

ChiPPS E-Journal

Children's Project on Palliative/Hospice Services

Released in collaboration with the National Hospice and Palliative Care Organization

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ChiPPS E-Journal
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**Issue Topic: Advance Planning in Pediatric Hospice/Palliative Care,
Part Two**

Produced by the ChiPPS E-Journal Work Group

Welcome to the 39th issue of the ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our E-Journal offers a PDF collection of articles that explore selected issues in advance planning in pediatric hospice/palliative care. Because this is a very important subject, we have decided to devote two issues to these discussions, of which this is the second. The articles in these two issues argue for the value of advance planning, describe tools for that purpose, offer suggestions concerning how to initiate advance planning conversations, and indicate who should be involved in this care. We appreciate that no two issues or limited collections of articles will do justice to these broad topics, but we hope that the articles in this issue and in the one that preceded it will spur discussion and implementation of advance planning as a cooperative enterprise with children, adolescents, their family members, and the professionals involved in their care. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's E-Journal Workgroup, chaired by Christy Torkildson. Archived issues of this publication are available at www.nhpc.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy at christytork@gmail.com or Chuck Corr at ccorr32@tampabay.rr.com.



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Issue #39:

Advance Planning in Pediatric Hospice/Palliative Care, Part Two

(Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles)

Futility and Fairy Tales

p. 4

Laurie Hicks, MD

We begin this issue with a brief poem by a new contributor meditating on planning for end-of-life care.

New York's Approach to Advance Care Planning in the Pediatric Population

p. 5

Patricia Bomba, MD, FACP

This article notes some of the unique issues that arise in advance care planning with children and describes the development in New York state of the Medical Orders for Life-Sustaining Treatment (MOLST) Program. A copy of the two-page MOLST document accompanies this article, which concludes that, "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."

Family of Terminally-Ill Ann Arbor Boy Challenging School District's End-of-Life Policy

p. 13

Ann Fitzsimons, BS, MBA

When a family with a child with a severe life-limiting condition finds that his health is declining long after his predicted life expectancy, they come to the conclusion that a Do Not Resuscitate (DNR) order would be in his best interests. However, the policy of the local school district is not to allow such orders. The situation is described in this brief article and a link to the original media report is provided, both showing a clear need for the discussion that follows in the next article.

Do Not Resuscitate Orders Go To School

p. 14

Kathy Davis, PhD, MSEd

Issues associated with Do Not Resuscitate (DNR) or Do Not Attempt Resuscitation (DNAR) orders and their implementation in school settings are complex. This article describes the background for such issues and shows why close collaboration between school personnel, families, and health care providers is needed. Suggestions for such collaboration are offered.

Perinatal Advance Directives

p. 22

Sheryl Allston, MDiv, BCC, Melanie Chichester, BSN, RNC-OB, CPLC, & Wendy J. Sturtz, MD

Helping families develop advance directives in perinatal situations is a challenging task. This article illustrates why and how that has been done in one hospital

EMS and the Pediatric Hospice Patient

p. 25

Monroe Yancie, AAS; CCEMTP; EMTP; EMS Educator

One important consideration in pediatric hospice and palliative care is coordination with emergency medical services. The goal is to achieve the smoothest cooperation and the best outcome for patients and families. This article sets forth some considerations that need to be taken into account to achieve that goal.

When It's the Doctor Who Can't Let Go

p. 28

Theresa Brown, PhD, BSN, RN

Although originally based on an adult care situation, this article reports a familiar example in which it is some of the physicians who cannot let go. The article ends with the observations that the job of physicians "might actually be easier if they found a way to better use what palliative care can achieve for patients, and not only at the end of life. Physicians also need to recognize that there are occasions when the patient's fate is not, in the end, the doctor's work. Every patient deserves care on his own terms, for each patient's life, and death, is his own."

Items of Interest

p. 30

In each issue of our ChiPPS E-Journal, we offer additional items of interest.



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FUTILITY AND FAIRY TALES

Laurie Hicks, MD

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One misty moisty morning when cloudy was the weather,
 Harold took out his purple crayon and drew up a chair
 and I sat down and said
 tell me, do you wish to go quietly into that good night
 or do you wish to rage against the dying light
 because isn't that what it's all about?
 Cardiopulmonary resuscitation-heart, lungs, bring me back to life.
 Pound, tube, crack, shock--
 rage, rage, cry, oh! but do not slip away.
 No go out fighting, but you are not fighting;
 you are still and we are fighting for you
 and your dearly beloved, we are gathered here to wonder
 why if a mouse asks for a cookie and also gets a glass of milk
 but a girl ask for lungs and does not get them
 do we then have to ask
 what is the purpose of fairy tales if they don't come true?

With thanks and apologies to:

Harold and the Purple Crayon. Crockett Johnson

Do not go gentle into that good night. Dylan Thomas

If You Give A Mouse A Cookie. Laura Joffe Numeroff



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

Patricia Bomba, MD, FACP

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Chair, New York's MOLST Statewide Implementation Team & eMOLST Program Director

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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 NYSPLH 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



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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 _____

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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FAMILY OF TERMINALLY-ILL ANN ARBOR BOY CHALLENGING SCHOOL DISTRICT'S END-OF-LIFE POLICY

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Parents are very brave to be able to get to the point where they can actually talk about and decide to implement an advance care plan for their medically-complex child. Despite what the popular culture might believe, creating an advance care plan for a child with a life-limiting or life-threatening condition does NOT mean that they do not love their child; in fact, quite the contrary. It suggests that they love their child so much that they have thought about what is or will be best for their child in the future, regardless of whether or not this is what they, as parents, want to do or have happen. However, even when families are able to progress to doing advance care planning for their child, that does not mean it will be an easy road, as this article will attest to.

Willy Pickett was diagnosed with a rare brain disorder as an infant and was given just two years to live. With excellent care and medical interventions, Willy has surpassed expectations and lived to be 11. However, his health has been declining in recent years, prompting his family to think about what the future might bring, and relatedly, what they think is best for Willy should he need to be resuscitated. After much soul searching and consulting with Willy's healthcare team, including palliative care, Willy's family decided to sign a DNR order for Willy should he code at home, at school, or in the hospital. However, at the current time, the school district has made it clear that they will not honor this DNR order if something were to happen to Willy at school. The school district's attorney was quoted as saying, "...It would be inappropriate to invalidate a school policy designed to protect students, teachers and the school district by holding that parents have the unwavering right to withhold medical care from a child."

Willy's parents have responded by filing a lawsuit against the school district in an effort to get them to honor the DNR order and deem the existing school policy unconstitutional. They also hope it will spare other families the grief and pain they are experiencing in knowing their end-of-life wishes for their child will not be honored. Seemingly, this is an issue in Michigan schools (as well as presumably in school districts across the nation) as it is estimated that one-third of Michigan schools have a policy where DNR's will not be honored, one-third do not, and the remaining one-third have never heard of a DNR order. Clearly, there is much work still to be done here by and on behalf of families like Willy's so that their end-of-life wishes are honored for their children at home and in the classroom.

The article by John Counts, "Family of terminally ill Ann Arbor boy challenging school district's end-of-life policy," was published by mlive.com, on March 29, 2015. It can be found at http://www.mlive.com/news/ann-arbor/index.ssf/2015/03/family_of_terminally_ill_ann_a_1.html



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DO NOT RESUSCITATE ORDERS GO TO SCHOOL

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Introduction

Children with serious health conditions are living longer and attending school despite being medically fragile (Wolfe & Selekman, 2002). An estimated 19.2%, or 14.2 million, school-age children have chronic health conditions which involve special healthcare needs (Bethell et al., 2011). In 2010, the American Academy of Pediatrics (AAP) estimated that, on any given day, 2,500 adolescents and 1,400 preadolescents are within 6 months of dying from their chronic condition including cancer and end-stage heart, liver, or kidney disease (Adelman, 2010). Deaths from serious illnesses have decreased in all pediatric age groups. However, those who are dying are far less likely to do so in a hospital. In 1998, for example, 43% of older children and young adults with a complex chronic condition (CCC) died at home, up from 21% in 1980 (Feudtner et al., 2002). Some of these children have a Do Not Resuscitate (DNR) order while they are in the hospital and they would like that DNR to follow them to school. Without a DNR at school, they may receive medical intervention that will cause them further harm or they will be forced to choose to stay home and be denied the education that the law guarantees them. For many children, school attendance is equated with “being normal” (Interview of C. Forman, 2008) and may enable a young person to “feel like I’m alive” (Interview of A. Woodbury, 2008).

Some progress is being made, while barriers continue to exist in ensuring that all children who want to go to school despite having DNR status can do so. Very few schools have adopted policies related to DNR orders. One study revealed that 80% of the nation’s 50 largest school districts and districts in 31 additional state capitals did not have a policy, regulation, or protocol supporting a student’s Do Not Attempt Resuscitation (DNAR) order in 2005 (Kimberly et al., 2005). Even when a school wants to support a child’s DNR it is difficult to do so unless there is a legal framework at the state or local level. Without that, school personnel may risk liability if they honor the DNR orders.

School personnel express fear regarding how they will manage a child with a DNR at school, as well as concern about the other students’ needs. Zacharski et al. (2013) reported that most deaths of students with DNR/DNAR orders did not occur at school. Despite this, the opportunity for a child to attend school and be ensured that his/her DNR request is honored is not guaranteed in all states, or in all school districts, or even in all schools across the United States. This group of children may constitute the last population of public school children who are left behind.

Legislation, Policy, and Practice

During the past 45 years, several pieces of legislation, health policy, and conventional wisdom have paved the way for acceptance of Do Not Resuscitate, or DNR/DNAR/AND, orders for children near the end of life. (NOTE: DNR describes the act of not providing chest compressions, electric shock, ventilation or medications to maintain heart beats in a person who has stopped have a pulse and/or breathing. More recently, Do Not Attempt Resuscitation [DNAR] and Allow Natural Death [AND] have been used to describe a more realistic, patient-centered description. For the purposes of this article, DNR will be used as an inclusive term.) The 1970s gave rise to federal education and civil rights legislation, as well as a statement from the American Heart Association (AHA) that would prove to have a far reaching impact on children and adolescents with chronic complex conditions or life-limiting diagnoses. Out of that statement came the attempt, by physicians, to determine for which patients CPR was, and was not, appropriate (Safar, 1989). Thus, the concept of DNRs was born. Section 504 of the Rehabilitation Act of 1973 and Public Law 94-172, the Education for All Handicapped Children Act of 1975 (later codified as the



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Individuals with Disabilities Education Act or IDEA), each ensure that all children will have the opportunity to attend school and receive necessary accommodations to be successful at school. The U.S. Department of Justice (2005) defined this further, stating that children with special healthcare needs are entitled to a free and appropriate education in the least restrictive environment. Thus, more children with complex chronic conditions (CCCs) and life-limiting diagnoses are attending school. And some of those adolescents or children's parents and physicians have agreed that cardiopulmonary resuscitation (CPR) does not constitute the best choice in healthcare for that child.

The AHA, in a 1974 statement, declared that cardiopulmonary resuscitation (CPR) was not indicated for all patients. The statement explained that those patients with terminal and irreversible illnesses, where death is anticipated, do not always merit CPR. In fact, in-hospital CPR was found to prolong pain and suffering or result in the patient being placed on a ventilator to keep them alive. In that scenario, loved ones must make the emotionally devastating decision of whether to remove the patient from the ventilator. This is the situation that patients and loved ones who choose DNR seek to avoid, knowing that the interventions and escalation of support may cause pain and suffering for the patient while leading to the same, inevitable outcome of death. CPR applied out of the hospital also results in potential complications, and often warrants a degree of concern regarding its lack of effectiveness. A summary of studies showed that typical survival to hospital discharge after Out of Hospital (OOH) CPR occurred for less than 10% of children, and many others incurred severe neurologic complications (Topjian et al., 2008).

The AHA report in 1974 encouraged physicians to educate patients, surrogates, and loved ones about the limits of CPR and engage them in discussions about their end-of-life wishes. Patients with serious illness or frailty, their loved ones or surrogates, and their physicians determine the type of care to be provided when CPR is not indicated. In addition to CPR, other types of care, including mechanical ventilation, electric shock, or medications to restart the heart, are discussed and the patient's/surrogate's wishes are identified. The types of medical procedures or care that will be provided are clearly defined at this new stage of illness, with the healthcare team emphasizing that *care* does not end but, rather, becomes better suited to the patient's needs. These discussions are called "goals of care" discussions, and the resultant care is known as "comfort care" due to the emphasis on keeping the patient comfortable and focusing on excellent physical, psychological, social/emotional, and spiritual care. Comfort care can be carried out in the hospital or in a hospice and palliative care setting. Some pediatric palliative care programs are engaging school personnel, early in the child's school career or diagnosis, to be part of the palliative process by providing increased focus on the child's psychological, social/emotional, and sometimes spiritual care.

When goals of care conversations occur in the hospital, the plan of care is documented in the patient's chart. Less frequently, these decisions are made in the doctor's office and then it is more difficult to document the patient's wishes for future reference. The need to document a patient's goals of care both inside and outside the hospital setting led to the development of the out-of-hospital DNR, or OOH DNR. The requirements and the paper form utilized for an OOH DNR vary from hospital to hospital and from state to state, with some states' criteria being very specific and detailed.

The OOH DNR ensures that a patient's wishes are known in all situations. For example, EMS providers are required to initiate all types of treatment, for which they are trained and qualified, in order to prevent a person's death. Usually, EMS personnel begin resuscitation immediately unless they see a valid OOH DNR. It is recommended that the patient/surrogate possess at least 2 copies of the OOH DNR at all times. Each state has their own DNR forms and those forms are typically not recognized from state to state.

Physician Orders for Life Sustaining Treatment (POLST)

The OOH DNR led to recognition that there is a group of patients who need a written plan that is more comprehensive and goes beyond resuscitation orders. As opposed to individuals who have an Advance Directive that informs loved ones of wishes for *future* end-of-life care wishes, patients who are seriously ill and whose doctor can say that they would not be surprised if the patient dies within a year, need a tool



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that outlines *current* medical care needs including, but not limited to, resuscitation orders. The Physicians Orders for Life Sustaining Treatment, or POLST, may address everything from aggressive medical treatment, at least for the foreseeable future, to resuscitation wishes. Like the OOH DNR, the POLST document has a wide degree of variability. Not all states have adopted a POLST and the ones that have vary in content and the plan name and acronym (TPOPP, MOST, MOLST, COST, etc.). An advantage to the POLST vs Advance Directive in this discussion is that a POLST is accepted for any person with a serious illness, regardless of age. Only persons age 18 and older can have an Advance Directive that is recognized. (<http://www.POLST.org> accessed 11/12/14) (POLST has gained the broadest base of recognition and acceptance and is used to represent all similar forms. Check your state to determine what is accepted there.)

Pediatric Issues

Fetuses, infants, and children with serious illness or anomalies, along with their parents, also engage in goals of care conversations with the doctor and healthcare team. During these conversations, the child's wishes and goals drive the direction of subsequent healthcare interventions. For some children, continued attendance at school, or a return to school if they have been absent for a lengthy period, is very important. It is widely accepted by education and healthcare professionals that school has benefits for all children, and the federal law IDEA guarantees all children the right to attend school. Students benefit from the social and emotional opportunities realized when interacting and spending time with their peers in a familiar environment where they can maintain their normal routine (Klick & Hauer, 2010).

Twenty years ago, the American Academy of Pediatrics (AAP) and the National Education Association (NEA) independently developed guidelines for foregoing life-sustaining CPR for children and adolescents who wanted to return to school (AAP, 1993; NEA, 1994). The AAP has turned their guidelines into a policy, which was updated in 2000 and 2010 (AAP, 2000; AAP, 2010; for the latter, see <http://pediatrics.aappublications.org/content/125/5/1073.full.pdf+html>). The stage has been set for the possibility of Do Not Resuscitate (DNR) or Do Not Attempt Resuscitation (DNAR) orders to go to school, enabling children with serious health conditions the opportunity to achieve success, spend time with friends, and develop to the greatest extent possible. The AAP guidelines advocate that pediatricians have a responsibility to support children, and recommend that parents develop a consensual agreement with school personnel regarding the child's medical needs at school (AAP, 2000). For children and adolescents, psychosocial well-being may be enhanced by school attendance. Being with friends and having the opportunity to develop optimally may be just what the doctor ordered. As the child's condition deteriorates, many children and adolescents have strong opinions about where they want to die, who they want to care for them, and who they would like to have with them at the end of their life.

DNR and POLST Orders Go To School

When a pediatric patient's disease progresses or their physical condition begins to deteriorate, children and adolescents, along with their parents and physicians, may have to make heart-wrenching decisions to stop aggressive treatment and elect care that focuses on pain and symptom management and comfort. A formal document may be written to reflect the child's and parent's decisions, made in concert with the physician's recommendations. Do Not Resuscitate orders or Physician's Orders to Limit Treatment (POLST) are the types of plans previously discussed that support the patient's goals of care. This document will be helpful in ensuring that all key stakeholders understand the decisions that have been made. Extending that information to schools when a child with a DNR or POLST wants to attend school is a relatively new concept. Although there have been several cases scattered throughout the U.S., the practice is far from being widely accepted or practiced in schools.

Educators' Concerns

Schools are not medical facilities, and school personnel often make that statement when engaging in conversation about DNR orders at school. That statement summarizes the concerns of school personnel, reminding others that this is a new frontier about which they know little and, therefore, feel a great deal of concern. School personnel have limited or no knowledge about medical issues, including DNR orders, and have likely received no training in college courses or in staff development on DNR or related topics. This lack of knowledge can create a climate of fear that has the potential to spread in the teachers'



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lounge, to parents, and to students. A study by Hone-Warren (2007) of school administrators' attitudes regarding DNR policies in the school setting was a significant contribution to the topic. Hone-Warren found three major themes representing administrators' concerns including: (1) lack of knowledge; (2) fear and anxiety; and (3) emotional aspects. Fifteen administrators participated in the study and only one felt that a child's DNR request could be accommodated by the school. The literature regarding school personnel perceptions of DNR orders at school is limited. Even less has focused on the attitudes of school staff other than the school nurse. Thus, this study, despite its limitations of small sample size, may offer some insight into the concerns that must be addressed before DNR orders at school may be more readily addressed.

The first topic, lack of knowledge of school personnel, was a pervasive concern in the study and one that is heard, anecdotally, from school personnel. One administrator was "shocked to learn that parents could write DNR orders for their children." A response from another administrator was that the family merely needed to note on the emergency form that they had chosen DNR for their child. Yet another thought there would be questions about the family's right to make a DNR determination for their child. Others expressed concern about how the DNR orders would be handled in school stating, "Administrators are not medically prepared to make this decision; an order would be a subjective decision and it would be difficult to follow a DNR if one thought another medical intervention could assist a life." Yet another responded, "District employees are not trained to determine if a situation is truly life or death" and "Qualifications of staff: is this a time a DNR is needed or a time for a Band-Aid?" Seven of the participants questioned the qualifications of themselves or their staff and concluded that such an order should not be honored at school. "I just don't think it is my place," stated one respondent. These comments express a common concern of school staff: How does a non-medical person determine if the child has reached the end of life and the DNR should be followed, or if he has choked on a piece of food and other interventions are appropriate.

Second, fear and anxiety responses were present for 11 of the 15 respondents with the following statements, "I think it would be horrendous" and "I would feel like I had abandoned the child." One participant acknowledged, "Educators are helpers, in general and it would be difficult. The whole domain of talking about death and children is near taboo, an emotionally laden issue that can cause conflict and stress." Seven participants believed that an ethical/moral dilemma exists and acts as a barrier to the development of a DNR order in the environment of school.

Finally, the emotional aspects of a DNR policy included comments that showed concern about the children's and the faculty's well-being. The reaction of others at school to the death of a child was mentioned as an emotional aspect. Three participants mentioned that the student body would experience a negative response to a student's death: "Children may have fears. They might be wondering, 'Would they save me?'" Another commented that "you would have to deal with the questions of kids and parents: 'Why didn't they do something?'" Others were concerned about how it would affect them, personally: "My plate is full. I don't need this, thank you." Other concerns centered around the fear of litigation and confidentiality. There were six participants who mentioned that they would not tell the local community about the DNR policy if one was enacted: "Don't advertise, don't make an announcement. It doesn't work that way. Just put a line or blurb in the parent handbook regarding, 'If you have a need for a DNR order at school, contact the school.'" Another stated, "You probably aren't going to have a 'Do Not Resuscitate Night' at school. Honestly, I can't see doing a lot of education with the community about it."

These concerns are consistent with what is reported in the literature and what has been observed in discussions with other school personnel (Interviews, USD #500, 2008). An attorney for USD #500 expressed concern about a state statute that required teachers or others on site who have CPR training to "work on the child and try to keep them alive until emergency medical personnel arrive on the scene. The statute tells us what we are to do and it is not stand by and watch and wait. We could be liable if we just stood by." Another administrator stated, "I can't imagine it. The child would fall to the floor and what? – the other kids would just stand around the child on the floor while the adults tried to keep everyone calm?"



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Barriers to DNR Orders at School

Common themes have identified sources of barriers which prevent the success of DNR orders in school. Warren identified three main concerns expressed by administrators. **Lack of knowledge** was one area reported by Warren, and it gives way to **fear and anxiety**. The common response to fear and anxiety is an **emotional response**. The same concerns may be expressed by teachers who are ultimately **responsible for the success**, or failure, of a DNR at school. When a student with a DNR comes to the classroom, the teacher does not have the information and knowledge that is required to make the experience a positive one. She may be concerned about all of the potential ‘worst case scenarios.’ He may be concerned about the **time** that he perceives will be involved in caring for a student with a DNR and wonders how he will be able to continue **spending ample time engaged in teaching other students**. Trying to imagine the death in the classroom and how she will **care for the student with a DNR** while **addressing the needs of the other students** in her classroom is also a possible fear of teachers. Finally, the **teacher feels sad, frustrated, or overwhelmed** by the presence of the child with a DNR in his or her classroom. The easiest solution is to attempt to prevent the child’s presence at school and the cycle of doubt and fear is perpetuated.

Some schools and school districts have, however, successfully implemented DNR orders at school. When that occurs, children are enabled to spend the rest of their lives living the life they choose. Although, obviously, it could occur that there have been no publicized reports of a child with a DNR order dying at school and research has reported that deaths do not usually occur at school.

Legislation, including Section 504 of the Rehabilitation Act which prohibits discrimination against a person solely on the basis of a handicapping condition and IDEA which guarantees a free and appropriate education to all children, serve to enable children with serious health conditions to attend school. The NEA and the AAP have developed guidelines and policies that acknowledge the appropriateness of the child with a DNR of attending school. All that remains is to make it happen on a consistent basis, at the school district and school level, ensuring that a child will have the right to attend school near the end of life, regardless of where he or she lives in our country. Further, state legislatures must first change any statutes or legislation that tie the hands of school personnel and create a barrier to providing education for a student with a DNR order.

Collaboration Between Home, Hospital, or Hospice and School

Teamwork between the child’s parents/caregivers, healthcare providers, and school team will be imperative to the successful incorporation of a DNR order at school. Patience and an attempt to ‘walk a mile’ in the other person’s shoes will be most helpful. Currently, the topic of DNRs at school evokes fear and emotional responses due to the unknown nature of what it might look like and what may be required of school personnel. Healthcare providers should prepare to afford a great deal of patience as they provide education and support to school professionals. Education should begin with administrators at the district level, proceed to building administrators, and then to teachers and building staff. Sometimes, it takes the child’s request for a DNR order at school to start the process and achieve buy-in among the school staff. The teacher, who may have argued against the idea of DNR orders at school on a hypothetical basis, may be the best champion of the real child in his classroom who wants to return to school with a DNR order. Working with a child who has a DNR order and gaining an understanding of what that means, on a human level, will likely provide the greatest degree of acceptance among school personnel.

Recommendations for Collaboration

First, a face-to-face conference between patient (if appropriate), parents/caregivers, healthcare providers, and the education team is an essential first step. Sitting around the table allows for communication that is honest and complete. Teachers and administrators can ask questions much more easily in a live setting than via telephone. Relationships between the various stakeholders begin, thus providing the school personnel with known resources when later questions or concerns are realized.

Education of teachers and others in the school is fostered in this setting and can continue via email or phone. In addition to educating the educators, parents and other family members may hear information



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that they may not have heard before, or which bears repeating. Healthcare providers learn about the child and family in a rich way that has not presented itself previously, now seeing them in their natural habitat.

Next, it is common knowledge that not only the content of the message, but the way it is presented is of utmost importance in determining if the message will be heard and appreciated. If school personnel feel immediate fear and trepidation in regard to a child's DNR orders, they are likely formulating responses regarding why this plan will *not* work, rather than looking for opportunities to contribute to its success.

A positive approach to introducing the OOH DNR may be as a segment of a more comprehensive POLST document. It may be easier and more familiar to educators to learn of the OOH DNR as a part of the overarching medical plan that addresses what, specifically, will be done for the child both while he/she is at home or hospital and while he/she is at school. Learning about how other symptoms will be treated may reduce concern about the child being in pain or having significant nausea, vomiting, or other symptoms while at school. Educators can feel confident that the child's medical needs have been addressed. This direction of discussion frees the teacher to begin seeing the child as their student, and not as a patient for whom they feel unprepared to provide care.

It is also important to discuss that DNR orders are not simply orders to do *nothing*. Rather, the DNR/DNAR should be only a part of a significant palliative care treatment plan that spells out the child's care, focused on managing pain and other symptoms as well as addressing the child's emotional, psychological, and spiritual needs. The focus is on what *can* be provided to the child for comfort, rather than the highlighting the previous treatments that are now ceasing. Educators are then free to become an integral part of the palliative care team, addressing the psychological and social/emotional needs of the child. The school nurse likely has already developed an Individualized Health Care Plan or IHCP for the student. Goals of care in the POLST and the IHCP can be integrated and developed to ensure that all providers are on the same page regarding the child's healthcare plan. Comparison of the POLST to the IHCP may further reduce school professionals' concerns by bringing familiarity to the new type of plan.

Another plus of a POLST format is, in contrast to an Advance Directive, the POLST can be used by patients younger than 18. Including the OOH DNR within the POLST document may afford a document that is more easily accepted by school personnel. Rather than focusing solely on the resuscitation status of the child, the POLST provides a holistic overview of all medical orders for the child, potentially offering comfort in the knowledge that the child is still receiving medical care. In addition, healthcare professionals and the patient or parents can team to provide education to the child's classmates, if desired by the child and parents. The information will vary, depending on the age and developmental level of the peers. At any age or stage, children can understand that their friend is sick, but that they are still the same person as before who enjoys being in school and being with their friends.

After helping school personnel develop general knowledge about DNR orders, the healthcare team provides education about the roles of school staff if the DNR must be implemented in the school setting. The goal is to get the child to the nurse's office and ensure that he/she is comfortable until emergency medical providers arrive. The school can develop a team that will be activated if the child's DNR must be implemented at school. For example, an administrator could be called to help transport the child to the nurse's office, thus freeing the teacher to stay with her class and provide support to them. Perhaps the school social worker or counselor could join the teacher, providing support for the teacher and additional care for the other students. The school nurse would attend to the child in his/her office until the EMTs arrive and ensure that the EMTs have a copy of the child's OOH DNR. The school secretary would be responsible for calling 911 and the child's parents.

Parents have the responsibility of frequent communication with the school nurse, teacher, or other school personnel. If the child is hospitalized or anticipated to be absent for an extended period of time, parents should inform the school. Parents also should talk to the appropriate school staff if there are concerns about any facet of the child's school experience. This type of communication will ensure that the school experience is positive, rather than resulting in a decision to stop attending school when it is still important to the child. It is likely that there will be aspects of the experience that need to be addressed or 'tweaked'



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along the way. Finally, parents will be the primary communicators with school staff as the child's health status changes. The entire team may be involved in determining when the time to stop attending school presents, or the parents may determine that independently.

Strong communication begins with the initial meeting between parents, healthcare providers, and the school team, and continues throughout the child's school attendance. Often, children with DNR orders at school become sicker or more fatigued and the decision is made to stop attending school. Thus, the child may be at home, in the hospital, or in a hospice facility when he or she dies. Wherever death occurs, the development of a strong team of all stakeholders will help ensure that the child's life was what he/she wanted it to be.

Conclusion

The path to developing OOH DNRs at school for students who want them, has been a long and winding road, and the journey has not ended yet. Since the early 1970s, legislation has been developing that speaks to the child's right to attend school, regardless of his/her disability. Education and medical organizations have supported a child's right to attend school and the school's responsibility to make that possible. Despite these steps, there are still barriers that make a child's reentry or return to school difficult when he/she has an OOH DNR.

The specifics of developing an OOH DNR that will be implemented at school are varied from school to school and from child to child. Prior to working to develop a plan for a specific child's OOH DNR orders at school, the school district must be surveyed to determine if they have a policy or have discussed the issue of DNRs at school. Even then, each school is likely to respond in various ways, even when in the same district. Not every state has the option of having an OOH DNR or a POLST type document to direct a patient's care when he/she is not in the hospital. However, it is possible, despite the lack of supports, for any child to have a DNR order which can be implemented at school and it is the responsibility of the healthcare professional to address the issue in the case of every child who wants to return to school.

Bringing a child's DNR into the school setting brings unique challenges and complexities. Developing a team comprised of the patient if appropriate, parents, school team, and healthcare providers is the first step. Establishing strong communication within the team is essential to success. The school staff has likely had no training, and possibly no personal experience, with DNRs and may not know what a DNR is (Warren, 2007). Knowledge is power, and providing education to school staff will empower them to engage a child with an OOH DNR as a student, rather than patient, to the greatest extent and as long as possible.

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One of the saddest events in the life of a family is the death of a baby. Sometimes parents are faced with the reality of saying hello and goodbye at the same time. Often, completely stunned by the unexpected outcome, they are left devastated and unable to plan in advance the way they and their baby want to be cared for in the death of their precious little one. In some situations parents have some warning, such as the parents of a baby who know well in advance, in fact, even early in their pregnancy that a good outcome is not expected. Also, parents of a baby in the Neonatal Intensive Care Unit who were not expecting the news that their baby most likely will not survive are often faced with decisions to be made about how to proceed. In the latter two circumstances, perinatal advance directives can aid families and the entire hospital interdisciplinary team to care well for the baby and family in their baby's dying.

Families in situations in which the reality or risk of losing a baby is realized suffer multiple losses in addition to the anticipated death of a newborn: loss of the expectation for a healthy baby, loss of a normal pregnancy, loss of normal parenting, loss of normal routines and life celebrations such as preparing a nursery or baby showers and birthday parties, loss of future hopes, loss of the opportunity for a joyous homecoming or welcoming, and an overall loss of control.

Original hopes and life plans often have to be realigned and new ones established. A sense of control and coping can be gained through identifying attainable new goals through a birth plan, or perinatal advance directive. When time after a baby is born may be much shorter than expected or much more precious than originally realized, identifying specific realistic wishes to accomplish and providing direction to the health care team on how to best provide compassionate care to their baby is important.

Our large tertiary care hospital has a perinatal palliative care team with the acronym, IMPACT (Infant, Maternal, Pediatric Advanced Care Team), to aid families in difficult situations. The team partners alongside the primary medical team that is already caring for the family and adds an extra layer of support for the family and staff. IMPACT's goal is to support the best quality of life for the baby (as defined by the family) by giving meaning, dignity, and comfort to babies and their families through holistic family-centered care. IMPACT cares for babies and their families who may be facing life-threatening situations and who pursue curative medical interventions or those who choose to place limits on medical care. Families who meet the team prenatally are assisted in developing a birth plan including advance directives for their baby to outline the goals of care and identify special opportunities for memory making.



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Also, IMPACT can assist in establishing a similar plan for babies in Labor & Delivery or the Neonatal Intensive Care Unit, if requested. IMPACT consists of neonatologists, neonatal nurse practitioners, nurses, and a chaplain and works very closely with social work, obstetrics, labor and delivery, and maternal-fetal medicine.

When a family knows in advance of the delivery that their baby will likely not survive or extraordinary measures will need to be implemented to keep their baby alive a consult is made to IMPACT. The neonatologist and often at least one other member of IMPACT will review the medical records of the mother and baby addressing questions they might have, ensuring the family's understanding of the medical situation, and clarifying the medical condition if needed. IMPACT will develop the birth plan together with the family, addressing each anticipated step along the way from prenatal visits to the delivery and the postpartum period. The goal is to establish a comprehensive unique plan of care that best aligns with the family's goals. Ultimately, we review appropriate advance directive options such as allowing a natural death while in a supported environment, offering a trial of medical support, or pursuing life-prolonging interventions such as respiratory support with intubation, oxygen without intubation, cardiovascular support, nutritional support, etc. Life-prolonging interventions may be desired while the family comes to terms with the reality of the diagnosis, or may be part of a plan for a special, hoped-for moment. The family may be awaiting a grandparent to arrive to say hello/goodbye, or deeply desire to be able to take their baby home, if only for minutes. These specific advance directives regarding the family's level of desired medical support often are better addressed after establishing a relationship that includes realizing a family's hopes and goals, and are often decided after much discussion.

An initial consult with the mother/family often takes two hours as they work through the questions, concerns, and the family's wishes and desires. It is important work to honor the life of a baby as well as the role of the mother/family in the process. In the beginning of all conversations, it is important to ask if the family has chosen the baby's name, and if so, inquire about the significance of the chosen name, and use the first name at all times in referring to the baby. The team will ask about how they are honoring the baby in pregnancy, knowing the baby may not survive. This begins by encouraging the family to acknowledge the life alive inside of the mother and recognizing the relationship that already exists. We often encourage the mother and family to actively create memories while still pregnant and offer possibilities such as keeping a diary, playing songs to the pregnant belly, reading books, listening to the heartbeat at each visit, offering a teddy bear that records the heartbeat, and obtaining ultrasound pictures at each visit that can be used in developing a memory book. Pictures of the mother's pregnant belly can also be stored in such a memory book. We also discuss experiencing memorable activities such as identifying special places to go to while pregnant, such as a park and swinging on a swing.

Details about the circumstances of the delivery are reviewed, including who should be present: family members, friends, religious support, medical team, and IMPACT team members. Also discussed is where the baby's initial time should be spent: together in mother's delivery room or transition to a private postpartum room, less intensive pediatric floor, or the Neonatal Intensive Care Unit. Through this discussion each family can establish the desired/anticipated mood for the day of delivery such as private and respectful or a traditional celebratory gathering. A family's interest in religious or spiritual support during pregnancy, after birth, and at the end-of-life is reviewed. IMPACT strives to support families through considering many possible activities to experience in the time that they have toward the end of the baby's life—to actively create memories and share lessons learned from previous family's experiences. We review special opportunities to consider such as holding their baby with warm blankets, bathing and dressing the baby, bringing special blankets or clothing for the baby, taking pictures, making footprints, making molds of the baby's hands and feet, obtaining a lock of hair, or creating artwork with imprints of hands of the entire family. We are fortunate at our hospital to be able to offer *Now I Lay Me Down To Sleep* photography services for families and many cherish the very sensitive and beautiful pictures that they provide. Other families have had a birthday cake celebration on the baby's birth, made Christmas ornaments with the baby's footprints on them, placed footprints on special cloths, and requested to listen to the baby's heartbeat with a stethoscope. Importantly, each family and baby's experience is unique and time is spent the way in which they feel most comfortable. Understanding that families may hold different cultural beliefs, we strive to be open-minded as to what families may deem



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appropriate, and embrace when they decline or choose something we had not yet considered.

We spend time providing reassurance that the staff will do their best to pay attention to their baby's comfort and the need for pain control through warmth, holding, drops of colostrum or sucrose, or sublingual opioid medication. Finally, when death has come, we focus on supporting them through their grief. The value of anticipatory guidance about physical changes and expectations through the dying process cannot be overstated. Education regarding physical changes and expectations through the dying process are critical, as many people are unfamiliar with what to expect as physical life ends. Preemptive discussions regarding autopsy, postmortem genetic testing, and funeral planning can be started prenatally to alleviate the need to spend time on those options in the sensitive time after a baby's death. We also provide information on available community and national resources such as support groups as well as funeral/after death options. We reinforce the awareness that any element of the birth plan/advance directive **may be altered at any point** and that the development of such a plan is a supported process.

After our team had been working with families for a while, we wondered about a structured advance directive for such a population. Recognizing the uniqueness of each family's experience and goals, it seems a greater benefit to have a consistent document for the perinatal population to prompt similar opportunities for all families. Our hospital recently embraced the document *5 Wishes* as a useful tool throughout the hospital for the adult population. We are grateful that our IMPACT team chaplain was aware of the *5 Wishes* document and reached out to the team to see if we knew such a document existed. We were aware of its use in the older pediatric population who could write and advocate for themselves, as well as one in place for teenagers and young adults. A similar document is lacking for the perinatal population and so we embraced the idea of working towards that goal. Currently a multidisciplinary team has been working on such a document and welcomes input from the larger perinatal palliative care community.

GOALS:

RESTORE CONTROL

REALIGN HOPE

CREATE MEANINGFUL MEMORIES

ACKNOWLEDGE AND HONOR A BABY'S LIFE



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EMS AND THE PEDIATRIC HOSPICE PATIENT

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Objectives:

- Discuss the hospice program history
- Review the various advanced directive history and paperwork
- Look at an EMS response for a hospice patient

Overview

When EMS responds to a hospice or Do-Not-Resuscitate patient, it is extremely stressful, especially when the patient is a child. The crew has to immediately decide whether to treat or withhold any care. The crew must be knowledgeable of the patient's paperwork and determine its validity.

The Hospice Program

Hospice care focuses on palliative care by alleviating pain and symptoms, and providing emotional and spiritual support to the seriously, chronically, or terminally ill patient.

The hospice concept was introduced in Europe in the 11th Century, when the Crusaders [1] treated incurable ill victims. During modern times, Dame Cicely Saunders, a Registered Nurse [2] (later became a Physician) started using the term "hospice" and provided specialized care for dying patients in 1948. She opened the first modern hospice in 1965, St. Christopher's Hospice, in suburban London. In 1965, Florence Ward, Dean of the School of Nursing at Yale University [3], invited Dr. Saunders to the University to become a visiting faculty member. After several years of research and a sabbatical, Dean Ward along with two pediatricians and a chaplain, founded the first hospice in the US in 1974 (Connecticut Hospice in Branford, Connecticut) [4]. It was also the first hospice to provide home care and today, over 90% of hospice care takes place at home. In 2010, 1,581,000 patients received hospice services.

Hospice for children is relatively new in this country. In 1983, only 4 of 1400 hospices would accept children. The Children's Hospice International (CHI) [5] was formed in 1996, helping to dramatically advance those mediocre numbers to 3,000 hospices accepting children and 450 centers that are child specific.

The Paperwork

There are several types of advanced directive forms floating in the medical world (e.g., The Living Will, Last Will, the Medical, Durable or Limited Power of Attorney, etc.). The only document that EMS will honor is the Do Not Resuscitate (DNR) form and the new Physician Orders for Life Sustaining Treatment (POLST) form.

The Do Not Resuscitate (DNR) Form

A DNR form [9] is a physician's order at the patient's (or his/her agent's) request to withhold CPR if he/she goes into cardiac arrest. It is signed by the patient (or agent) and the physician.

The DNR's start in the US was inside a New Jersey Supreme Court (1976) [6], which allowed the parents to remove the ventilator from their daughter. Strangely, she lived for 9 additional years after the ventilator was pulled [7]. In 1991, Congress passed the Patient Self Determination Act, which forced hospitals to honor a person's healthcare decision. Basic life support (BLS) and Advanced Cardiac Life Support (ACLS) will not be performed if a valid written DNR order is present. The DNR form must be completed and signed by the patient (or agent) and physician. Every state has a DNR form for out-of-hospital responders. They may use other names such as "do not attempt resuscitation" (DNAR), "no code," or "end of life."



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Physician Orders for Life Sustaining Treatment Form (POLST)

The POLST [8] addresses a patient's wishes in addition to the DNR order. In addition to the choice to receive CPR, the patient can also choose or deny the following: comfort care and symptom relief, limited or full treatment, antibiotic treatment, and hydration via a feeding tube.

The National POLST Program originated in Oregon (1991) [8], when it was discovered that patient's end-of-life care preferences were not honored. Fourteen states have endorsed the form and the rest of the country (minus 6 states) is developing the form (See Pennsylvania's form). POLST is also termed as MOST (Medical Order for Scope of Practice, COLST (Clinician's Order for Life-Sustaining Treatment), and POST (Physician Order for Scope of Practice).

What Happens When You Call EMS

When someone calls 911, the Emergency Medical Dispatcher (EMD) [10] will perform a series of steps: obtain the patient location and callback number; interrogate the caller for the nature of illness or injury with details; match the interrogation with the correct EMS vehicle response mode (red-lights and siren versus routine driving response); and provide pre-arrival instructions. Note that the EMD Center is part of the same EMS system, which works under the same guidelines as the EMS responders. Therefore, being a DNR or hospice patient will not modify the way that EMS responds. But, when you call EMS, you should inform the dispatcher that the call is an "Expected Death Situation" and/or "The patient has a "Do-Not-Resuscitate (or POLST) form." This will tell the dispatcher not to provide CPR instructions (which are normally given) to the caller. The EMD dispatcher will also inform the EMS crew about the patient's status, so they can expect to withhold CPR upon arrival, if the appropriate form is immediately provided.

Upon arrival, if the patient has a DNR form or POLST form (endorsed states only) [8], the medic will honor the form if it is present, valid, and signed by the patient (or agent) and physician. Conversely, if the form is not visible or valid, the medic will not hesitate to perform care. In some areas, the EMS crew will perform BLS-only care until they contact their medical control hospital for instructions if the family states that a form exists, but cannot provide it. The bottom line—when there is any doubt about a DNR or POLST status; the prudent medic will be a patient advocate and deliver patient care.

Much of the palliative care provided by an Advanced Life Support (ALS) medic unit is similar to the care provided in the Emergency Department. This includes: positioning the patient for comfort; oxygenation; maintaining the appropriate body temperature; nebulizer therapy and administering IV/IM medications such as analgesics, sedatives, and anti-emetics as needed.

If the family does not want to call EMS, the child can be transported via personal vehicle, but take into consideration that the ride may be uncomfortable (due to the vehicle's size and patient positioning) and dangerous (driving under duress could cause a vehicular crash). If the patient is on hospice, the hospice staff may be able to provide comfort care recommendations over the phone in an effort to avoid transport to the hospital. Some areas may have non-emergent medical transporters available to provide more comfortable transportation in non-emergent situation (such as attending a clinic appointment). Most hospice or palliative care programs should be able to provide information regarding these services in their area.

Summary

When a person is in a hospice program or with a DNR has a medical emergency, do not hesitate to call EMS. EMS will only honor the DNR form and, if state endorsed, the POLST form. If the form is not immediately available upon arrival and valid, EMS will provide patient care. Of course, EMS will follow their state and local protocols. If the patient is in a hospice program, advanced planning will help the family feel more comfortable with steps to take in an emergency situation. Note that an individual can be enrolled in a hospice program without agreeing to sign a DNR form [11].



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WHEN IT'S THE DOCTOR WHO CAN'T LET GO

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Sometimes it's the doctors, not the families, who can't let a patient go.

My elderly patient had lived much longer than seemed possible at the time of his cancer diagnosis. Ten years later, though, his relapsed lymphoma had become medically unstoppable.

The palliative care team was called in to manage his growing confusion and discomfort, and to discuss what we call "goals of care." That's what palliative care does: it focuses on keeping symptoms under control for the seriously ill and, for patients who can't be cured, addressing how they want to die, including the option of hospice care. Now that this patient's disease could not be restrained, what did he want? He could no longer answer, but his wife and son, sad but clear-eyed, chose to stop all treatment aimed at curing his cancer.

Hearing this, his oncologist, standing beside me at the nurse's station, cried, heartbroken that her patient of so many years would not rally one more time.

That evening, though, the patient's primary care doctor came to the hospital, seeing himself; it seemed, as the cavalry. There was hope yet, he said. The patient needed rehab to make him strong enough for more chemotherapy, not palliative care and hospice. So the patient—disoriented and unable to speak—went to an inpatient rehabilitation unit. He died there, a few weeks later.

I'm sure the primary care doctor meant well, but there's no question that his actions made the situation worse because he deprived the patient and his family of comfort at the man's life's end. And this was far from the first time I've seen something like this happen. Such situations arise in part because modern health care still embraces a false dichotomy between curative treatment and palliation, between making a patient healthy and relieving his or her pain.

Palliative care itself suffers from an identity problem, in that many people equate palliation with hospice—i.e., end of life. This mistaken association can make a palliative care consultation feel like a death sentence to even the most open-minded clinicians, patients, and family members. Striving for a cure is historically seen as a unique pathway that restores health; easing suffering is a separate, non-curative path that ends with the patient dying.

And it's true that palliative care does offer symptom management to patients who are expected to die soon, as my lymphoma patient was. But it is more than that. It also helps patients with long-term illnesses like congestive heart failure and chronic obstructive pulmonary disease; people who are expected to live with their illness, but need careful managing of their symptoms. If it becomes clear that a patient receiving palliation along with curative treatment will not survive her illness, then the palliative care group works with the medical team to help her make the transition to hospice and help her decide how to spend the last of her time on earth.

Palliative care can extend life, too. A well-known 2010 *New England Journal of Medicine* article co-written by Jennifer S. Temel, an oncologist at Massachusetts General Hospital, established that patients with a certain type of lung cancer who received early palliative care not only reported better quality of life and reduced symptoms of depression, but also lived longer than patients who received only traditional oncology care—a result that has since been found with other forms of cancer.

Often, though, the palliative care team is consulted late in the illness, as was the case with my patient. One reason is money; to put it in the crass language of hospital accounting, palliative care is de-



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incentivized. It saves hospitals money by reducing costly and often futile care at the end of patients' lives, but earns little compared with the expensive drugs and scans used in curative treatment.

But another barrier is the attitude of physicians themselves. Many oncologists, focused on keeping patients alive for as long as possible and hoping, always, to beat the odds, find it hard to discuss what might happen if they don't.

It was the same with my patient's oncologist. Hearing about the move away from palliation to rehabilitation, she sounded relieved. "Well, if he goes to hospice he'll just die," she said—as if there were another alternative. She knew better than anyone that our bag of chemotherapy tricks was empty, but facing that reality proved too hard.

Had the palliative care team been consulted earlier, it could have worked with the primary care doctor, the nurses on the floor, and the oncologist to understand and communicate the patient's wishes over a period of time, perhaps even when the patient could still speak for himself. Instead, the patient got lost in the back and forth, as did his family, caught between the rock of his imminent death and the hard place of arranging for rehabilitation that was presented as his salvation, but offered no real help or comfort.

Doctors face a difficult paradox. Their job is to keep patients alive, but part of that means keeping at bay the dark awareness that everyone dies. Because doctors are supposed to cure, efforts directed elsewhere, even palliative care, can feel like surrender. But their job might actually be easier if they found a way to better use what palliative care can achieve for patients, and not only at the end of life.

Physicians also need to recognize that there are occasions when the patient's fate is not, in the end, the doctor's work. Every patient deserves care on his own terms, for each patient's life, and death, is his own.

Theresa Brown is an oncology nurse and the author of *Critical Care: A New Nurse Faces Death, Life, and Everything in Between* (New York: Harper Studio, 2010). Originally published in the print edition of *The New York Times*, Sept. 6, 2014. Reprinted by permission of the author.



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ITEMS OF INTEREST:

In each issue of our ChiPPS E-Journal, we offer additional items of interest.

1. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL. For upcoming E-Journal issues, we plan to address issues related to: a starter kit or "how to" tools for new programs in pediatric palliative/hospice care, and respite care. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

2. READER'S CORNER. Our Reader's Corner columns provide brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.

3. ON BEING PRESENT, NOT PERFECT. The conversations that matter most in healthcare are often the most sensitive and challenging. From conveying serious diagnoses to ethical quandaries surrounding end-of-life care, these conversations are the bedrock of the patient-provider relationship. When they go well, patients' health outcomes, trust, and satisfaction with care are enhanced. In her highly praised TEDTalk, [On Being Present, Not Perfect](#), Elaine C. Meyer, PhD, RN draws on both professional and personal experience to illustrate the profound gaps in healthcare communication and how to close them. She unveils her vision to establish an emotional standard of care for patients and their families through honest, direct and genuine healthcare conversations. She introduces the "one-room schoolhouse" educational approach and shares the Wizard of Oz metaphor blending [Courage, Brains and Heart](#) to guide healthcare conversations. She also provides a helpful companion [Facilitator's Guide](#) to deepen the learning potential of the Talk. For more information, visit www.ipepweb.org or contact Elaine Meyer, Director, Institute for Professionalism and Ethical Practice, Boston Children's Hospital at elaine.meyer@childrens.harvard.edu.

4. PEDIATRIC CONVERSATION STARTER KIT AVAILABLE. A new resource created by The Conversation Project for parents of critically ill children, [Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child](#), is available for free download. The Kit offers advice and provides stories from parents and palliative care specialists who have been there, and offers questions that can help parents navigate the approach to the conversation based on the personality and cognitive level of the child.

5. PEDIATRIC ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES ARTICLES IN PALLIATIVE MEDICINE.

- "Advance Care Planning in palliative care: A qualitative investigation into the perspective of Paediatric Intensive Care Unit staff" by Sarah Mitchell and Jeremy Dale, *Palliative Medicine* 2015, Vol. 29(4) 371–379.
- Novel legislation for pediatric advance directives: Surveys and focus groups capture parent and clinician perspectives, by Renee D Boss, Nancy Hutton, Pamela L Griffin, Beth H Wiczorek and Pamela K Donohue. *Palliative Medicine* 2015, Vol. 29(4) 346–353.

6. FAMILIES' PERSPECTIVES OF QUALITY OF LIFE IN PEDIATRIC PALLIATIVE CARE PATIENTS.

Medical and academic institutions began prioritizing Pediatric Palliative Care (PPC) less than two decades ago. Although policies and institutions claim to improve the Quality of Life (QoL) of PPC patients and their families, family-defined QoL remains ambiguous. This research investigates the definitions of QoL for PPC patients according to their primary caregivers. [Read](#) the full article by Erin Gaab, *Children* 2015, 2(1), 131-145.

7. PEDIATRIC PALLIATIVE CARE CONFERENCES, TRAININGS AND MEETINGS:

- **PEDIATRIC PAIN MASTER CLASS** will be held June 20-26, 2015, in Minneapolis, MN. The



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Pediatric Pain Master Class offers state of the art education in pain management for the pediatric patient from a holistic and interdisciplinary perspective. The program features a faculty of internationally recognized experts who will cover pharmacological, medical, psychosocial and integrative aspects of pediatric pain management. Learn more and register [here](#).

- **7th CARDIFF INTERNATIONAL CONFERENCE on PEDIATRIC PALLIATIVE CARE** is planned for **July 8-10, 2015**, in Cardiff, Wales, UK. The conference, "Medicine and Compassion: Tool for the Task...Or Dangerous Distraction?" is sponsored by the International Children's Palliative Care Network (ICPCN) and by Cardiff University. More information is available at www.icpcn.org.
- **NHPCO's PEDIATRIC PALLIATIVE CARE TRAINING AND INTENSIVE.** Held in conjunction with NHPCO's 15th Clinical Team Conference in Grapevine, TX, the two-day Pediatric Palliative Care Training will be held **Oct. 13-14, 2015**. This two-day preconference seminar will provide pediatric palliative care training for new and developing pediatric palliative and hospice care professionals. Following the two-day training, the Pediatric Intensive will be held during the Clinical Team Conference, **Oct. 15-17**, and is an intermediate level session track designed to develop professionals and organizations to provide care to infants and children facing life threatening conditions and their families. Visit NHPCO's education [webpage](#) for more information and registration details.

Please e-mail pediatrics@nhpco.org to have your pediatric palliative care educational offering listed in the ChiPPS E-Journal.

8. NEW PEDIATRIC GLOBAL PARTNERSHIP. [Global Partners in Care](#), NHPCO's International Affiliate Organization, would like to congratulate [Akron Children's Hospital](#) in Akron, OH, for their new partnership with [Happy Feet Home](#) in Mumbai, India. When asked why his organization chose to partner with Happy Feet Home, Chair of the Department of Pediatrics, Dr. Norm Christopher stated, "*While almost half a world apart, the Haslinger Family Palliative Care Center at Akron Children's Hospital and the Happy Feet Home in Mumbai have the same primary goal -- to provide children who have life-shortening conditions with every opportunity to live a high-quality and dignified life. We are pleased and proud to be sharing our experiences with our international partner to help us be even better prepared to advance our common mission: comprehensive, compassionate care for the world's most vulnerable citizens.*" To learn how your organization can [become a global partner](#) with a pediatric hospice and palliative care organization in a developing country, contact info@globalpartnersincare.org.

9. DUCHESS OF CAMBRIDGE SENDS MESSAGE RE: UK'S CHILDREN'S HOSPICE WEEK. [Children's Hospice Week 2015](#) takes place in the UK **May 11-17**. It is the UK's only awareness raising and fundraising week for children with life-limiting conditions and the services, like children's hospices, that support them. [Read](#) the Duchess of Cambridge, Kate Middleton's emotional letter urging people to support Children's Hospice Week.

10. SIGN UP FOR EHOSPICE TO RECEIVE INTERNATIONAL PEDIATRIC NEWS. ehospice is a globally run news and information resource committed to bringing health care professionals the latest news, commentary and analysis from the world of hospice, palliative and end of life care. Sign up to receive news about international pediatric hospice and palliative care initiatives plus news from the U.S. and other countries at www.ehospice.com.



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Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to pediatrics@nhpco.org requesting to be added to our mailing list. . If you are a member of NHPCO, you can go to the **Communications Preferences** tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the NHPCO/ChiPPS Web page at www.nhpco.org/pediatrics for further materials and resources of interest.

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Pediatric Resources

Free for Healthcare Professionals:

- ChiPPS E-Journal - quarterly publication
- NHPCO's Facts and Figures on Pediatric Palliative Care and Hospice
- Pediatric Palliative Care Standards of Practice for Hospice Programs
- Pediatric Concurrent Care - Briefing and Implementation Toolkit
- Brochures for Families with Seriously Ill Children - English and Spanish available

Education Opportunities:

- NHPCO Clinical Team Conference & Pediatric Intensive:
 - Held Annually, Special Pediatric Session Track
- Pediatric Palliative Care Training:
 - Two Day Preconference, NHPCO Clinical Team Conference and Pediatric Intensive



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NHPCO gratefully acknowledges ChiPPS (Children's Project on Palliative/Hospice Services) whose members serve as NHPCO's pediatric advisory council and are responsible for many of these resources.



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