



## Make Each Day the Best it Can Be, One Day at a Time

A Conversation about Palliative Care with Elizabeth Collins, MD,  
Medical Director of Palliative Care, Lahey Health

### 1. *What is Palliative Care?*

The word 'palliate' comes from the origin, 'to cloak' or to reduce severity and lessen burden. Although the goals of medicine are to cure disease whenever possible, to minimize symptoms and prevent suffering is always the goal, even when a disease is no longer curable.

Palliative Care is based on the understanding that how each of us 'experiences' disease can be different. It focuses on that experience, addressing any symptom, physical or not, in order to help each patient, one at a time, live and survive with a quality of life that they want. Palliative Care can often help patients with serious life threatening diseases, live better and sometimes even longer, because it tries to lessen the burdens of disease, even while treatments aimed to potentially 'cure' are sought.

### 2. *Who can use Palliative Care?*

Palliative Care is a specialty in medicine, just as gastroenterology or neurology. It is not limited to a specific disease or organ, as the others are. However it is appropriate for any person with a serious or life limiting disease, whether or not cure is possible, to help support that patient and family, and help guide treatments to align with patients goals, as well as always minimizing any symptom that causes distress. Serious and life limiting diseases can include serious injury, cancer, heart failure, dementia, as well as chronic diseases. Palliative Care is available for patients of all ages, from birth through elderly.

### 3. *How does it work?*

A wise person once said, "To care for a patient requires a whole person, until you find one, use a team". Palliative Care is a team approach to patient care that utilizes the services of experts in symptoms, physical as well as emotional and spiritual, as they are needed for each individual as well as their family, or support system. At the least the team includes a physician, nurses, social workers and clergy. A patient's primary doctor may refer a patient for Palliative Care, not as default, but to add to the existing medical team, to improve the patient's experience.



Patients and families also may request referral to Palliative Care, which is available in most health organizations, either as an inpatient consult service or an outpatient service. There are many visiting nurse (VNA) programs that also can provide 'palliative care' to homebound patients. Once a patient is referred, an initial assessment is often made by a physician/advanced practice nurse, and then a team is assembled based on the specific needs of that patient at that time. As nothing in life is stagnant, this team 'walks with the patient and family' and continues to readdress needs as they arise, always focusing on how to make each day the 'best it can be, one day at a time'.

#### *4. How does the Palliative Care team interface with the other treating teams?*

To understand each individual's expectations, goals and wishes, as well as their fears and symptoms, is the focus of palliative care practitioners. To address each of them, as well as possible, but also to ensure that everyone involved with that patient's care is aware of these issues. It is only then that the best treatments can be recommended, that will likely be best aligned with each individual's goals. As disease improves or declines, the Palliative Care team is there to continue to help facilitate the best outcome, even when cure is not possible.

#### *5. How can Palliative Care help keep patients in 'in control' of their disease as it progresses?*

No matter what a person's age or stage of disease, it's important to know who the person is and his/her hopes and goals of care. Everyone is different whether we have a disease we can recover from or a disease we live a long life with. It is important to understand a patient's personal goals, whether it be to have all aggressive treatments to extend life even if for a week or two, to have more good days than bad, or to be able to attend a family members wedding. Palliative Care clinicians are trained to help communicate these wishes with not only the treatment team, but also with the patient's family. These conversations are the core of helping each patient live their life as well as they can and with the support and understanding of their family.

#### *6. What's the difference between Palliative Care and Hospice Care?*

Hospice care is palliative care for a person who is nearing the end of life and expected to live 6 months or less. This is often when curative treatments have failed or when a patient's symptom burden outweighs continued aggressive treatments. It however does not mean the 'discontinuation of care' but actually the accentuation of care that focuses purely on a patient's comfort and often is provided in the home or home-like setting, supporting the patient and family at the end of life.

#### *7. Where do I find Palliative Care?*

Ask your primary care physician or doctor treating you for a list of Palliative Care providers in your area.

## Massachusetts Health Care Proxy Instructions and Form

**Instructions:** To create a valid Massachusetts Health Care Proxy, first, print this document so you have the instructions and the blank form in front of you. You can use the instructions as a checklist as you fill out the form.

- On the first part:**
  - Print your full name in the blank space, followed by your address.
- My Health Care Agent is:**
  - Print the name and address of the person you are appointing as your Health Care Agent.
    - Remember – your Agent can be any adult you trust to make medical decisions for you based on your choices and preferences for care;
    - But your Agent cannot be a person who is employed in the facility where you are a patient unless they are related to you by blood, marriage or adoption.
  - Then fill in the phone numbers (home, a business, a cell phone) where your Agent can be quickly and easily reached.
- My Alternate Health Care Agent:**
  - It's a good idea to appoint an Alternate Health Care Agent in case your Health Care Agent can't be reached in a reasonable amount of time. Here, if you choose to, fill in the Alternate Agent's information just as you did above.
- My Health Care Agent's Authority:**
  - Here is where you give your Agent the authority to make decisions for you.
  - If there are certain decisions you don't want your Agent to make, or any instructions you have, list here. If there are no limits or instructions, just leave this area blank so your Agent has full decision making authority for any health care situation that comes up.
- SIGNED and Date:**
  - Sign your full name and fill in the date you sign it.
- Witness Statement and Signature:**
  - Two adults must be present as witnesses when this document is signed, and they must sign and date this document after you do. Keep in mind that they are not being given any authority at all and are there only to witness you sign the document, or witness another person sign it at your direction;
  - Any adult can be a witness except your Health Care Agent and Alternate Agent;
  - Have Witness One sign, then print his or her name and the date;
  - Then have Witness Two do the same thing in their space.
- Health Care Agent Statement: (Optional)**
  - This section isn't required in Massachusetts, but it can be helpful because it lets your care providers know that the Agents you appointed have accepted their roles and responsibilities. If you choose to use this section, have your Agent(s) sign and date in the spaces provided.

That's it! Filling out this form is all you need to do to create a valid Massachusetts Health Care Proxy.

# Massachusetts Health Care Proxy

I, \_\_\_\_\_ Address: \_\_\_\_\_,

appoint the following person to be my Health Care Agent with the authority to make health care decisions on my behalf. This authority becomes effective if my attending physician determines in writing that I lack the ability to make or communicate health care decisions myself, according to Chapter 201D of the General Laws of Massachusetts.

## My Health Care Agent is:

Name: \_\_\_\_\_ Address: \_\_\_\_\_

Phone(s): \_\_\_\_\_; \_\_\_\_\_; \_\_\_\_\_

If my Agent is not available, willing or competent to serve and to make a timely decision, I appoint as

## My Alternate Health Care Agent:

Name \_\_\_\_\_ Address: \_\_\_\_\_

Phone(s): \_\_\_\_\_; \_\_\_\_\_; \_\_\_\_\_

## My Health Care Agent's Authority

I give my Health Care Agent the same authority I have to make all health care decisions including end of life care and life-sustaining treatment decisions, except (list limits to authority or give instructions, if any)

\_\_\_\_\_  
\_\_\_\_\_.

I authorize my Health Care Agent to make health care decisions based on the choices and preferences contained in my personal directive if I have one, and on his or her assessment of my wishes. I give my Health Care Agent the same rights I have to the use and disclosure of my health information and medical records as governed by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), 42 U.S.C. 1320d. Photocopies of this Health Care Proxy have the same force and effect as the original.

I sign my name and date this Health Care Proxy in the presence of two witnesses.

**SIGNED:** \_\_\_\_\_ **DATE** \_\_\_\_\_

## Witness Statement and Signature

We, the undersigned, have witnessed the signing of this document by or at the direction of the signatory above and state the signatory appears to be at least 18 years old, of sound mind and under no constraint or undue influence.

### *Witness One*

Signed: \_\_\_\_\_

Print Name: \_\_\_\_\_

Date: \_\_\_\_\_

### *Witness Two*

Signed: \_\_\_\_\_

Print Name: \_\_\_\_\_

Date: \_\_\_\_\_

## Health Care Agent Statement (Optional):

We have read this document carefully and accept the appointment.

Health Care Agent \_\_\_\_\_ Date \_\_\_\_\_

Alternate Health Care Agent \_\_\_\_\_ Date \_\_\_\_\_

## Personal Directive

### Instructions and Form

**Instructions:** To create a Personal Directive, first print this document so you have the instructions and the blank form in front of you. You can use the instructions as a checklist as you fill out the form.

A Personal Directive is a personal statement in which you give your Health Care Agent information and instructions about the kind of care you want and don't want. If you become unable to make effective decisions for yourself, your Agent will use this document to make health care decisions on your behalf and represent your instructions and preferences to your family and care providers.

Start by reading the questions in the sections provided and write down what is important to you. You may find some questions don't apply; it's alright to leave them blank. You can choose to check the boxes or write in your preferences and choices in your own words.

- On the first line** print your full name in the blank space, followed by your address.
- I. My Personal Preferences, Thoughts and Beliefs**
  - In this section, you let others know your thoughts about the care that's right for you.
- II. My Preferences for Life-Sustaining Treatment**
  - Before filling out this section, talk with your doctor about your specific medical condition and the risks and benefits of life-sustaining treatment at your stage of health.
- III. People to Inform about My Preferences and Choices**
  - List the names of family, friends, or others you'd like to inform, if any.
- IV. My Religious, Spiritual and Cultural Affiliation**
  - Talk with clergy and advisors; add your preferences or instructions, if any.
- V. Organ Donation**
  - Indicate your preferences here, if any.
- VI. Funeral Arrangements**
  - Indicate your preferences here, if any.
- VII. Other Instructions and Preferences**
  - In this section, you can include any messages you'd like your Health Care Agent to deliver or any action you'd like your Agent to take.
- SIGNED and Date**
  - Sign your full name and fill in the date you sign it.
- Witness Statement and Signature (Optional)**
  - This section is not required, but it can be helpful to have your signature witnessed

That's it for now. Filling out this form is all you need to do to create a Personal Directive.



## II. My Preferences for Life-Sustaining Treatment

Life-sustaining treatment refers to medical procedures such as cardiopulmonary resuscitation, artificial hydration and nutrition, and artificial ventilation/breathing intended to prolong life by supporting an essential function of the body, when the body is not able to function on its own. *Talk to your doctor about your medical condition and the specific risks and benefits of treatments at your stage of health.*

**1. Cardiopulmonary Resuscitation (CPR)** is a medical treatment used to restart the heartbeat and breathing when the heartbeat and breathing have stopped. My preferences are:

- I do not want CPR attempted if my heartbeat and breathing stop, but rather, want to permit a natural death;
- I want CPR attempted unless my doctor determines any of the following:
  - I have an incurable illness or irreversible injury and am dying
  - I have no reasonable chance of survival if my heartbeat and breathing stop
  - I have little chance of long-term survival if my heartbeat and breathing stop and the process of resuscitation would cause significant suffering
- I want CPR attempted if my heartbeat and breathing stop;
- I do not know at this time and rely on my Health Care Agent to make the decision.

Other thoughts and instructions on CPR:

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## 2. Treatments to Prolong My Life:

If I reach a point where I can no longer make decisions for myself and my doctor believes it is reasonably certain that I will not recover my ability to know who I am:

- I want to withhold or stop all life-sustaining treatments that are prolonging my life and permit a natural death. I understand I will continue to receive pain and comfort medicines, and food and fluids by mouth if I am able to swallow;
- I want all appropriate life-sustaining treatments for a *short term* as recommended by my doctor, until my doctor and Agent agree that such treatments are no longer helpful;
- I want all appropriate life-sustaining treatments recommended by my doctor;
- I do not know at this time and rely on my Health Care Agent to make treatment decisions.

Other thoughts and instructions on life-sustaining treatments:

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### III. People to Inform about My Preferences and Choices

List any care providers, family, and friends, advisors you want to inform, or prefer not to inform:

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### IV. My Religious, Spiritual and Cultural Affiliation

- I am of the \_\_\_\_\_ faith. Please contact \_\_\_\_\_ at \_\_\_\_\_ (name/place of clergy). I would like the following:  
\_\_\_\_\_
- I would like a spiritual or cultural ceremony. Please contact \_\_\_\_\_ at \_\_\_\_\_ (name/place of advisor). I would like the following:  
\_\_\_\_\_
- I do not want any religious or spiritual considerations.

Other thoughts and instructions:

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### V. Organ Donation

- I do not want to donate my organs.
- I do want to donate my organs. My preferences are: \_\_\_\_\_  
\_\_\_\_\_

### VI. Funeral Arrangements

- I'd like a service or gathering. My instructions: (type, location, invitees, etc.)
- I'd like a burial in a casket. My instructions:
- I'd like to be cremated and want my ashes distributed or buried. My instructions:
- I'd like all the arrangements to be made by \_\_\_\_\_. My instructions:  
\_\_\_\_\_

## VII. Other Instructions and Preferences

I'd like my Health Care Agent, my family, my doctors and all those concerned with my care to know:

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I sign this Personal Directive after giving much thought to my personal preferences and treatment choices. I direct my Health Care Agent to represent my preferences and choices and for all others to honor them.

**SIGNED:** \_\_\_\_\_ **Date:** \_\_\_\_\_

### **Witness Statement and Signature** *(Optional)*

We, the undersigned witnesses, on this date, \_\_\_\_\_, have witnessed the signing of this Personal Directive and that the signatory appears to be 18 years old, of sound mind, and under no constraint or undue influence.

Witness #1

Witness #2

Signed: \_\_\_\_\_

Signed: \_\_\_\_\_

Print Name: \_\_\_\_\_

Print Name: \_\_\_\_\_

Date: \_\_\_\_\_

Date: \_\_\_\_\_

## Things to Know about Life-Sustaining Treatment

Contributed by Elizabeth Collins MD,  
Medical Director of Palliative Care at Lahey Health

Life-sustaining treatment refers to medical treatments that are used to prolong life by supporting an essential body function, such as the heart beating, breathing or adequate nutrition, when that body function is not able to work on its own. Dr. Elizabeth Collins offers some general information on Cardiopulmonary Resuscitation (CPR), Artificial Ventilation/Breathing, and Artificial Nutrition. Talk with your doctor about your specific medical condition and the risks and benefits of life-sustaining treatment at your stage of health. Whether you choose life-sustaining treatments or not, you will be treated for symptoms and receive comfort care at the end of life.

### Cardiopulmonary Resuscitation (CPR)

#### 1. What is CPR?

- Cardiopulmonary resuscitation (CPR) is a medical treatment that is performed in an emergency situation on a person who has stopped breathing and has no heart beat. It is an attempt to restore blood circulation to save a person's life
- CPR involves a person or persons pressing on the chest, forcing breaths either mouth-to-mouth or mechanically with a breathing machine, and sometimes electric shock to restart the heart

#### 2. When is it generally recommended?

- It may be indicated for any person who is expected to live a longer life who has suddenly stopped breathing and has no heart beat

#### 3. When is it generally not recommended?

- It may not be indicated for weaker, older people with a chronic or terminal illness
- For this group there is about 3% chance that CPR will be successful, however patients may not recover to the same condition as before their heartbeat and breathing stopped
- Even if you are revived, complications may occur that require artificial ventilation to support your breathing, or that cause permanent conditions like not being conscious or unable to interact, think, or speak with others

#### 4. What happens if a person decides not to have CPR?

- The heart beat and breathing will not be restarted but every measure will be taken to treat symptoms, provide comfort, and allow a natural death

## Things to Know about Life-Sustaining Treatment

Contributed by Elizabeth Collins MD,  
Medical Director of Palliative Care at Lahey Health

### Artificial Ventilation/ Breathing

#### 1. What is artificial ventilation?

- Artificial ventilation is an invasive treatment that does the work of breathing for a person who is critically ill and unable to breathe naturally. Oxygen is delivered through a tube inserted through the mouth and into the windpipe (intubate), and connected to a machine (ventilator) which performs the breathing function. This is an emergency treatment meant to help a person whose lungs are failing. It is a “rescue” intervention for short term use, requiring the person to be in an Intensive Care Unit, often sedated, and unable to speak.
- Non-invasive ventilation (e.g CPAP or BIPAP), is another treatment used for respiratory distress. Oxygen is forcefully delivered through a face mask into your lungs. It is a ‘rescue’ intervention for short term use. (Note: CPAP or Continuous Positive Airway Pressure is often used for sleep apnea which is not a form of life-sustaining treatment.)

#### 2. When is it generally recommended?

- It may be indicated if you have had a serious accident or illness and ventilation is required to help you recover to where you can breathe on your own

#### 3. When is it generally not recommended?

- It is generally not indicated if ventilation is necessary to merely prolong the natural dying process and is not being used as bridge to help a critical ill person breathe independently

#### 4. What happens if a person decides not to have artificial ventilation?

- You can receive oxygen through your nose and any medications that would treat shortness of breath and other symptoms to keep you comfortable until a natural death occurs

## Things to Know about Life-Sustaining Treatment

Contributed by Elizabeth Collins MD,  
Medical Director of Palliative Care at Lahey Health

### Artificial Nutrition

#### 1. What is artificial nutrition?

- Artificial nutrition provides needed nutrition through a tube placed directly into the digestive tract (*Gastrostomy or G-tube*) or delivered intravenously (Parenteral) for certain people who cannot safely or comfortably eat naturally
- Intravenous fluids provide needed hydration, but do not provide nutrition and cannot sustain life when a person cannot eat naturally

#### 2. When is it generally recommended?

- It may be indicated to supply adequate nutrition which allows a person to recover until he or she can eat by mouth, or to provide nutrition that is needed to live

#### 3. When is it generally not recommended?

- It may not be indicated for a person who is near the natural end of life either from advanced disease (i.e. cancer or dementia), or whose quality of life would not benefit from receiving artificial nutrition
- It may not be indicated for a person at the end of life, where artificial nutrition would prolong dying and often not provide improvement of symptoms or quality of life

#### 4. What happens if a person decides not to have artificial nutrition?

- Without artificial nutrition a person will be offered anything that provides comfort while allowing a natural death to occur

## Things to Know About a Durable Power of Attorney

### 1. What is a Durable Power of Attorney?

- A durable power of attorney is a legal document in which you appoint a trusted person to manage and protect your financial matters- your money, property and business affairs- if you are not able to manage your financial matters yourself
- The trusted person you appoint is called an ‘Attorney-in-fact’, who follows your instructions and makes financial decisions on your behalf to manage and safeguard your financial matters

### 2. Who can sign a Durable Power of Attorney?

Every competent adult has the choice to sign a Durable Power of Attorney. An adult must be:

- 18 years old and older; able to understand that he or she is giving another person the legal authority to manage his or her financial affairs if the adult becomes disabled or incapacitated; and under no constraint or undue influence to sign the legal document

### 3. Who can be my Attorney-in-Fact?

- Any adult you trust - a spouse, family member, a friend, or a professional or business entity, preferably someone who has the ability to be financially responsible

### 4. How does a Durable Power of Attorney work?

- You have the right to manage your money, property, and business as you like
- This document tells your Attorney-in-fact when to step in to help you (either immediately or if you become disabled or incapacitated), and lists the exact decision making powers you give your Attorney-in-fact to act on your behalf
- “Durable” means your Attorney-in-fact can act even if you become incapacitated

### 5. What decision making authority can I give my Attorney-in Fact?

- You can give your Attorney-in-fact *limited powers* with authority to perform tasks like paying the bills, signing checks, buying or selling property, or managing your business, or
- You can give your Attorney-in-fact *general powers* with authority to manage all financial affairs
- You tell your Attorney-in-fact what’s important to you in taking specific actions and making financial or business decisions

### 6. Can I change my mind or cancel or revoke a Durable Power of Attorney?

- You can appoint a new Attorney-in-fact, change the decision making authority, cancel or revoke the document as long as you are competent

### 7. How do I complete a Durable Power of Attorney?

- Although it is not required in Massachusetts, it is generally recommended that you ask an attorney to draft a Durable Power of Attorney for you. An attorney can tailor the document to your situation and include specific powers to help ensure your Attorney-in-fact can provide for your long term care and safeguard your estate all though your lifetime.

## Things to Know about MOLST and CC/DNR

A Conversation with Mary A. Valliere, MD,  
Clinical Consultant Massachusetts MOLST Expansion Project

### 1. What is Medical Orders for Life Sustaining Treatment also known as “MOLST”?

MOLST is a medical document that communicates your decisions about life-sustaining treatments to your care providers. It’s like a prescription from your doctor that gives medical orders to the rest of your health care team (doctors, nurses, EMTs). The MOLST form tells the care team that you and your doctor or care provider have discussed your current medical condition and the role of life-sustaining treatments, and that you made decisions about the treatments you want or do not want and documented those decisions on the MOLST form. Anyone involved in your care will follow the MOLST form and honor your choices.

### 2. What is on the MOLST form?

The MOLST form is a one page document that has a front side and a back side. The *front side* lists three life-sustaining treatment decisions often made in emergency situations: 1). whether or not to be resuscitated in the event that your heart stops, 2). whether or not you want to have ventilation (help with breathing), and 3). whether or not you want to be transported to the hospital. You write down your decisions about each so the emergency medical team can look at the form and know the care you want.

The *back side* of the MOLST form lists other life-sustaining treatment decisions where you document your preferences and choices regarding ventilation, dialysis, artificial nutrition and artificial hydration. This information is important for the health care team when you reach the emergency room or a hospital. They will read the back of the MOLST form and follow your specific decisions.

### 3. Who can use a MOLST form and how does it work?

The MOLST form is not for everyone. It is appropriate to use if you have an advanced illness, and you reach a point in your illness where your doctor would not be surprised if you died in the next year. Your doctor or care provider will talk to you about the kinds of treatments you may or may not want to be attempted as your disease progresses. You will make decisions about the treatments and document them on the MOLST form. Both you and your doctor or care provider sign the form. You keep the original MOLST form and take it with you when you go to different care setting (hospitals, nursing facilities, etc).

### 4. Can patients ask their doctor or care providers about completing a MOLST form?

Yes. You can simply ask, “Is it time to talk about life-sustaining treatments and write down my decisions in a MOLST form?” Your doctor or care provider, who knows the clinical progression of your illness, might respond that it is not yet time, or agree that it is the right time to start to a MOLST conversation. The MOLST form is not designed for patients to fill out on their own. Your doctors and care providers will have a copy of the MOLST form to use after your discussion about life-sustaining treatments.

## Things to Know about MOLST and CC/DNR

A Conversation with Mary A. Valliere, MD,  
Clinical Consultant Massachusetts MOLST Expansion Project

### 5. What happens after the MOLST form is completed?

After the MOLST form is filled out and signed, the original form stays with the patient to be shared with the next person on the health care team. The MOLST form acts like a baton. For example, if a doctor sees you in the emergency room and you have a conversation about your life-sustaining treatments decisions, you can fill out the MOLST form to reflect how far you got in your conversation. You keep the original form and take it to the next health care provider, for example, your primary care doctor, to say “this is how far we got and I’d like to pick up the conversation with you.”

### 6. Can a patient change the decisions he or she made on the MOLST form?

Yes. The MOLST form is the patient’s property and can be updated, changed or even canceled. The form is intended to be changed as your health care needs and your decisions for care change overtime.

### 7. What is the difference between the MOLST form and a Comfort Care/Do Not Resuscitate Verification Form (CC/DNR)?

The Comfort Care/Do Not Resuscitate Verification Form (CC/DNR) was created as a quick communication tool for emergency medical teams (EMT) coming to your residence in an emergency, which verifies for the EMT that you had a conversation with your physician and there is a Do Not Resuscitate medical order in effect. Only EMTs are obligated to follow the CC/DNR form; other licensed health care professionals are not. The CC/DNR form only documents one decision- Not to be resuscitated if your heart or breathing stops.

The MOLST form gives you the choice to decide: yes, I do want to be resuscitated or no, I do not want to be resuscitated. MOLST also lets you document your preferences and choices about a range of other life-sustaining treatments that could be attempted in the course of your illness.

### 8. Which form should I use, MOLST or CC/DNR?

MOLST is considered a more advanced version and will someday replace the CC/DNR form. While both documents are valid, the recommendation in the state is not to create new CC/DNR forms, but to honor the forms for people who already have a CC/DNR. Doctors are beginning to use MOLST forms in place of CC/DNR forms because MOLST is a better tool to communicate treatment decisions.

Read more about MOLST and view a sample form at [www.molst-ma.org](http://www.molst-ma.org)