment of a spouse or domestic partner, adult child, parent, adult sibling or close friend to be designated as a surrogate with authority to make medical decisions for an individual not able to make their own decisions concerning their health care. This includes the right to withhold or withdraw life-sustaining treatment, including artificial nutrition and hydration. The law is effective only if the patient is in a hospital, nursing home or hospice setting. The law fills in some gaps if an individual does not have a health care proxy; however, because of the delays inherent in deciding who is an appropriate surrogate under the Family Health Care Decision Act, it is preferable for all individuals to have a health care proxy.

What is HIPAA?

The CDC (Centers for Disease Control & Prevention) describes HIPAA in the following way:

"The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that required the creation of national standards to protect sensitive patient health information from being disclosed without the patient's consent or knowledge. The US Department of Health and Human Services (HHS) issued the HIPAA Privacy Rule to implement the requirements of HIPAA. The HIPAA Security Rule protects a subset of information covered by the Privacy Rule." (hhs.gov)

These requirements were put in place to give patients more control over their health information and set boundaries for the release of health records. Generally, it protects an individual by allowing them to make choices about the information they choose to share, how much information they share, and who they choose to share it with.

Can patients request their medical records?

Yes, patients may request copies of their medical records. Also, the guardians of a person may request access if they have consented to the health care, or the care was provided in an emergency without consent.

Medical Records require a written authorization by the patient. A signed HIPAA form can be completed by the patient to send specific information to a chosen provider. On the form, the patient checks off and initials the information they choose to share and names the entity they choose to share with. As an example, one may request recent lab work to be sent but exclude disclosure of mental health records or history of drug or alcohol abuse to Dr. Smith at stated address. HIPAA forms must be signed, initialed, and dated. The patient adds a date that this request for records expires. Some entities have separate forms that must be completed. When requesting records for oneself, the entity may charge a minimal fee per page. When sharing with another professional for continuation of care, or if supporting an application for government benefits, there is no charge.

Medical records can be obtained by a designated representative with written authorization, HIPAA and/or an entity's own Medical Records Request Form. To obtain medical records, call or visit the medical records department of the provider. Complete a HIPAA or requested form; select the records you would like and who you would like them sent to (check with your provider about online requests).

Why share this information?

As you age, there are often changes to where you seek medical care. Parents move in with adult children or closer to where they live. People make the decision to move to Independent or Assisted Living Facilities. Following an injury or sickness, you might be admitted to a Rehabilitation Center or Skilled Nursing Facility. In these situations, the ability to access medical records allows your team of experts to assess, consult, and create a healthy and safe plan going forward. Aging brings new diagnosis that may or may not be linked to previous medical conditions. Normal aging lessens one's ability to recall a life's worth of past medical history. At times, cognitive impairment makes this process even more challenging. Understanding diseases and conditions empowers service providers to manage limitations and unmet needs, and predict future needs to accommodate the identified person. We are all aware that non-compliance with medical orders result in poor overall health.

HIPAA allows you to access their medical records or grant others permission to access records for these purposes. It puts control in the hands of you, the patient, the most crucial part of any treatment team.

Where can I find a HIPAA release?

New York State Department of Health has a standard HIPAA form which can be found at: nycourts.gov/forms/Hipaa_fillable.pdf

What is palliative care?

Palliative care is the specialized health care treatment including interdisciplinary endof-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life including hospice. Palliative care is appropriate at any stage of a serious illness, whether that illness is potentially curable, chronic or life-threatening.

This type of care is focused on providing patients with relief from the symptoms, including the pain and stress of a serious illness, assisting with medical decisions and establishing goals of care – whatever the diagnosis and regardless of the prognosis. The goal of palliative care is to improve quality of life for the patient, and family and caregivers. Palliative care is provided by doctors, nurse practitioners, nurses, social workers and other practitioners who work with a patient's health professionals to provide an extra layer of support. Palliative care is

appropriate at any age and at any stage of a serious illness, and can be provided together with curative treatment. Palliative care is covered by Medicare, Medicaid and most commercial insurance.

Has any legislation been passed in New York State concerning palliative care?

The Palliative Care Information Act, introduced in February 2011, is a critically important patient's rights law. Seriously and terminally ill patients now have a clearly defined right to receive information and counseling about their palliative care and end-of-life options, including hospice, enabling them to make informed treatment decisions.

What information should attending health care practitioners offer as a result of the Palliative Care Information Act legislation?

The law requires them to provide information and counseling regarding palliative care and end-of-life options appropriate to the patient, including:

- Prognosis
- Range of options appropriate to the patient
- Risks and benefits of various options
- Patient's "legal rights in comprehensive pain and symptom management of the end of life"

Appropriate means it must be consistent with the patient's psychosocial circumstances and cultural and religious beliefs. Information needs, patient preferences and options may need to be revisited as the disease progresses. The delivery of palliative care and end-of-life counseling need not, and should not, be the same for every patient. The practitioner should be sensitive to the patient's emotional cues, preferences and ability to absorb information.

What is hospice care?

Hospice care is a formal system of care, specific to end of life for individuals who have a lifelimiting illness that is no longer responsive to curative treatment. The patient must be certified by a physician to have approximately six (6) months or less to live. Hospice care is provided by certified hospice agencies.

Hospice care is comfort care and is not provided together with curative treatment, but can be provided with palliative care. Hospice care is covered by Medicare, Medicaid and most commercial insurance. The Medicare Hospice Benefit covers nursing care, durable medical equipment, some home health aide services, social work visits, pastoral care and other supportive services for the patient and their family. Hospice care is provided in a patient's home, but can also be provided in nursing homes, assisted living facilities, hospice residences and hospitals. Under the hospice program, your own doctor can continue to participate in your care plan. The Medicare Hospice Benefit also provides bereavement support for 18 months after the passing of the patient.

Can I be admitted to hospice if I lack capacity?

Yes. A health care agent appointed under a health care proxy can consent to hospice enrollment when the patient lacks capacity. The patient must also be certified by a physician that death is likely to occur within six (6) months if the disease runs its natural course to be eligible under the Medicare Hospice Benefit.

How to I direct who controls my remains after I pass away?

New York State Public Health Law § 4201(2) provides for the designation in a written instrument of a person who shall have the right to control the disposition of the remains of a deceased person. To complete New York State Department of Health Form 5211, which can be found in Appendix E, you need to decide who you are going to choose to make decisions about your funeral, burial and/or cremation. This is the person you choose as your "agent" (you can also choose an alternate called a successor agent). You will need to decide on any special instructions you would like to provide, such as the name of a funeral home, a cemetery where you wish to be buried, or any religious or cremation directions.

If you have a pre-need agreement where you have already paid for your funeral, you should complete the form linked below (Appendix E), check the "yes" box and provide the name of the funeral firm where you have a pre-need funeral agreement.

The form requires two witnesses to watch you sign the form once it has been completed. The witnesses much be 18 years old and cannot be named as the agent or successor agent.

The forms have been provided in Q&A Appendices as Appendix E (seniorlawday. info/qa-appendices/) and can also be found at:

health.ny.gov/forms/doh-5211.pdf - Disposition of Remains Form English