

## Advance Care Planning Use Questionnaire

**1) Please provide your contact information, including the name of your organization (if applicable), name of contact person, title, phone number, and e-mail address.**

New York State Association of Health Care Providers (HCP)  
Tom Conlon  
Associate for Public Policy  
518.463.1118 ex. 811  
conlon@nyshcp.org

### ***Questions for Healthcare Providers Only***

While HCP is not itself a health care provider, the responses to the questions in this section are based on feedback from HCP members that are home care agencies that provide home care services across the State.

**2) Do you assist individuals in filling out a Health Care Proxy, Nonhospital DNR, and/or MOLST?**

- a. If yes, who do you typically assist in filling out forms? For example, are the majority that fill them out over 65, over 85, female, male, recently diagnosed with an illness, etc.?**

Home care agencies are required at time of admission to educate and inform all clients of these options and typically encourage their clients to consider the completion of advance care planning forms. They often supply the "Health Care Proxy Forms" and the related "Guidance on Advanced Planning" when a case is opened. Home care agencies also often request copies of any existing Health Care Proxy Forms, MOLST, and non-hospital DNR forms at that time.

For those agencies that provide considerable end-of-life care and/or complex medical care, the nursing staff are involved in the process and do make themselves available to support clients and families as they make these difficult decisions, especially when it comes to completing and updating the MOLST. In managed long term care cases, case managers often work with clients on establishing health care proxies.

- b. If yes, which form do you use most often?**

It varies from agency to agency as well as with the types of services being offered.

**3) Do you regularly have advance care planning conversations with patients?**

- a. If so, how often do you initiate advance care planning conversations?**

In home care, particularly when providing care to chronically ill clients, advance care planning is encouraged when a case is opened and further discussions take place if there is a significant change in the status of care, for example if a client requires palliative or hospice care. Again, for those home care agencies that provide end-of-life care, clinical staff do initiate these conversations as needed, encouraging clients and families to prepare in advance with their medical provider(s) and, as appropriate, involving legal counsel to protect their wishes.

It is also a question on the UAS assessment, so the question is covered by the UAS nurse, who may work with the client on the forms. UAS is used to determine managed long term care (MLTC) service authorizations for Medicaid cases and is conducted when someone enrolls and then receives a 6 month reassessment. In MLTC cases, case managers also work with clients on establishing health care proxies.

**b. If so, who do you typically have the conversation with? For example, are the majority that you have the conversation with over 65, over 85, female, male, do caregivers bring it up first, recently diagnosed with an illness, etc.?**

Generally, this discussion takes place with clients, both male and female, when the case is opened and/or if a client or family member expresses concern or has questions. On average, client age is above 65 and tracking varies from agency to agency.

Given the challenges with acceptance of end-of-life care conditions, it is not uncommon for the conversations to be initiated by compassionate caregivers who understand the prognosis of an acute or chronic life-limiting condition and the reluctance of individuals to begin talking about their fears and anticipated losses. These conversations are best held in collaboration with medical providers who are skilled and knowledgeable in palliative/comfort and hospice care.

**4) Explain the barriers to regularly discussing advance care planning with your patients.**

The primary barrier appears to be understanding the difference between caring for someone at the end-of-life and providing end-of-life care. While they are intertwined, they are not the same. Recognizing end-of-life conditions and dynamics can be difficult. Family patterns of communication and interaction can be strained at the end-of-life unless individuals have been willing to hold these discussions along the way. Guiding caregiving staff in the recognition of these issues and how to compassionately introduce critical questions regarding care preferences is most important.

Aside from hospice/palliative care agencies, there are few licensed or certified home care agencies that have pursued advanced training in end-of-life care, but there are exceptions. For example, one of our member agencies has an administrator who has received end-of-life care certification and she provides training in end-of-life care to her staff with special attention given to the role of the home care aide and nurses.

**5) How easy is it to learn if a patient has a Health Care Proxy, DNR, or MOLST?**

This can be challenging in home care. It can be difficult to obtain a copy if a client is not coming from a hospital setting with a complete discharge summary. Clients may have difficulty remembering if they have forms and where they are located, and family members may or may not know where forms are kept for their family members receiving care.

**6) How easy is it to access advance care planning documents during a health emergency?**

It can be very challenging to locate the documents in an emergency in home care. A common way of keeping a current document on file is to have one placed on the home refrigerator and copies filed with the agency, providers and family. In cases where an agency knows that the client has the documents and the location, access to that location varies and may not be accessible – or quickly enough – during an emergency.

**7) Do you track the use of the Health Care Proxy, MOLST, and nonhospital DNRs in your organization? If so, how do you track the use and do you find the documents utilized often and appropriately?**

In home care, tracking varies from agency to agency, but once forms are secured tracking may only occur if the client's situation changes. Most agencies rely on chart audits and clinician judgment to assure that the documents are current.

**8) What are the most common errors made in completion of the Health Care Proxy, MOLST, and nonhospital DNR?**

Again, in home care, errors vary due to a variety of factors including when and where the forms were completed. If completed at home, the health care proxy can be missing a witness signature. Documents, particularly the MOLST, appear to be most current and on hand when there is a medical provider who is willing and able to make home visits. When done in tandem with a visit from the home care RN, the document can be updated from visit-to-visit. The challenge here is the shortage of providers available for in-home visits whether in person or via tele/video conferencing.

**9) Do you or your organization offer advance care planning education for patients, public, and/or health care providers? If so, would you be interested in having a contact for you or your organization listed on a NYS Department of Health Advance Care Planning website?**

Home care agencies provide training for their nurses, clients and staff, but would not typically offer training for the public or other health care providers. Interest in being listed on a NYS Department of Health Advanced Care Planning website would vary depending upon the agency. Offering standard training in this type of planning would be beneficial to clients, families and agency clinicians and administrators.

**Questions for All Respondents**

**10) If you have discussed end-of-life wishes and advance care planning with family members, friends, and/or your health care provider, how easy or difficult was it to begin the conversation? What changes would make these forms easier for patients.**

It is routine to begin advance care planning discussions when opening a case because it becomes part of the discussion about the client's status, overall health and interest in how home care services can assist everyday living. It can be challenging for clients and/or their families to face end-of-life situations and begin those conversations. In the home care population, the increased frequency of hospital visits (emergency, observation and inpatient) in a short period of time typically indicates that an individual is entering the end-of-life cycle. While this may not mean imminent death or active dying, it is a way to help individuals and families understand that they are in a different phase with plateaus and the likelihood of regaining health is not anticipated. Options such as comfort care and selecting interventions of choice are ways to start and continue this discussion.

It would be helpful to have one standard document that is introduced as a routine part of practice and care, and takes the individual and family through a series of questions and decisions that may be used now or down the road. Sharing this document or information that indicates the status of completion, designated individuals with access to the form and storage/location of the form would be helpful to all providers involved in the individual's care. In home care, the biggest challenges are holding the

conversations, knowing the conversation has been held, and getting a copy of the documents, especially the MOLST, which will guide care planning.

An example of a document that would be helpful to get providers on the right path is as follows:

I \_\_\_\_\_ have completed a health care proxy / advanced directives / MOLST and my physician, Dr. \_\_\_\_\_, has these document(s) on file and knows my wishes. I \_\_\_\_\_ give permission to \_\_\_\_\_ to discuss these documents and my wishes with my physician to plan accordingly for my care.

**11) Are the current advance care planning forms (MOLST, Health Care Proxy, DNR) easy to understand? Please explain.**

No. They are not the same and they do not necessarily provide the same information. It would be helpful to have similar wording on all forms, or for the forms to clarify how they are different and how they interface with other documents. Another option would be to combine them into a universal form with different categories.

**12) If you have a Health Care Proxy, MOLST, or nonhospital DNR, who initiated the conversation and when? Were you satisfied with how that conversation went?**

An administrator from one of our member agencies reported that she initiated a health care proxy and living will through her attorney after experiencing horrific challenges with older relatives who believed they did everything to plan for their wishes and sadly found out that their decisions did not cover them as well as they had hoped. As a result of the gaps in the documents, one relative lived with an indwelling catheter and g-tube after a stroke even though he specifically indicated “no tubes” on his living will. Not everyone has these experiences, nor does everyone have access to an attorney in advance of a health crisis.

**13) What types of material or educational tools would be useful to you in having the conversation around advance care planning?**

It would be helpful and make it easier for clients, families and staff if there was a video, such as YouTube, or a DVD to walk them through the process. YouTube has become quite popular in getting information out to the general public and would be most efficient as videos could be updated as needed.

**14) How easy is it for you to fill out and understand the Health Care Proxy form?**

The form is not difficult to fill out but standardized wording and/or conformity with the other forms would be helpful.

**15) Is there any language or other changes you would like to see to the Health Care Proxy? Please explain.**

No.

**16) How easy is it for you to fill out and understand the MOLST?**

What is helpful with the MOLST is that it is completed in the context of an informative, open and direct conversation with the provider. As long as the client has the opportunity to ask questions and clarify

their expectations, this form is “easy” to complete because the provider guides them through the process.

**17) Is there any language or other changes you would like to see to the MOLST? Please explain.**

The key to the MOLST is the conversation with the provider, individual and family. This is most important and will determine what interventions are selected.

**18) What do you believe are some of the reasons why more people are not having the conversation on advance care planning?**

In general, people may not recognize an end-of-life care situation and many are not comfortable having end-of-life conversations. At times, it can be family members that do not want to face the reality for themselves and their loved one. With medical advances and access to state-of-the-art medical care in this country, people are living longer with chronic, life-limiting conditions and they do not always have a sense of urgency regarding the need to plan ahead. Compassionate providers and caregivers are instrumental in introducing the value of advance planning and helping all understand the course of a disease. Having videos or simplified or integrated materials that help start the conversations would be beneficial in removing barriers.