

NEW YORK'S APPROACH TO ADVANCE CARE PLANNING IN THE PEDIATRIC POPULATION

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Introduction

Advance care planning is a continual process of planning for future medical care in the event an individual is unable to make medical decisions. Advance Care Planning assists an individual in preparing for a sudden unexpected illness or injury, from which an individual may recover, as well as the dying process and ultimately death.

Initiating advance care planning early is relevant at all ages, as no age group is immune from acute illness or injury, complex chronic conditions, or death. Improving communication and advance care planning is critically important for all ages facing the end of life, including children and adolescents.

Advance care planning for children differs from adult advance care planning, as it depends on the stage of child development, which affects communication and the patient's understanding of illness and death. Further, there are differences between children's diseases and causes of death, as well as greater involvement of family members as decision makers; and the emotional impact of the child's illness on parents and siblings (Zhukovsky, 2008).

Providing families with timely, accurate information and support in shared decision-making is vital in caring for children with serious illness. Sharing information and working with a family to define goals for care (and secondarily what sorts of medical therapies make sense to do or not to do) can be challenging when the discussion involves seriously ill children and their parents.

Discussions with families and children about goals for care should start when a child is diagnosed with a serious illness and continue throughout the course of the child's illness. Goals for care are not static and may change over time, depending on the nature and trajectory of the illness. Participation in systematic advance care planning programs may enhance positive emotions and facilitate communication, lead to treatment modifications, and support having death occur at home (Lotz et al., 2013).

Parents of children who will not survive need time for making decisions and preparing for their child's death. Physicians can help parents improve their decision-making capability by providing the opportunity to make decisions that accord with the family's values and beliefs; by ensuring parents have a thorough understanding of the child's health status and prognosis, and by affording opportunities within each clinical encounter to build trust and reinforce parents' competence (Hinds et al., 2010). Parents believing that "they have acted as 'good parents' in such a situation is likely to be very important to their emotional recovery from the dying and death of their child" (Hinds et al., 2010).

Background

Infants die, most often as a result of heritable or congenital disorders or sudden infant death syndrome. Injuries are the leading cause of death for children; by adolescence and young adulthood, accidents and violence cause more than 70 percent of deaths (Heron, 2013). In general, the number of pediatric deaths due to trauma and other acute causes has declined, while the number attributable to complex chronic conditions has risen. A third of pediatric deaths are among children with one or more complex chronic conditions, including a wide array of often-rare diseases that require specialized care and often involve developmental disabilities. The three most common trajectories near the end of life are sudden death (such as from trauma), fluctuating decline (such as worsening heart failure), and constant medical fragility



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(as with some neurologic impairments) (IOM, 2014).

The typical barriers to conducting advance care planning in adult populations are also present when the patient is a child or adolescent—reluctance to discuss dying, cultural norms that support family-level decisions, clinician time constraints, unpredictable disease trajectories, and insufficient clinician preparation to conduct such discussions. In addition, the process is made more difficult by concerns regarding the child’s cognitive and emotional development and both the child’s and parents’ readiness to participate in such conversations; the emotional burden on parents and caregivers; differences in understanding of prognosis between clinician and child/parent; unrealistic expectations among parents; and the need for a three-way conversation and communication among parents, children, and clinicians (Durall et al., 2012).

Nonetheless, advance care planning models suitable for children and adolescents (“minor patients”) have been developed. Under New York State Public Health Law, a “minor patient” means any person younger than 18 years old. In New York, people younger than 18 can become emancipated through marriage, with the birth of a child, by living independently, or through court decisions; young people in any of those situations are treated as adults.

An approach to advance care planning was developed in New York with two programs that support advance care planning as a process and appropriate completion of two types of documents created as part of that process, each unique and specific to the appropriate population:

1. Community Conversations on Compassionate Care (CCCC): advance directives for all individuals 18 years of age and older; or emancipated minors
2. Medical Orders for Life-Sustaining Treatment (MOLST): medical orders for life-sustaining treatment for seriously ill persons of all ages facing the end of life. MOLST is New York’s nationally-endorsed Physician Orders for Life-Sustaining Treatment (POLST) Paradigm program.

Community Conversations on Compassionate Care (CCCC) and Advance Directives

Community Conversations on Compassionate Care (CCCC) is an advance care planning program designed to motivate all adults 18 years of age and older to start advance care planning discussions that clarify personal values and beliefs; choose the right spokesperson; and complete a health care proxy. CCCC combines storytelling and “Five Easy Steps” that focus on the individual’s behavioral readiness to complete a health care proxy (CCCC Five Easy Steps, n.d.).

Individuals are advised to choose the ideal Health Care Agent, who must:

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

In the CCCC model, when a child approaches his/her 18th birthday and has the ability to decide, it is recommended the young adult choose a health care agent and complete a health care proxy. People younger than age 18 who are married, have a child of their own, are living independently or are otherwise emancipated can also choose a health care agent and complete a health care proxy form.



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Similarly, the life-cycle model proposed in the IOM Report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, suggests an initial conversation about values and life goals should occur at some key maturation point—such as obtaining a driver’s license, turning 18, leaving home to go to school, work or into the military, or marriage (milestones when risks may change or the locus of responsibility shifts).

CCCC has generated positive outcomes, as noted in the CCCC Workshop Attendee Responses, 2002-2004 and the 2008 End of Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions (CCCC Workshop Attendee Responses, 2004; Excellus BlueCross BlueShield, 2008). CCCC is nationally recognized as an example of a preferred practice: “Develop and promote healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals” (NQF, 2006).

The CCCC program was developed to support the Medical Orders for Life-Sustaining Treatment (MOLST). Program at a time when no one, not even a concerned family member, had the right to make decisions about medical treatment for patients who lacked capacity, except DNR, unless the patient had signed a health care proxy or left “clear and convincing evidence” of his or her treatment wishes.

Medical Orders for Life-Sustaining Treatment (MOLST): ACP for Seriously Ill Children

Medical Orders for Life-Sustaining Treatment (MOLST) is a clinical process that results in completion of the MOLST form, a set of medical orders that reflect the parents'/guardians' preference for life-sustaining treatment they wish their child to receive and/or avoid. MOLST is approved for use and must be followed by all providers in all clinical multiple settings, including the community. MOLST is the only medical order form approved under NYS PHL that EMS can follow both Do Not Resuscitate (DNR)/Allow Natural Death and Do Not Intubate (DNI) orders in the community in New York.

MOLST emphasizes discussion of family values and beliefs, the goals for the child’s care, and shared medical decision-making between health care professionals and the child’s parent or guardian. Clinicians are guided in the process by use of the New York State Department of Health MOLST Checklist for Minor Patients. This Checklist and the associated MOLST Chart Documentation Form integrates a standardized 8-Step MOLST Protocol to guide a thoughtful discussion and process, as well as incorporate the ethical framework and legal requirements for making decisions to withhold or withdraw life-sustaining treatment in New York State. The ethical framework and legal requirements to withhold/withdraw life-sustaining treatment in NYS must be followed whether or not the MOLST form is used (Bomba, 2005; New York State Department of Health, 2012; MOLST Chart Documentation Form, 2013).

Capacity Determination

The capacity of children to participate in end-of-life decision making cannot be assumed and must be individually determined at each decision point (Hinds et al., 2010). Capacity begins at least by age 10 and in some cases by age 6. Many children can judge the balance between the burdens and benefits of treatment; children aged 5-6 often express their views in drawings and stories.

For minors with decision-making capacity, document the child’s views and preferences for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child’s wishes differ from those of the adult decision maker (NQF, 2006).

Appropriate Cohort

MOLST is generally for children with serious health conditions, for whom their physician would not be surprised if they died within the next year. Physicians are advised to consider a MOLST discussion if the child:

- Has medical decision-making capacity and wants to avoid or receive life-sustaining treatment.
- Lacks medical decision-making capacity and the child’s parent or guardian has already chosen to withhold certain life-sustaining treatment because of their known poor prognosis.



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- Might die within the next year.
- Is highly likely to experience clinical decompensation and discussion regarding consideration of life-sustaining treatment is appropriate.

These patients may:

- Want all appropriate treatment, including cardiopulmonary resuscitation (CPR).
- Want to avoid all life-sustaining treatment.
- Choose to limit life-sustaining treatment
- Want to avoid any attempt to initiate cardiopulmonary resuscitation (CPR) and prefer to Allow Natural Death (DNR order)
- Want to avoid placement of a tube down the throat into the windpipe connected to a breathing machine (intubation) and request a “Do Not Intubate Order” (DNI order).

Pediatric palliative care is interdisciplinary care that aims to improve quality of life and reduce suffering of children with a life-threatening medical condition. Advance care planning is a key pillar of palliative care and provides families with timely and accurate information and support in decision making. The care plan prevents or treats pain and symptoms and supports the child and child’s family.

All seriously-ill children should receive palliative care, but all are not appropriate for MOLST. Predicting the time course and prognosis of disabling genetic or congenital disorders that affect children is problematic. The MOLST for Minor Patients Workgroup, composed of pediatric palliative medicine experts, developed clinical guidelines to help with making end-of-life decisions using MOLST. Research has yet to fully establish their usefulness in clinical practice (MOLST for Minor Patients Workgroup, 2013a).

The clinical examples are based on the Association for Children with Life-threatening or Terminal Conditions & their Families (ACT) criteria and illustrate when thoughtful MOLST discussions should and should not be considered (MOLST for Minor Patients Workgroup, 2013b):

1. *Life-threatening conditions for which curative treatment may be feasible but can fail.* A “goals for care discussion” may be particularly important during phases of prognostic uncertainty and when treatment fails. For example, if a child experienced severe head injury as a result of acute trauma in a motor vehicle accident, a thoughtful MOLST discussion is appropriate. Generally speaking, a child who has relapsed Acute Lymphocytic Leukemia within a year of diagnosis has a poor prognosis, yet cure is possible; thoughtful goals for care and MOLST discussions are appropriate. In contrast, a child with newly diagnosed ALL has an excellent prognosis, and a MOLST discussion is *not* appropriate at the time of initial diagnosis.
2. *Conditions in which there may be long phases of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is anticipated.* Young children with cystic fibrosis, Duchenne’s muscular dystrophy, or well controlled HIV are *not* appropriate to have a MOLST discussion, as death may not happen for years. However, if health status and quality of life declines secondary to a serious complication or disease progression (e.g. a patient with cystic fibrosis who is listed for a lung transplant), thoughtful goals for care and MOLST discussions are appropriate.
3. *Progressive conditions without curative treatment options, in which treatment is exclusively palliative and may commonly extend over many years.* A child with Spinal Muscular Atrophy Type I typically experiences steady decline with a life expectancy of only a few years. Thoughtful MOLST discussions are appropriate earlier in the course of disease.
4. *Conditions with severe neurological disability which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not considered progressive.* Children with severe anoxic encephalopathy often have profound patient care needs, including poor airway control. Thoughtful goals for care and MOLST discussions are appropriate. *Not* every child with cerebral palsy is appropriate for a thoughtful MOLST discussion. However, complications such as scoliosis, severe restrictive lung disease, recurrent aspiration pneumonias, and feeding intolerance do put the child at risk for frequent hospitalizations, as well as ventilator



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support. With progressive complications, the condition ultimately can become life-threatening. In summary, as these children grow and develop such complications, MOLST discussions are appropriate. For a child who has phenylketonuria and is on an appropriate diet, thoughtful MOLST discussions are *not* appropriate.

Care Plan to Support MOLST

In order to be effective, MOLST orders must be supported by a person-centered, family-oriented care plan and family and caregivers must be educated about what to do in an emergency. Children nearing the end of life face symptoms similar to those of adults. Studies of children with cancer have found the patient symptoms most frequently reported by parents to be pain, fatigue, dyspnea, change in behavior, and loss of appetite (Pritchard et al., 2010; Wolfe et al., 2000). Pediatric palliative care experts can provide a holistic approach to managing these symptoms while meeting the child's and family's goals for care.

Conclusion

Children with serious illness and their families deserve timely, accurate information and support in shared decision-making. While challenging, the communication and shared decision-making process is rewarding and the ultimate in professionalism.

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Additional Resources

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

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT _____

ADDRESS _____

CITY/STATE/ZIP _____

DATE OF BIRTH (MM/DD/YYYY) _____

Male Female

eMOLST NUMBER (THIS IS NOT AN eMOLST FORM) _____

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

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

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

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

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

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

Check *one*:

CPR Order: Attempt Cardio-Pulmonary Resuscitation

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

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

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

SECTION B Consent for Resuscitation Instructions (Section A)

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

SIGNATURE _____

Check if verbal consent (Leave signature line blank)

DATE/TIME _____

PRINT NAME OF DECISION-MAKER _____

PRINT FIRST WITNESS NAME _____

PRINT SECOND WITNESS NAME _____

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

SECTION C Physician Signature for Sections A and B

PHYSICIAN SIGNATURE _____

PRINT PHYSICIAN NAME _____

DATE/TIME _____

PHYSICIAN LICENSE NUMBER _____

PHYSICIAN PHONE/PAGER NUMBER _____

SECTION D Advance Directives

Check all advance directives known to have been completed:

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



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

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT _____

DATE OF BIRTH (MM/DD/YYYY) _____

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

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

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

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

Instructions for Intubation and Mechanical Ventilation *Check one:*

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

Future Hospitalization/Transfer *Check one:*

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

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

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

Antibiotics *Check one:*

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

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

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

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

PRINT NAME OF DECISION-MAKER _____

PRINT FIRST WITNESS NAME _____

PRINT SECOND WITNESS NAME _____

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

Physician Signature for Section E

PHYSICIAN SIGNATURE _____ PRINT PHYSICIAN NAME _____ DATE/TIME _____

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This MOLST form has been approved by the NYSDOH for use in all settings.



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