

## **ADVANCE HEALTH CARE DIRECTIVES IN NEW YORK**

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**April 2022**

### **1. OVERVIEW- THE IMPORTANCE OF ADVANCE PLANNING**

New York law gives you the right to accept or reject medical treatment, including life-prolonging procedures, such as mechanical ventilation and tube or intravenous feeding. You can also stop such treatments, once started, at any time, such as dialysis or a pacemaker. This is known as the right to self-determination. As long as you are able to do so, you can let your doctor and family members know what care you may or may not want. But if you are not able to do so because of incapacitation or incompetence, the only way to be sure that your wishes will be known and honored is to plan for future medical care. 'Advance directives' are written instructions about health care treatment that you make before you lose decision-making capacity.

Advance care planning is a continual process and not merely a single document or isolated event. Periodic reviews are important to ensure that the documents you have signed are still in accord with your wishes. Planning ahead assists you in preparing for a sudden unexpected illness, from which you expect to recover, as well as the dying process and ultimately death. Preparing a few legal forms helps to ensure that your health care wishes are followed and that decisions are made by

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David C. Leven, Executive Director Emeritus and Senior Consultant, End of Life Choices New York provided very helpful additions to this paper.

people you trust. Those forms include the following: (1) Health Care Proxy; (2) Living Will; (3) 'Do Not Resuscitate' Order (DNR); (4) Medical Orders for Life Sustaining Treatment (MOLST). Each of these documents is discussed below.

## **2. WHERE DO ADVANCE HEALTH CARE DIRECTIVES FIT INTO OVERALL ESTATE PLANNING?**

Estate planning is the process of arranging, during your lifetime, for the management of your assets and affairs when you become incapacitated or die. A complete plan includes the following documents:

Last Will and Testament- this is a document that directs the distribution of your 'probate assets' (those owned by you that do not have a named beneficiary) after your death. This article explains the importance of a Last Will- <https://www.lawhelpny.org/resource/frequently-asked-questions-about-wills-in-new> In some instances creation of a Trust may also be advisable (there are many types of trusts).

You should also execute documents needed while you are still alive:

Power of Attorney- this document gives your agent- someone you trust- the authority to manage your finances if you become incapacitated. For example, your agent can withdraw funds from your bank account for your benefit to pay for medical care or treatment. The agent's power lasts until you cancel the POA or pass away (at which point your Will provisions govern). However, your agent cannot make health care decisions for you. See this helpful article- [Power of Attorney Frequently Asked Questions, State of New York \(ilrg.com\)](#)

Health Care Directives- while a POA agent can handle your financial affairs if necessary, you must appoint a health care agent, pursuant to the completion of a health care proxy, to make decisions regarding treatment or withdrawal of treatment if you cannot make such decisions for yourself.

## **3. ADVANCE CARE PLANNING DOCUMENTS**

### **A. HEALTH CARE PROXY**

You can appoint a health care agent- someone you trust to make health care decisions for you if you are unable to make decisions for yourself. You can give

your agent as little or as much authority as you want. Decisions might include the following: whether you want life support initiated/continued/removed if you are in a permanent coma or have a terminal illness; and whether you want artificial nutrition (a feeding tube) and hydration and under what circumstances.

Your agent can start making decisions for you when your doctor determines that you are not able to do so. Your agent also has the right to obtain medical information and records in order to make informed health care decisions for you. The NYS Department of Health has a health care proxy form on its website, see <https://www.health.ny.gov/publications/1430.pdf> That document also contains responses to frequently asked questions.

You can only name one agent at a time, although you can name a successor agent, called an alternate agent, who can step in if the original agent cannot or will not serve in that role. Your agent's health care decisions are final unless an objecting family member or facility obtains a court order overriding the decision or disqualifying the agent.

It is very important to select an agent who understands your wishes and will advocate on your behalf, even if their wishes differ from yours. You also want to appoint a person who will not be too emotionally involved to make important life and death decisions, who communicates and interacts well with people, and who can manage potential conflict between family members.

For example, while individuals often name an adult child as agent, sometimes that child may be very uncomfortable 'pulling the plug' on their parent even though the health care proxy/living will explicitly states that the parent does not want extraordinary measures to be taken if there is no reasonable expectation of recovery. Make sure to have an honest discussion about your wishes with family members or anyone else you are considering naming as your health care proxy.

The Health Department suggests that everyone older than 18 have a HCP, and that it should be updated every few years and during major life events, such as:

- going to college (when a child turns 18, parents no longer have an automatic legal right to make health care decisions for that child);
- getting married or divorced;
- having or adopting children;
- receiving a new medical diagnosis; and the like.

**While you may wish to consult an attorney when completing a health care proxy, you do not need either an attorney or notary public to do so-** you only need to have two witnesses sign your document (your agent cannot sign as a witness).<sup>1</sup> For helpful guidance in completing a HCP, see ‘Plan Today, Trust Tomorrow,’ a short video prepared by End of Life Choices- New York <https://www.youtube.com/watch?v=6XoE3l2IfwU>

## **B. LIVING WILL**

In a Living Will you can leave specific instructions about medical treatments you may or may not want, when you are no longer able to decide for yourself. A Living Will serves as written evidence of your wishes. While New York does not have a law governing Living Wills, New York’s highest court has stated that Living Wills are valid as long as they provide ‘clear and convincing evidence’ of your wishes. Notably, casual statements made to family members such as ‘don’t keep me alive on machines,’ or ‘nature should be permitted to take its course’ may not be specific enough for procedures to be withdrawn- make your wishes clear! The NY Attorney General’s Office has created a Living Will template, see this link- <https://ag.ny.gov/sites/default/files/livingwill-template-fillin.pdf>

**Artificial nutrition and hydration.** In general, your agent can make decisions in accordance with your wishes if known to your agent, or otherwise in accordance with your best interests. However, with regard to the administration or withholding of artificial nutrition (a feeding tube) and hydration, your agent must have specific knowledge of your wishes. While you can orally convey your wishes to your agent, because of the ‘clear and convincing evidence’ rule, it is advisable to put them in writing. This leaves no doubt if this situation arises.

Finally, while health care proxy forms and Living Wills can be separate documents, some attorneys recommend combining them into one document called a ‘Health Care Proxy/Living Will.’ That way the proxy is being given specific written instructions. Other attorneys, however, advocate for these documents to be kept separate. In that instance, the Living Will is used as a guide for the health care agent. But not given to health care providers unless it is thought to be helpful in situations where the agent is questioned as acting in accordance with the wishes of the patient or in his/her best interests or in good faith.

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<sup>1</sup> However, this author does believe that you should use an attorney in preparing your Will and Power of Attorney!

**Dementia as a special case.** As noted below, the NYS Health Department lists dementia as one of a number of serious health conditions for which a ‘Do Not Resuscitate’ Order may be appropriate. Several organizations have opined that a ‘standard’ HCP/LW may not be sufficient to address the unique challenges posed by a dementia diagnosis. See for example, <https://theconversationproject.org/tcp-blog/with-dementia-more-is-needed-than-a-boilerplate-advance-directive/>

End of Life Choices New York has prepared a Dementia Advance Directive to avoid prolonging late stage dementia. See <https://endoflifechoicesny.org/directives/dementia-directive/> Additionally, Compassion & Choices, a national organization devoted to end of life issues, has developed a ‘Dementia Values & Priorities Tool,’ designed to assist individuals in providing clear care instructions to family members, to take the burden off of them to make difficult decisions when the individual can no longer do so. See <https://values-tool.compassionandchoices.org/>

### **C. NONHOSPITAL ORDER NOT TO RESUSCITATE (DNR)**

A nonhospital DNR order is commonly used for someone with a serious health condition, advanced age, or terminal illness and must be signed by a health care provider. See this link for a copy of such a DNR <https://www.health.ny.gov/forms/doh-3474.pdf> If someone has a nonhospital DNR order, and they stop breathing or their heart stops beating, cardiopulmonary resuscitation (CPR) will not be started by emergency medical services (EMS) staff or others involved in your treatment outside of a hospital. Examples of serious health conditions include: advanced stage cancer diagnosis; congestive heart failure; chronic obstructive pulmonary disease (COPD); a dementia diagnosis; or frailty when a person nears the end of their natural life. CPR can include actions such as: mouth-to-mouth resuscitation; chest compressions; electric shock; inserting a tube to open your airway (intubate); and/or injecting medication to restart your heart.

Notably, a DNR order is only a decision about CPR, and does not relate to any other treatment. Do not resuscitate does **not** mean do not treat. Other appropriate treatments, as well as measures to relieve pain and to reduce suffering will still be

administered. ‘Comfort care,’ also known as palliative care, should be available to all patients who need it.

In order to alert medical personnel such as EMS staff about your DNR, you can carry it with you, post it on your refrigerator, and/or wear a DNR bracelet or necklace to indicate that you have a DNR order.

#### **D. MEDICAL ORDERS FOR LIFE SUSTAINING TREATMENT (MOLST)**

The New York State Department of Health has approved a ‘Medical Orders for Life-Sustaining Treatment’ (MOLST) form. This form allows doctors to record your preferences regarding CPR, mechanical intervention, and other life sustaining treatments on one form as a medical order. Completion of the MOLST begins with a conversation or a series of conversations between the patient, the patient's health care agent or surrogate if needed, and a health care professional that defines the patient's goals for care, reviews possible treatment options, and ensures shared, informed medical decision-making. A MOLST is intended for patients with serious health conditions who:

- want to avoid or receive any or all life-sustaining treatment;
- reside in a long-term care facility or require long-term care services; and/or
- might die within the next year.

A MOLST must be completed by a health care professional and signed by a New York State licensed physician, nurse practitioner or physician assistant to be valid. A valid MOLST form serves as a Medical Order Form and can be transferred with you from one health care setting to another. A sample MOLST form is available at <https://www.health.ny.gov/forms/doh-5003.pdf>

#### **E. IF YOU DON'T HAVE AN ADVANCE HEALTH CARE DIRECTIVE**

If you can no longer make your own health care decisions and have not appointed a health care proxy, the Family Health Care Decisions Act provides a prioritized surrogate list (spouse/domestic partner, then adult child, then parent, etc). Your surrogate must make health care decisions in accordance with your wishes, including your religious and moral beliefs. If your wishes are not known, the

surrogate makes decisions according to your ‘best interests.’ The surrogate decision maker is also permitted to direct the withdrawal of life-sustaining treatment if specific clinical criteria are met. For more information, see the NYS Bar Association’s Family Health care Decisions Act Resource Center, <https://nysba.org/fhcda-resource-center/>

Of course, the best way to ensure that your specific wishes are met is to execute a Health Care Proxy and Living Will. Notably, reliance on the Family Health Care Decisions Act can be problematic for a number of reasons: it is very complicated; conflicts can easily arise; it is unlikely that the surrogate will know your wishes and, even if they do, there are very difficult standards for making decisions to withhold or withdraw life sustaining treatment; and finally, the person who is designated as the surrogate by the Act may not be the best person to make decisions.

#### **F. APPOINTMENT OF AGENT TO CONTROL DISPOSITION OF REMAINS (‘DORA’)**

New York has a law giving you the right to designate someone to handle your remains. A DORA is a document that takes effect upon your death, when the health care proxy terminates. Such a document may seem unnecessary to many individuals, but it does provide a means of providing burial instructions to the named agent. Keep in mind that a Will is often not read until a probate proceeding has begun and the burial or other disposition has already occurred. Thus, the terms of a DORA become applicable prior to the Will. Pre-planned funeral arrangements can be used in conjunction with the Disposition of Remains document. Notably, litigation over one’s remains- which happens more often than one might think- can be avoided with this document, giving those left behind guidance and peace of mind. For more information see [https://www.health.ny.gov/professionals/funeral\\_director/disposition\\_of\\_remains.htm](https://www.health.ny.gov/professionals/funeral_director/disposition_of_remains.htm)

#### **CONCLUSION**

If you become unable, even temporarily, to make health care decisions, someone else must decide for you. Naming a health care agent that you trust, and talking with them and to your doctors on a continual basis about your values, wishes, and goals, will ensure that you receive the health care that you desire.

## ADDITIONAL RESOURCES

### NYS Department of Health

- ‘Advance Care Planning and Advance Directives FAQ’-  
[Advance Care Planning and Advance Directives FAQ \(ny.gov\)](#)
- ‘Deciding about Health Care- a Guide for Patients and Families’  
<https://www.health.ny.gov/publications/1503.pdf>  
In addition to discussing advance directives, this publication covers (1) decisions to withhold or withdraw life-sustaining treatment in hospitals and nursing homes, (2) decision-making standards for legal guardians and surrogates in hospitals and nursing homes, and (3) resolving disputes in hospitals and nursing homes if surrogates disagree.

### NY Attorney General’s Office

- ‘Advanced Directives- Making Your Wishes Known and Honored’  
<https://ag.ny.gov/sites/default/files/advancedirectives.pdf>