



# The Palliative Care Patient: Pursuing A Final Peace

by Julie Aberger

### EMT Objectives

After reading this article, the EMT will be able to:

- define palliative care and identify the types of patients for which it was developed;
- discuss important considerations when encountering palliative care patients in the field;
- understand the composition and functions of palliative care teams;
- identify and understand the directives contained in DNR and POLST forms.

*A 59-year old woman with colon cancer metastasized (spread) to the liver, pancreas, lung and brain presents to the ED with new onset of shortness of breath and abdominal pain. On exam she is in moderate respiratory distress, lungs clear, tachypneic, tachycardic, mildly hypertensive, hypoxic, her abdomen is diffusely tender with a hard palpable mass. Her daughter is at her bedside. Per daughter, mom was feeling short-of-breath all day, and then fainted returning from the bathroom to bed; witnessed by daughter; denies head trauma.*

*The ED physician orders the standard treatment for the patient: labs; chest x-ray, C-T scan for possible pulmonary embolus; admit to ICU. -From a physician's history of a patient seen in the emergency department. (To be continued...)*

### Introduction

Every day, a large proportion of people with serious illness appear at the emergency department (ED). Indeed, the ED has become a sort of "staging area" for these patients, i.e., it

is up to the physician to quickly diagnose and determine whether the patient is moved to more immediate aggressive care within the hospital, or is symptomatically treated and discharged.

Most EMTs know, first-hand, the disastrous consequences a severely ill or injured patient endures when he is kept alive with ventilators and feeding tubes, passed from one specialist to the next. Those excruciating calls where we witness the suffering of the seriously ill patient often cause us to question the wisdom of modern medicine.

*"My husband died in pain; no one else should anymore,"* reads one recent headline in an urban newspaper. A wife made an impassioned plea for state legislation that would provide medications to assist patients to die. Her husband had had pancreatic cancer that necessitated a feeding tube to allow gastric juices to flow out of his stomach. She wrote: *Before he passed away, he was groaning, agitated, his arms and legs would flail, and he was in pain – nothing made him comfortable. He died suffering and he deserved better.*

In the past 15 years a new medical specialty has evolved in response to this deleterious side effect of high tech medicine. It is called "palliative care," and its purpose is to provide seriously ill patients with the option of symptom-directed medical care in place of disease-directed treatments whose purpose is to cure.

This is not "giving up," on a patient, but instead aims to decrease suffering and restore peace and dignity to the

critically ill person in the time he has left.

In 2004, my daughter, Kate Aberger, became an emergency medical physician. Eight years later, she left full-time ED work and began the practice of palliative care. Here is the story of her transition.

### Fighting The "Battle"

When Kate first began practicing in an ED in north Jersey, she fought to preserve life for all patients, keeping them alive and winning the "battle" with death. Physicians are healers, their life-saving practices based on science-based evidence. There was little thought given to the process of "dying." After several years, however, she began to founder, weighing what she had experienced in the ED with what seemed to her ethically wrong.

*The most difficult patient...[wrote Kate] was the chronically ill or terminally ill patient who came in extremis, usually from a nursing home. Resuscitating them was tantamount to assault and battery on someone who would not benefit at all from my intervention. When I asked the family if they wanted "everything done," they said, of course, yes. I failed to see the impossibility of the choice I had offered.*

*Night after night I persisted, with little thought given to the future of those patients. I focused solely on getting them to the next level of care: the ICU, the floor, surgery, CT scan, even back to the nursing home. I found myself rationalizing to assuage my guilt and helplessness: "Let them sort it out." "The family will catch on sooner or later." "I don't want to take away hope." "Who am I to determine when patients have crossed the imaginary line between life and death?" It*

became a moral struggle: Is living at any cost “winning?”

Palliative care evolved out of this ethical dilemma: How do physicians treat patients with serious chronic or terminal illnesses? Should all medical treatments be exhausted and life prolonged in spite of futile prognoses?

Today I argue that people with serious illnesses are one of these populations that are chronically underserved, passed on from specialist to specialist with few taking responsibility for their medical dilemmas as human beings. Conversations about serious illness and death are one of these issues no one wants to deal with. Instead of asking “Why us?” let us ask “If not us, then who?”

### Why We Don’t “Give Up”...

Why would a patient or her family want to prolong painful treatments when they’ve been told such treatments are futile?

Psychologically, some people have a tendency to assume that a course of treatment will succeed even when the outcome is uncertain, a psychological state called *optimism bias* (“The doctors don’t know just how stubborn Dad is.”) Others believe if they think positively, their condition will improve, a condition called *performative optimism* (“I understand I may die...I guess I have to hope more.”) Others believe in miracles, (“God’s not ready for Mom yet.”) And some differ in their opinions, (“Fred’s looking better every day. He was lying there in a coma. Now he’s in there talking!”)

It’s not a simple misunderstanding between the patient and the physician: People don’t understand bad prognoses due to emotional and psychological mechanisms that must be addressed.

### Physicians’ Oath

Physicians are bound by their professional ethics to “Do No Harm,” but what does that actually mean? (While some medical schools ask their graduates to abide by the Hippocratic Oath, others use a different pledge — or none at all.) The Oath states:

*“The physician must be able to tell the antecedents, know the present, and foretell the future — must mediate these things, and have two special objects in view with regard to disease, namely, to do good or to do no harm.”* There is no clear priority given to the avoidance of harm over the goal of providing help.

As high tech as our modern medicine has become, seriously ill patients now find themselves hopelessly ensnared in specialists, hospitals, tests, medicines, and treatments, while often not even understanding what’s wrong with them. Poor and conflicting communication between multiple specialists and patient/family generates confusion; reconciling differing reports is overwhelming. Very often patients and their families are unable emotionally to “take in” what the physician is saying. They do not understand the medical system or how it works.

Kate described the painful realization of watching physicians deal with her father who was dying of a muscle-wasting disease that defied diagnosis. At an office visit, after years of care, his neurologist bluntly told the family that he simply had no other treatment options, and to contact hospice:

*This doctor, like many of us, may have been driven by a sense of failure, fear of death, powerlessness and impotence that we feel in the face of serious illness and death. Instead of dealing with these emotions, physicians shut down and pass off the patient to the next specialist. Besides, he might have not been trained in the art of having a conversation with a patient and family about serious illness and death. I believe our medical system failed my father — no diagnosis, no treatment, and then abandonment. [2011]*

### What Is Palliative Care and Who Is A Candidate?

According to the Center to Advance Palliative Care: “Palliative medicine is specialized medical care focusing on providing relief for people living with serious illness. The goal is to improve quality of life for both the patient and the caregivers.”

What are some medical conditions that palliative care treats? Serious illnesses include but are not limited to:

cancer, heart disease, lung disease, kidney disease, Alzheimer’s, amyotrophic lateral sclerosis (ALS) and many more.

But palliative care is **not** restricted to terminal patients; it is appropriate at any stage of serious illness, treating the patient’s symptoms of pain, depression, shortness-of-breath,

-continues on page 10

fatigue, constipation, nausea, loss of appetite, difficulty sleeping, and anxiety. In short, it improves the patient's quality of life by decreasing debilitating symptoms.

Good palliative care comprises a team – physicians, nurses, social

workers and chaplains – who meet all the needs of the patient and his family/caregivers. Specialists like neurologists, urologists, cardiologists, pediatricians, etc., are now being taught to combine palliative treatment with their medical specialties, widening their scope of practice to care for the patient not only during serious illness, but beyond.

Palliative care is available in a variety of settings, including the hospital, outpatient clinic and at home. Most insurance plans, including Medicare and Medicaid, cover its costs.

### **P = Palliate**

What exactly does today's palliative care provide to those struggling with serious illness, or at the end of life?

Palliative care has a humanistic bend that sees beyond the patient's diagnosis and recognizes the whole person and his uniqueness. The patient is not “an MI,” or “a pancreatic CA,” or “a CVA.” The palliative care team, operating within the limitations of a diagnosis, devises “goals of care” that are a source of direction and support for the patient and his family. The team also provides the expertise in managing complex physical and emotional symptoms such as pain, shortness of breath, depression, nausea as well as spiritual help if requested. It is an ongoing process and the team follows the patient's course of disease, very often until death.

Andrew Thurston, MD [KevinMD.com], writes eloquently:

*I'm a palliative care doctor, and the truth is this: I do have an agenda, but it's not something sinister or laced with deception. My goal is simple: to make sure we treat our patients as people. Not as “cancer” or “kidney failure” or “stroke” but as the unique, individual, storied people that they are. People with their own goals and values – people with their own definitions of what it means to live, even as they approach that infinite tunnel... This, to me, is the distilled essence of palliative care: patients as people.*

### **Hope With Realism**

How does a palliative care team initiate treatment? What does the

process look like? What is discussed? Some patients are conscious and oriented; others may be demented, obtunded or comatose. In that case their health care proxy represents them, commonly a family member. The patient may be old, young or even a newborn; obstetricians are now integrating palliative care into their practices.

***Some patients may be demented, obtunded or comatose. In that case their health care proxy represents them.***

A member of the palliative care team begins with a carefully scripted conversation. *[Italicized comments are remarks a palliative care team member might make to the patient or his family.]* Most use a method called ADAPT, a “talking map” to guide them through complex, often emotional conversations. It's a series of guideposts that may or may not apply to all patients. (Understand that patients and families often need a great deal of repetition to become comfortable and clear with the process; often this process is not linear.)

Before meeting the patient, the team must have in place all the patient's necessary medical information and those involved in her care. They also establish a location to speak with the patient that ensures privacy. Patient's families or caregivers are invited to be part of the process, if the patient consents. If she has a POLST, an Advanced Directive or a Living Will, the patient's wishes are documented unless, of course, the document is old. In that case, it is reviewed with the patient and updated. (See pages 12 and 13)

The conversation usually begins with a question for the patient.

*What have you understood from your other doctors about your illness (cancer, congestive heart or kidney failure, etc.) so far?*

In addressing a critical prognosis, the team must first know what the patient knows. Anxiety and fear head the list of causes why patients don't understand their disease or its

## CEU Article: Palliative Care

*-continued from page 10*

progress, or simply deny it. Most people have little understanding of disease or the human body. And all too often patients with “co-morbidities” – e.g., diabetes, congestive heart failure, COPD – have conflicting reports from individual specialists and there is often a lack of coordination in treatment.

If the patient doesn’t know or is unable to understand the critical nature of his illness, the team member gently informs her (and/or family members) in clear, simple sentences. Less is more: Lengthy explanations of a disease and its progress are avoided; palliative care recognizes that often the patient/family is unable to take in too much information at once.

*The CT scan shows that the cancer is getting worse.*

The palliative team stops after making the critical statement. Most patients have an immediate emotional response, for example, tears, anger, outrage, fear. The team acknowledges that response with empathy:

*I can see this news is not what you were hoping for.* Everything is done to equip the patient for the next step, that is,

thinking about the future, no matter how limited the time.

*Do you want to know the prognosis about how much longer you may have to live? If you're unsure, let's talk about the pros and cons.*

Most patients want to know “how long?” Team members find that talking about the future in terms of events, e.g., a wedding, a trip, a birthday, is more useful than defining a chronological time. Planning on

being present at a graduation or an anniversary, for example, may provide a more meaningful goal than living a number of weeks or months. Patients are often ambivalent about their desire to know more, but the team gives them (and their families) as much time and emotional space as they need to absorb the information.

*What are your goals?* This does not mean winning the Indy 500 or flying

*-continues on page 12*



## Sidebar: BLS and Palliative Care Patients

There are several medical orders you and your crew may encounter in the field. How do these documents differ?

- An **Advance Directive** allows the patient to direct who will make health care decisions for him and to state his wishes for medical treatment if he becomes unable to decide for himself in the future. His Advance Directive may be used to accept or refuse any procedure or treatment, including life-sustaining treatment.

Anyone can fill out an Advance Directive in New Jersey if he or she is 18 years or older and is able to make his or her own decisions. A lawyer is not required.

A patient should talk to his/her doctor about it and give the doctor a copy. The patient should also give a copy to his/her health care representative, family member or others who are close to him/her. The patient can revoke or change any of these documents at a later time.

New Jersey has two kinds of Advance Directives: a "Proxy Directive" and an "Instruction Directive." It is the patient's decision whether to have both kinds or to just have one of them.

Figure 1: First page of an Instruction Directive

The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care

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**INSTRUCTION DIRECTIVE**

I understand that as a competent adult I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction concerning my care and they will require information about my values and health care wishes. In order to provide the guidance and authority needed to make decisions on my behalf:

A) I, \_\_\_\_\_, hereby declare and make known to my family, physician, and others, my instructions and wishes for my future health care. I direct that all health care decisions, including decisions to accept or refuse any treatment, service or procedure used to diagnose, treat or care for my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures, be made in accordance with my wishes as expressed in this document. This instruction directive shall take effect in the event I become

### Proxy Directive

(Durable Power of Attorney for Healthcare)

A Proxy Directive is a document the patient uses to appoint a person to make healthcare decisions for him in the event he becomes unable to make them himself. This document goes into effect whether the patient's inability to make healthcare decisions is temporary because of an accident or permanent because of a disease. The person that the patient appoints is known as his "healthcare representative" and they are responsible for making the same decisions the patient would have made under the circumstances. If they are unable to determine what the patient would want in a specific situation they are to base their decision on what they think is in the patient's best interest.\*

### Instruction Directive (Living Will)

An Instruction Directive (See Figure 1) is a document the patient uses to tell his physician and family about the kinds of situations in which he would want – or not want – to have life-sustaining treatment in the event he is unable to make his own healthcare decisions. The patient can also include a description of his beliefs, values, and

Medical Society of New Jersey  
**MSNJ**

# DO NOT RESUSCITATE

**ALL FIRST RESPONDERS AND EMERGENCY MEDICAL SERVICES PERSONNEL ARE AUTHORIZED TO COMPLY WITH THIS OUT-OF-HOSPITAL DNR ORDER.**

This request for no resuscitative attempts in the event of a cardiac and/or respiratory arrest for: \_\_\_\_\_, has been ordered by the physician whose signature appears below. This order is in compliance with the patient's/surrogate's wishes and it has been determined and documented by the physician below that resuscitation attempts for this patient would be medically inappropriate.

It is expected that this DNR order shall be honored by all **Emergency Medical Services (EMS)** personnel, **First Responders**, and other healthcare providers who may have contact with this patient during a medical emergency.

PATIENT/SURROGATE SIGNATURE: \_\_\_\_\_

PATIENT ADDRESS: \_\_\_\_\_

**THE ABOVE NAMED PATIENT IS UNDER THE CARE OF:**

PHYSICIAN NAME: \_\_\_\_\_ PLEASE PRINT NAME

PHYSICIAN ADDRESS: \_\_\_\_\_

TELEPHONE NUMBER: ( ) \_\_\_\_\_ - \_\_\_\_\_

MEDICAL FACILITY AFFILIATION: \_\_\_\_\_

PHYSICIAN SIGNATURE: \_\_\_\_\_ DATE: \_\_\_\_\_

**THIS DOCUMENT SHOULD BE PROMINENTLY DISPLAYED AND READILY AVAILABLE TO EMS PERSONNEL (see reverse for instructions)**

**INSTRUCTIONS FOR FIRST RESPONDERS/EMS**

**ALL PATIENTS HAVE THE RIGHT TO MAKE HEALTHCARE DECISIONS INCLUDING THE RIGHT TO ACCEPT OR REFUSE LIFE-SAVING MEDICAL TREATMENT.**

1. ASSESS THE PATIENT FOR THE ABSENCE OF BREATHING AND/OR HEARTBEAT.
2. IF THE PATIENT IS NOT IN CARDIAC AND/OR RESPIRATORY ARREST, PROVIDE ALL NECESSARY CARE, INCLUDING TRANSPORT IF REQUIRED.
3. IF THE PATIENT IS IN CARDIAC AND/OR RESPIRATORY ARREST, DO NOT INITIATE CPR AND RESUSCITATIVE EFFORTS.
4. FOLLOW LOCAL EMS PROTOCOLS FOR PRONOUNCEMENT.
5. DOCUMENT ALL PERTINENT INFORMATION ON YOUR RUN SHEET AND ATTACH A COPY OF THIS OUT-OF-HOSPITAL DNR ORDER.
6. ONLY THE INDIVIDUAL(S) (PATIENT, SURROGATE, OR PHYSICIAN) WHO SIGNED THIS FORM MAY RESCIND IT AT ANY TIME.
7. PHOTOCOPIES OF THIS DOCUMENT ARE PERMITTED AND SHALL BE HONORED AT ALL TIMES.

THIS DOCUMENT, ITS INTENT AND ASSOCIATED POLICIES ARE SUPPORTED BY:

Medical Society of New Jersey  
New Jersey Department of Health and Senior Services  
Office of EMS  
American College of Emergency Physicians, New Jersey Chapter  
New Jersey State Nurses Association  
New Jersey Health Decisions  
New Jersey Hospice and Palliative Care Association  
Academy of Medicine of New Jersey  
New Jersey MICU Advisory Council  
New Jersey State First Aid Council  
Office of the Ombudsman for the Institutionalized Elderly  
New Jersey Hospital Association

IF THERE ARE ANY QUESTIONS CONCERNING THE TREATMENT AND/OR PRONOUNCEMENT OF THIS PATIENT, CALL:




CONTACT PERSON: \_\_\_\_\_ TELEPHONE: ( ) \_\_\_\_\_ - \_\_\_\_\_

Figure 3: A New Jersey POLST Form, Front and Back

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

### NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

Follow these orders, then contact physician/APN. This Medical Order Sheet is based on the current medical condition of the person referenced below and their wishes stated verbally or in a written advance directive. Any section not completed implies full treatment for that section. Everyone will be treated with dignity and respect.

PERSON NAME (LAST, FIRST, MIDDLE)		DATE OF BIRTH			
A	<b>GOALS OF CARE</b> (See reverse for instructions. This section does not constitute a medical order.)				
B	<b>MEDICAL INTERVENTIONS:</b> Person is breathing and/or has a pulse <input type="checkbox"/> <b>Full Treatment.</b> Use all appropriate medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See section D for resuscitation status. <input type="checkbox"/> <b>Limited Treatment.</b> Use appropriate medical treatment such as antibiotics and IV fluids as indicated. May use noninvasive positive airway pressure. Generally avoid intensive care. <input type="checkbox"/> Transfer to hospital only if comfort needs cannot be met in current location. <input type="checkbox"/> <b>Symptom Treatment Only.</b> Use aggressive comfort treatment to relieve pain and suffering by using any medication by any route, positioning, wound care and other measures. Use oxygen, suctioning and manual treatment of airway obstruction as needed for comfort. Use Antibiotics only to promote comfort. Transfer only if comfort needs cannot be met in current location. Additional Orders: _____				
C	<b>ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION:</b> Always offer food/fluids by mouth if feasible and desired. <input type="checkbox"/> No artificial nutrition. <input type="checkbox"/> Defined trial period of artificial nutrition. <input type="checkbox"/> Long-term artificial nutrition.				
D	<table border="0"> <tr> <td> <b>CARDIOPULMONARY RESUSCITATION (CPR)</b>            Person has no pulse and/or is not breathing  <input type="checkbox"/> Attempt resuscitation/CPR  <input type="checkbox"/> Do not attempt resuscitation/DI-NAR            Allow Natural Death         </td> <td>  <b>AIRWAY MANAGEMENT</b>            Person is in respiratory distress with a pulse  <input type="checkbox"/> Intubate/use artificial ventilation as needed  <input type="checkbox"/> Do not intubate - Use O2, manual treatment to relieve airway obstruction, medications for comfort.            Additional Order (for example defined trial period of mechanical ventilation) _____         </td> </tr> </table>			<b>CARDIOPULMONARY RESUSCITATION (CPR)</b> Person has no pulse and/or is not breathing <input type="checkbox"/> Attempt resuscitation/CPR <input type="checkbox"/> Do not attempt resuscitation/DI-NAR Allow Natural Death	 <b>AIRWAY MANAGEMENT</b> Person is in respiratory distress with a pulse <input type="checkbox"/> Intubate/use artificial ventilation as needed <input type="checkbox"/> Do not intubate - Use O2, manual treatment to relieve airway obstruction, medications for comfort. Additional Order (for example defined trial period of mechanical ventilation) _____
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E	If I lose my decision-making capacity, I authorize my surrogate decision maker, listed below, to modify or revoke the POLST orders in consultation with my treating physician/APN in keeping with my goals. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Health care representative identified in an advance directive <input type="checkbox"/> Other surrogate decision maker Print Name of Surrogate (address on reverse) _____ Phone Number _____				
F	<b>SIGNATURES:</b> I have discussed this information with my physician/APN. Print Name _____ Signature _____ <input type="checkbox"/> Person Named Above <input type="checkbox"/> Health Care Representative/Legal Guardian <input type="checkbox"/> Spouse/Civil Union Partner <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Other Surrogate Has the person named above made an anatomical gift? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown (These orders are consistent with the person's medical condition, known preferences and best known information.) PRINT - Physician/APN Name _____ Phone Number _____ Physician/APN Signature (Mandatory) _____ Date/Time _____ Professional License Number _____				

4/12/17 SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED

general care and treatment preferences. This is to guide his physician and family when they have to make healthcare decisions for him in situations not specifically covered by his Advance Directive.\*

- \*NJDOH: "Advance Directive"

## Do Not Resuscitate (DNR) Form

A DNR, "Do Not Resuscitate" form (See Figure 2) is a medical order that applies only to resuscitation measures for cardiopulmonary arrest. It does not address the need for intubation or other interventions. The document is not portable and only binding in the institution that issued it, such as the hospital where the patient is being treated. Once she leaves the hospital, the DNR is no longer valid at other institutions; a new DNR must be issued.

## Practitioner Orders for Life-Sustaining Treatment (POLST) Form

In NJ, advance health care planning now offers POLST, or "Practitioner Orders for Life-Sustaining Treatment." (Practitioners are licensed physicians or advance practice nurse or APN.) This document is a set of medical orders that gives seriously ill or frail elderly patients more control over their end-of-life care. And unlike a DNR, it retains its effectiveness wherever the patient goes, i.e., valid at an ED, all hospitals, nursing homes or the patient's residence.

**Unlike a DNR, a POLST retains its effectiveness wherever the patient goes, i.e., valid at an ED, all hospitals, nursing homes or the patient's residence.**

Produced on a distinctive green form (See Figure 3) and signed by both the doctor/APN and patient/surrogate, POLST specifies the types of medical treatment that a patient wishes to receive toward the end of life. As a result, POLST prevents unwanted or medically ineffective treatment, reduces patient and family suffering, and ensures that patients' wishes are honored by healthcare professionals.

POLST is intended for those with terminal, progressive illness and limited life expectancy. It is not indicated for healthy persons. It does not replace the need for an Advance Directive that designates a legal healthcare decision maker.

POLST contains explicit directions about resuscitation for EMS providers in Section D: Whether to do CPR or not, and allow natural death. It also includes directions for airway management for a patient with a pulse in respiratory failure. For the medics, this section includes specific direction including **Do Not Intubate** orders, the use of O<sub>2</sub> for non-invasive support, and medications for comfort.

The POLST document must be signed by the patient (or his surrogate) and the health care practitioner (physician or nurse practitioner) for it to be valid. Crews should review the content of orders prior to initiating treatment. EMS should bring the POLST form with the patient to the hospital.

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

PRINT PERSON'S NAME (LAST, FIRST, MIDDLE) \_\_\_\_\_ DATE OF BIRTH \_\_\_\_\_

PRINT PERSON'S ADDRESS \_\_\_\_\_

CONTACT INFORMATION

PRINT SURROGATE HEALTH CARE DECISION MAKER \_\_\_\_\_ ADDRESS \_\_\_\_\_ PHONE NUMBER \_\_\_\_\_

### DIRECTIONS FOR HEALTH CARE PROFESSIONAL

**COMPLETING POLST**

- Must be completed by a physician or advance practice nurse.
- Use of original form is strongly encouraged. Photocopies and faxes of signed POLST forms may be used.
- Any incomplete section of POLST implies full treatment for that section.

**REVIEWING POLST**

POLST orders are actual orders that transfer with the person and are valid in all settings in New Jersey. It is recommended that POLST be reviewed periodically, especially when:

- The person is transferred from one care setting or care level to another, or
- There is a substantial change in the person's health status, or
- The person's treatment preferences change.

**MODIFYING AND VOIDING POLST** - An individual with decision making capacity can always modify/void a POLST at any time.

- A surrogate, if designated in Section E on the front of this form, may, at any time, void the POLST form, change his/her mind about the treatment preferences or execute a new POLST document based upon the person's known wishes or other documentation such as an advance directive.
- A surrogate decision maker may request to modify the orders based on the known desires of the person or, if unknown, the person's best interest.
- To void POLST, draw a line through all sections and write "VOID" in large letters. Sign and date this line.

**SECTION A**

What are the specific goals that we are trying to achieve by this treatment plan of care? This can be determined by asking the simple question: "What are your hopes for the future?" Examples include but not restricted to:

- Longevity, cure, remission
- Better quality of life
- Live long enough to attend a family event (wedding, birthday, graduation)
- Live without pain, nausea, shortness of breath
- Eating, driving, gardening, enjoying grandchildren

Medical providers are encouraged to share information regarding prognosis in order for the person to set realistic goals.

**SECTION B**

- When "limited treatment" is selected, also indicate if the person prefers or does not prefer to be transferred to a hospital for additional care.
- IV medication to enhance comfort may be appropriate for a person who has chosen "symptom treatment only."
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), or bilevel positive airway pressure (BiPAP).
- Comfort measures will always be provided.

**SECTION C**

Oral fluids and nutrition should always be offered if medically feasible and if they meet the goals of care determined by the person or surrogate. The administration of nutrition and hydration whether orally or by invasive means shall be within the context of the person's wishes, religion and cultural beliefs.

**SECTION D**

Make a selection for the person's preferences regarding CPR and a separate selection regarding airway management. A defined trial period of mechanical ventilation may be considered, for example, when additional time is needed to assess the current clinical situation or when the expected need would be short term and may provide some palliative benefit.

**SECTION E**

This section is applicable in situations where the person has decision making capacity when the POLST form is completed. A surrogate may only void or modify an existing POLST form, or execute a new one, if named in this section by the person.

**SECTION F**

POLST must be signed by a practitioner, meaning a physician or APN, to be valid. Verbal orders are acceptable with followup signature by physician/APN in accordance with facility/community policy. POLST orders should be signed by the person/surrogate. Indicate on the signature line if the person/surrogate is unable to sign, declined to sign, or a verbal consent is given. Remind the person/surrogate that once completed and signed, this POLST will void any prior POLST documents.

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED

to the moon, but: *What is important to you to accomplish now?*

- Medically: *Do you want to continue curative treatments? Do you want to continue to treat symptoms that make your daily life intolerable such as nausea, vomiting, sleeplessness and pain?*

- Emotionally: *If time weren't limited what would be most important to you now? Do you want to see your grandson graduate from high school next spring? Do you want to see your estranged son once more?*

***From the patient's responses, the palliative team works to create a plan, balancing hope with realistic goals.***

From the patient's responses, the palliative team works to create a plan, balancing hope with realistic goals. The dialogue continues with the palliative caregiver saying: *I will do my best to make sure you have what you need.*

Or: *Here's what I can do now that will help you do those important things. What do you think about it?*

If the patient is unclear or uncertain what he should do, the team member then seeks to identify the issues with more short questions such as:

*Tell me more about...* Rather than assume what the patient's issue is, the team member probes with a different type question.

Other questions that might elicit more direction from the patient include:

*What do you think about...?*

*Could you say more about what you mean when you say that...?*

*Does that make sense?*

*As I listen to you, it sounds the most important things are [x, y, z].* The patient is frequently reminded that he is not alone, that the team is working with him, balancing his hopes with the facts and reality of his prognosis.

### **More Voices**

Palliative care also extends to patients who are unable to make their own decisions, e.g., the patient who is seriously ill and has dementia or is unconscious, or is a child or baby. Then the patient's caregivers – e.g., family, friends – are invited to meet with the palliative care team. The narrative is similar to the patient-centered conversation, but obviously, there are many more voices. For instance, a patient's adult children may all appear together with the patient's siblings, and the team is challenged with listening and speaking with many people at once.

During a group meeting, after introductions, each person has an opportunity to talk about the relationship they have with the patient. The palliative care team member then explains the most current information about the patient's medical condition, again in short, concise sentences. Then, highlighting the patient's voice, the team member asks:

*If [patient's name] could speak, what do you think she would say?*

The palliative care team member listens and then, together with the family, devise a plan based on what they believe the patient would have wanted. Often there is conflict within

the family, and heated discussions often ensue. But consensus is always sought.

The palliative care process is more than one meeting, or one conversation. It is ongoing; the team stays with the patient throughout, very often until the time of death. If they chose, patients and families are never left to face difficulties alone. The patient is kept comfortable, e.g., out of pain, often through hospice services.

*-continues on page 15*



## **Hospice**

Hospice can be an important part of palliative care. Its services are designed to meet the needs of people when their life expectancy is six months or less. Care involves a team-oriented approach to medical care, pain management as well as emotional and spiritual support. *At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. (National Hospice and Palliative Care Association)*

Hospice focuses on caring, not curing, and in most cases, care occurs at home, although hospice services are also available at most hospitals and nursing homes. Hospice staff – physicians, nurses, home health aides, social worker, etc. – provides the necessary medical supplies, and drugs to keep the patient comfortable. They coach the family on caring for the patient, and are on-call 24/7. Their services usually extend six months.

## **Palliative Care for Our Patient**

*(Continued from above...)*

How will the ED physician use palliative care to treat our 59-year old mother with metastatic cancer? The physician's history of the patient continues:

*First, the symptoms of pain, nausea and vomiting are brought under control with medications. The patient suffers constantly from abdominal pain and has been prescribed both long- and short-acting morphine; however, on further questioning, she admits she is not taking any opiates, and only an occasional Tylenol because she "does not want to feel drugged." The patient is essentially opiate naïve, therefore, I gave her 5mg of morphine, 4mg ondansetron [antinausea] and 25mg Benadryl. After a half an hour, the patient is resting comfortably, and able to walk with assistance to the bathroom. Her vital signs have normalized; her chest x-ray and labs as well.*

*Second, with these results, goals of care are discussed with the patient and her daughter. Further history reveals the patient had extensive chemotherapy and radiation, most recently whole brain radiation that shrank*

*the tumor foci briefly. But a recent repeat scan of the brain shows a recurrence. Her oncologist stated there are no further chemotherapy options, but discussed possible experimental treatment.*

## **The Conversation**

*Now that the patient is comfortable, and the daughter is less anxious, the doctor sits down with them.*

*"What do you think is going on with your cancer?" she asks the patient gently.*

*"I think I am in the final stage, I think I am dying," the patient replies. For a minute, the physician says nothing, allowing the woman's words to resonate.*

*"I think you are right," the doctor then responds. "If conditions were ideal, where would you want to be?"*

*"Home," the woman says without hesitation and her daughter agrees. From a 10-year old Advance Directive the patient had filled out before she became ill, the doctor*

*-continues on page 16*



## CEU Article: Palliative Care

-continued from page 15

reads out loud: "No machines, no heroics, no experimental treatments." The patient nods, reaffirming her wishes.

The doctor explains that a likely cause for her shortness of breath is the fact that she is not treating her pain adequately and trying to endure it without meds. Another worrisome possibility is a blood clot in the lung (pulmonary embolus).

They discuss the possibility of a CT scan for pulmonary emboli, but when the doctor explains to the patient and her daughter that its result will not change the management or the outcome, they agree it should not be done. (Anticoagulants are contraindicated in metastatic cancer.) Since the doctor is able to control her symptoms with a small dose of morphine, she is confident that with coaching, the daughter will be able to give it orally at home.

How best to honor this patient's wishes to go home?

"The best way to get you home is to use hospice service," the doctor says, explaining just what hospice is, what it does and doesn't do. In her case, she has a primary caregiver –

her daughter – and symptoms that can be controlled with oral meds. Hospice provides all the medical equipment they need, including medications. There is a hospice nurse on call 24/7; home health aides that come weekly as well as social workers and bereavement services. They will allow her and her family to make the most of the time she has left.

**Hospice focuses  
on caring, not curing,  
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care occurs at home.**

The patient and daughter readily agree. The physician calls the local hospice agency, and they arrange to meet the family and patient at home later that day. Finally, the physician says goodbye and the patient is discharged to her home.

### In the End...

Palliative caregivers are skilled communicators: they listen carefully, speak only when needed, gently prod-

ding or proposing alternative options. The treatment they prescribe – be it symptom-directed or disease-directed – wholly respects the choices the patient and/or his family has made.

As a palliative care physician, my daughter has been thanked, blessed, cursed, reviled and sternly ordered out of the patient's room. In spite of the circumstances, she finds great meaning in her work. She has prayed with patients, laughed, cried, held hands, given hugs and sat by them when they drew their last breath, privileged to be in their presence.

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