PALLIATIVE CARE, HOSPICE, AND ADVANCE DIRECTIVES

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- No financial interest, arrangement or affiliation with any organization that can be perceived as a real or apparent conflict of interest

AGENDA

- Palliative Care
  - What is it and how can it help
- Hospice
  - A small piece of Palliative Care
- Advance Care Planning
  - Why it matters
  - Legal Documents and Conversation Starters

IT'S ABOUT LIVING YOUR BEST LIFE!

WHAT IS PALLIATIVE CARE?

A type of care that focuses on your and your family as a whole entity outside of a specific illness.

Initially it can be provided by your primary doctor, or you can see a specialist in more complex cases

Either way the focus is to help manage acute/chronic life altering illness through symptom management and goals of care discussions.

Focus on defining individual pt/family values and using that information to guide complex medical decision making.

PALLIATIVE CARE FOCUS

Acute and Chronic Symptom Management

Goals of Care and Values Identification, and Support

Cancer related Pain Management
Symptom Management-dyspnea, nausea, insomnia, anxiety, anorexia, diarrhea, constipation, depression, pain, others…

Advance Care Planning/ assistance with goals of care discussions
End of Life Care/Transition to Hospice
Extra layer of support

WHO SHOULD CONSIDER PALLIATIVE CARE?

Patients with chronic progressive life limiting illness.

Patients with newly diagnosed life-threatening illness

Patients requiring complex symptom management (nausea, constipation, shortness of breath, anxiety)

Patients with complex medical situations who need help/family needs help with medical decision making.

Patients who would qualify for discharge to home with hospice or another institution for end-of life care if it was consistent with their goals.

THERE IS A LOT WE CAN DO…

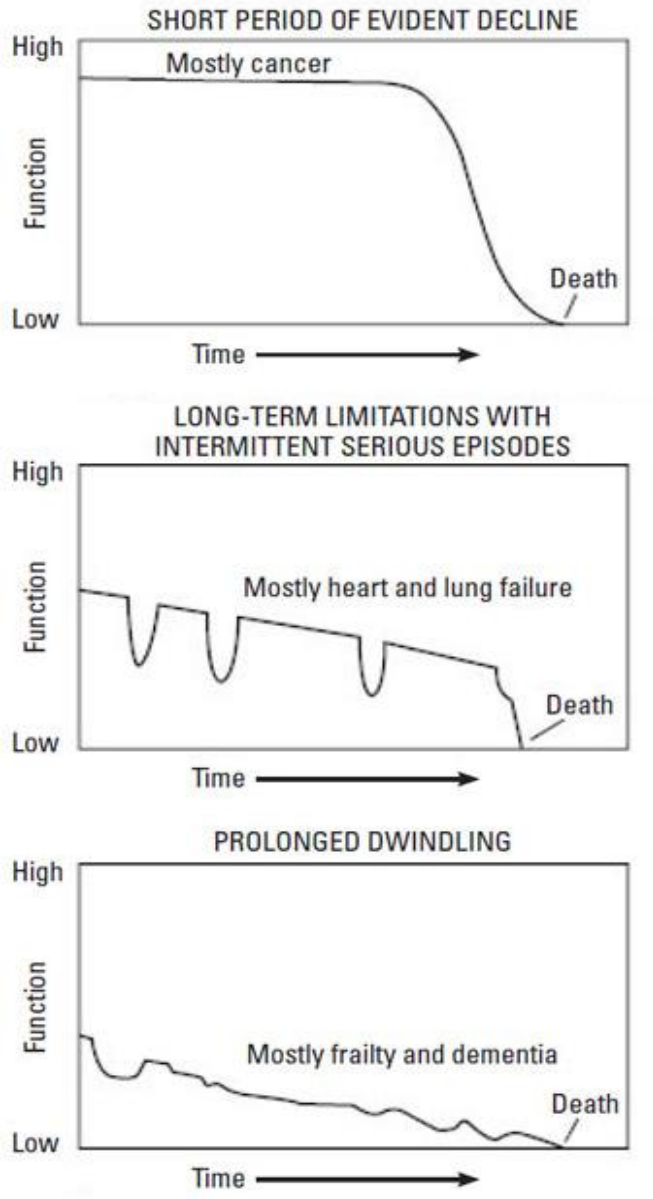
But do YOU want us to?...

IF WE MAXIMIZE MEDICAL TREATMENTS….

What does life look like in the future? Is that c/w your values?

ILLNESS TRAJECTORIES

- Unlike cancer diagnoses, organ failure due to chronic disease and dementia have more unpredictable diagnosis



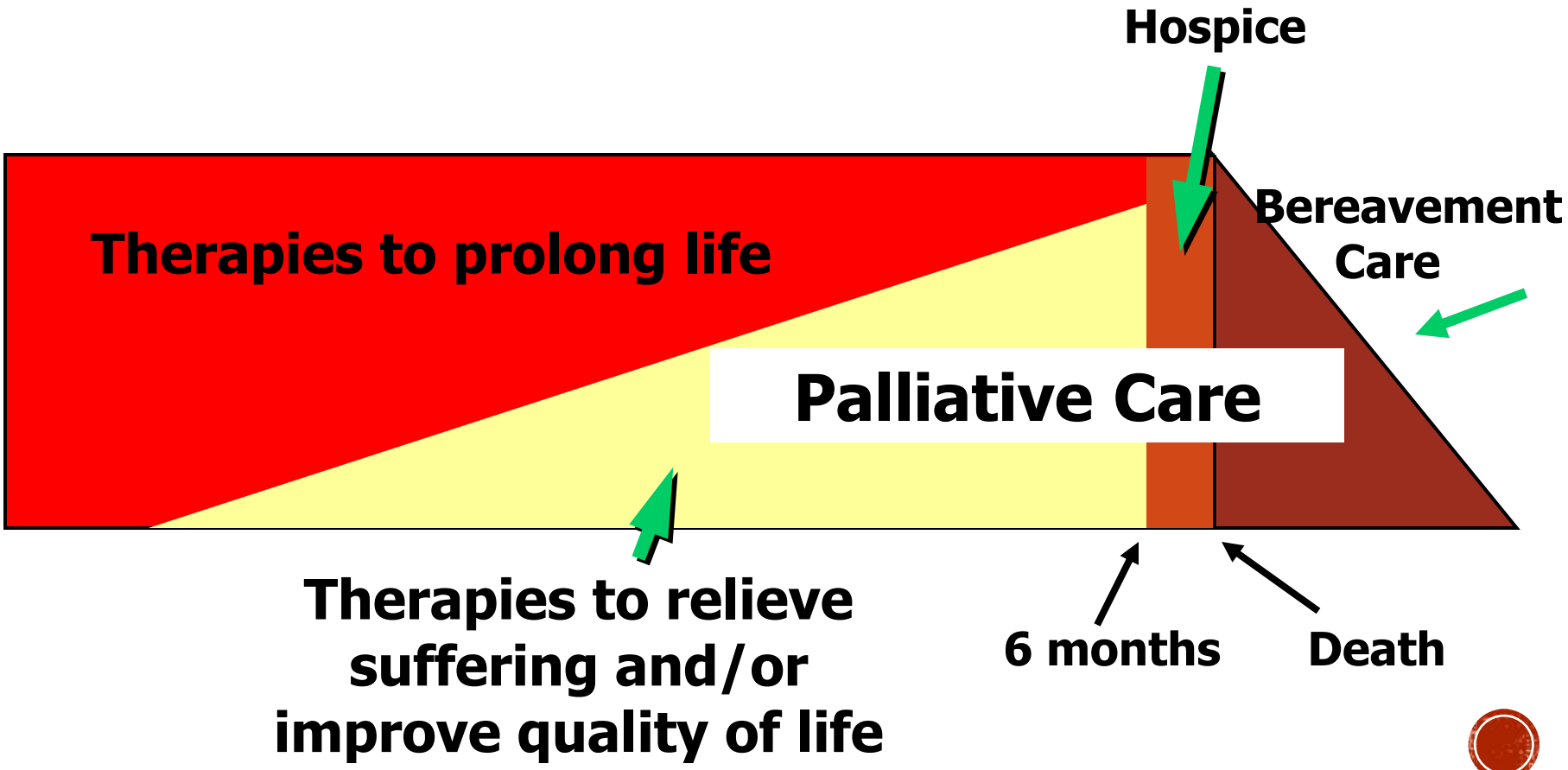
BENEFITS OF PALLIATIVE CARE

- It's a medical specialty that provides an extra layer of support
- Improves patient satisfaction-you "feel better"
- Collaboration of care with the health care team
- Align medical treatment to personal preferences
- Develop "goals of care" –a dynamic plan that may change with disease progression or change in personal goals
- Focus is on healing, with or without a cure

BENEFITS OF PALLIATIVE CARE

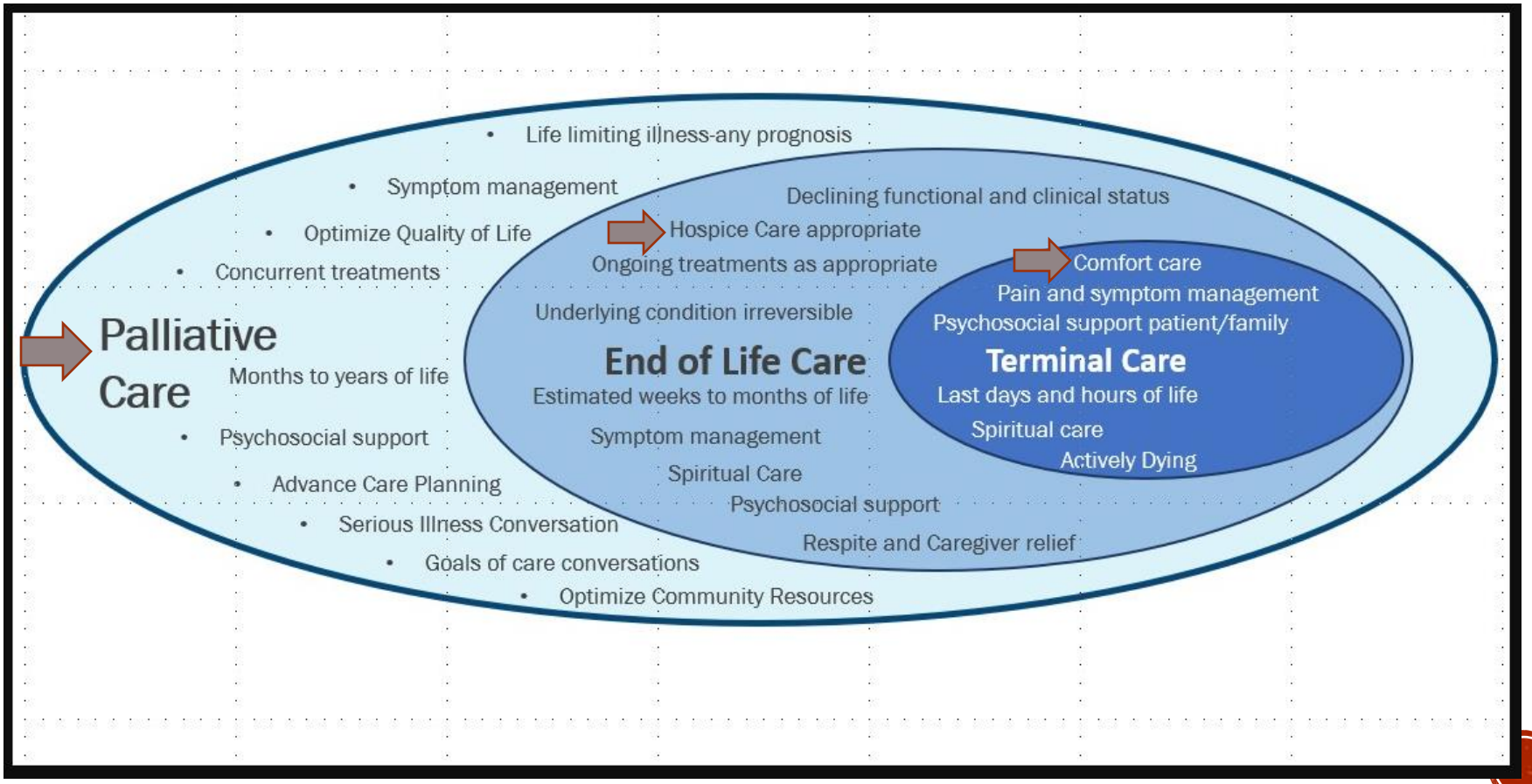
- Can continue with curative treatments while on Palliative Care Plan
- Can have quality of life while getting treatment for a serious illness.
- Can work through potential conflict within families about a patient's/resident's goals of care

CARE


Hospice
Therapies to prolong life
Bereavement Care
Palliative Care
Therapies to relieve suffering and/or improve quality of life
6 months
Death

PALLIATIVE CARE SPHERE

HOSPICE IS A LATER-STAGE PART OF A PALLIATIVE CARE PLAN



HOW DO YOU ACCESS PALLIATIVE CARE?

- Talk to you/your family members PCP/specialists about getting a Palliative Care Referral outpatient.
  - Southbury PC, Danbury PC, Pulmonology Office, Oncology, Home Visits* (are a few options)
- If hospitalized at DH request a Palliative Care Consult from the doctor or nurse, or call 203-739-6662.

- Palliative Care is covered the same as other Consultant appointments would be through insurance.

HOSPICE CARE

THE FINAL CHAPTER BUT NOT THE LAST PAGE

- *"As sickness progresses toward death, measures to minimize suffering should be intensified. Dying patients require palliative care of an intensity that rivals even that of curative efforts even though aggressive curative techniques are no longer indicated, professionals and families are still called on to use intensive measures, extreme responsibility, extraordinary sensitivity and heroic compassion." Eric Cassel, MD*

"Hospice is not the fast track to the end of the race...it's simply choosing a smoother ride for the journey."

Unknown

WHAT IS HOSPICE CARE?

- Hospice is a model of care that was initially developed in England in 1967 (Cecily Saunders – SW, RN, MD) to address the specific needs of the dying patient and their families.
- Hospice care is a **benefit** covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.
- Medicare endorsed it in the 1980s
- The focus of hospice relies on the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.
- Hospice focuses on caring, not curing and, in most cases, care is provided in the person's home.

WHAT IS HOSPICE CARE?

- All Hospice is Palliative Care but not all palliative care is hospice.
- You have to have a diagnosis of 6 months or less to qualify for Hospice, and goals be hospice oriented.
- If you outlive that 6 months, can re-certify for another 6 months, ongoing.
- Symptom management
- Support for patient and family as the disease progresses
- Spiritual Care for existential distress, meaning
- Social Work
- Bereavement Support

WHERE DOES HOSPICE TAKE PLACE

Hospice care can be provided at home, in a nursing home, in a hospice or another freestanding facility, or within some hospitals.

PATIENTS APPROPRIATE FOR HOSPICE

- Transition to Hospice is a continuation of Palliative Care for those with life expectancy of 6 months or less who no longer wish for or are eligible for life prolonging interventions
  - Decline surgery
  - Unable/Declining Chemotherapy
  - Prefer to be home and not rehospitalized
- Have to meet eligibility for Hospice as outlined in NHPCO guidelines
  - Certification by attending physician and hospice medical director as being terminally ill with a prognosis of 6 months or less to live, should the illness run its normal course.
  - CHF EF <20%, Dementia Fast 7C – Failure to thrive alone does not make someone hospice eligible.

HOSPICE: WHAT DOES THE BENEFIT PROVIDE?

- 4 Levels of Hospice Care:
  - Home hospice/ Nursing home care/Routine Inpatient Care
  - Continuous 'Home' Hospice
  - GIP: General In Patient
  - Respite Care
- RN Services: As needed, a few times a week to continuous for acute symptom management
- Aide Services: 3 time a week, 2 hours a day.
- 100% DME cost
- 100% medication costs for symptoms related to terminal illness.
- Counseling, bereavement, volunteers, pastoral care.
- RN on call 24/7 with Physician back up.
- ***Patients DO NOT have to be homebound***

HOSPICE: WHAT DOSE THE BENEFIT NOT PROVIDE?

- **Hospice does not mean FREE 24 Hour Care!**
- **24 hour Home Health Care – is NOT Provided.**
  - Patients can receive Hospice Benefit at ECF, but room and board only covered if patient is on Medicaid.
    - $400-600+ a day at area ECFs, at times comfort rates are available for less.
  - Patients do not stay in the Hospital long term if they do not meet in-patient criteria.
  - Families can come together to help care for Hospice patient – Consider FMLA.
  - Patients and Families can private hire 24 hour care.
  - For some patients with Medicaid - Aides can be provided through CCCI

PC AND HOSPICE: WHAT DO THEY HAVE IN COMMON?

- Transition to Hospice is a continuation of Palliative Care for those with life expectancy of 6 months or less (and values c/w hospice care).
- Both focus on patient's values and making sure treatment plan is in alignment with those values and both offer support services
- Both treat whole person. Not only their physical symptoms but also their spiritual and emotional health.
- They take into account family and social dynamics and their role on the patients well being.
- The focus is on quality of life as defined by the patient.
- Symptom management is of the utmost importance to achieve that quality of life.

ADVANCE CARE PLANNING

A GUIDE TO NAVIGATION COMPLEX MEDICAL DECISION MAKING

WHY ADVANCE CARE PLANNING MATTERS

- You/or your loved ones can speak up and have a say in your care.
- Advance care planning puts you in the driver's seat.
- Getting health care often involves choices that impact your life and wellbeing in different ways.
- Treatments only work if they work for you.

BENCHMARK CASES

- Karen Ann Quinlan
- Nancy Cruzan
- Terri Schiavo

THE LEGAL OUTCOME

- Choose or refuse any medical or surgical intervention, including artificial nutrition and hydration.
- Make advance directives.
- Name a surrogate to make decisions on their behalf.
- The Court also said that surrogates can decide on a certain course (e.g., treatment or not) even when all concerned are aware that such measures will hasten death, as long as causing death is not their intent.

MEET BILL...

ADVANCE CARE PLANNING

90% of people say that talking with their loved ones about end-of-life care is important.

***27%** have actually done so.

60% of people say that making sure their family is not burdened by tough decisions is extremely important.

***56%** have not communicated their end-of life wishes.

80% of people stated that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of life.

* 7% reported having has this conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)

ACP AND COVID

- COVID motivated conversations between patients and families around wishes and serious illness
- 59% of 50-80-year-olds stated they had a conversation with loved ones about their preferences in the event they became seriously ill from COVID
- 46% of those polled stated they completed at least one ACP document
- 23% who had not had a conversation stated they do not wish to talk about such things, and 15% stated they didn't know how to have the conversation

www.healthyagingpoll.org, April 2021

PATIENTS HAVE THE RIGHT TO MAKE DECISIONS

- In general, patients have the legal right to make health care decisions about the medical care they receive.
- If they do not want specific treatments, they have the right to tell their physician they do not want them and to have their wishes followed.
- They also have the right to receive information from their physician to help them make health care decisions:
  - What treatments may help them.
  - How each treatment may affect them.
  - What may happen if they decide against treatment.

TOPICS ADDRESSED BY ADVANCE CARE PLANNING TOOLS

- Assigning a Health Care Proxy
- Code Status: Full Code vs. Do Not Resuscitate
- Artificial Nutrition and Hydration (Feeding Tubes, IV Hydration)
- Dialysis
- What Type of testing and treatments are ok (labs, radiology tests)
- Rehospitalization – is that ok? If not then it may be time to talk about treat in place +/- hospice care.

KEY COMPONENTS TO ADVANCE CARE PLANNING

1. The Legal Documents
   - Advance Directive: Living Will/HC Proxy
   - MOLST form
2. The Conversation about your Values
   - Informal with Providers or Family
   - Values Box on Advance Directive Form
   - The Serious Illness Questions
   - Conversation Project

WHAT IS AN ADVANCE DIRECTIVE?

- A legal document through which you can:

- 1. Appoint someone to be your voice regarding health care decisions at the point in which you cannot communicate directly; and or

- 2. Provide directions or express your preferences concerning health care decisions

PEARLS OF ADVANCE DIRECTIVES

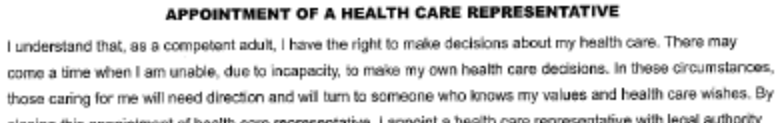
- No attorney is needed to complete an Advance Directive
- No charge ($) to complete the document
- Does not need to be notarized
- Make 3 copies and give one copy to the physician and to the Health Care Representative
- Discussions and completing a legal document can be a gift to your family so the burden of decision-making is off their shoulders by following YOUR wishes.

- Adv Directives can be or changed - complete a new document and indicate that this new document supersedes previous adv directive documents

PART 1: HEALTH CARE PROXY

- A person whom you authorize in writing to make any and all health care decisions on your behalf, including the decision whether to withhold or withdraw life support systems.
- HCR does not act unless you are unable to make or communicate your decisions about medical care.
- HCR will make decisions on your behalf based on your wishes (stated in living will or otherwise).
- In the event your wishes are not clear or a situation arises that you did not anticipate, your HCR will make a decision in your best interests based upon what he/she knows of your wishes.

APPOINTMENT OF A HC REPRESENTATIVE



APPOINTMENT OF A HEALTH CARE REPRESENTATIVE

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 incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction and will turn to someone who knows my values and health care wishes. By

APPOINTMENT OF A HEALTH CARE REPRESENTATIVE

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I appoint _____ to be my health care representative. If my attending physician determines that I am unable to understand and appreciate the nature and consequences of health care decisions and to reach and communicate an informed decision regarding treatment my health care representative is authorized to make any and all health care decisions for me, including the decision to accept or refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition and the decision to provide, withhold or withdraw life support systems, except as otherwise provided by law which excludes for example psychosurgery or shock therapy.

(Witness)

x_____

(Number and Street)

x_____

(City, State and Zip Code)

(Witness)

x_____

(Number and Street)

x_____

(City, State and Zip Code)

PART 2: LIVING WILL

A document that expresses wishes concerning life support (CPR, ventilation, artificial means of providing nutrition and hydration) and other health care preferences that becomes operative only if:

1. Patient has a terminal condition or is permanently unconscious;
2. A doctor finds that patient is unable to understand health care decisions and communicate an informed decision; or
3. Patient specifically states other wishes

CONNECTICUT LIVING WILL

CONNECTICUT STATUTORY LIVING WILL
(Other properly executed/witnessed forms are also valid in Connecticut)

If the time comes when I am incapacitated to the point when I can no longer actively take part in

Specific Instructions

Listed below are my instructions regarding particular types of life-support systems. This list is not all-inclusive. My general statement that I not be kept alive through life-support systems provided to me is limited only where I have indicated that I desire a particular treatment to be provided.

	Provide	Withhold
Cardiopulmonary Resuscitation	_____	X
Artificial Respiration (including a respirator)	_____	X
Artificial means of providing nutrition and hydration	_____	X
_____	_____	_____

Other specific requests: _____

_____

Witness _____ Address _____

_____

CONNECTICUT LIVING

Specific Instructions

Listed below are my ...ction... ...ding particular types of life-suppo... ...tems. This list is not all-inclusive. M... ...eral state... ...t I not be kept alive through life... ...port systems provided to me is ...d only where ... ...dicated that I desire a partic... ...eatment to be provided.

DNR

	Provide	Withhold
Cardiopulmonary ...citation		X
Artificial Respiration ...ding a respirator)		X
Artificial means of pro... ...utrition and hydration		X

Other specific requests: _____

WHAT DOES DNR MEAN?

- **D**o **N**ot **R**esuscitate
- Resuscitation of a person means providing cardiopulmonary resuscitation (chest compressions), intubation (tube to attach a breathing device to) and mechanical ventilation. It may also include electrical shocks or medications through intravenous access

- **DNR does NOT mean Do Not Treat**
- Based on goals of care/Pt Values: if natural death is a goal, DNR may be appropriate

RESUSCITATION: THE FACTS

- People believe that survival after CPR is 75% - TV doesn't help
- Overall rate of survival from out of the hospital CPR is 7.6%.
- CPR in-hospital survival rate is ~17% overall, 6.7% in 70s, 2.4% in 90s
- One Study found that less than 2% of pts with cancer or heart, lung, or liver disease who were resuscitated survived 6 months.

- https://www.npr.org/sections/health-shots/2023/05/29/1177914622/a-natural-death-may-be-preferable-for-many-than-enduring-cpr

CONNECTICUT LIVING WILL

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	Provide	Withhold
Cardiopulmonary Resuscitation		X
Artificial Respiration (including a respirator)		X
Artificial means of providing nutrition and hydration		X

Other specific requests: **I would like a trial of life support measures for an acute reversible illness, but would not want long term life support.**

CONNECTICUT LIVING WILL

Specific Instructions

Listed below are my instructions regarding particular types of life-support systems. This list is not all-inclusive. My general statement that I not be kept alive through life-support systems provided to me is limited only where I have indicated that I desire a particular treatment to be provided.

DNR 

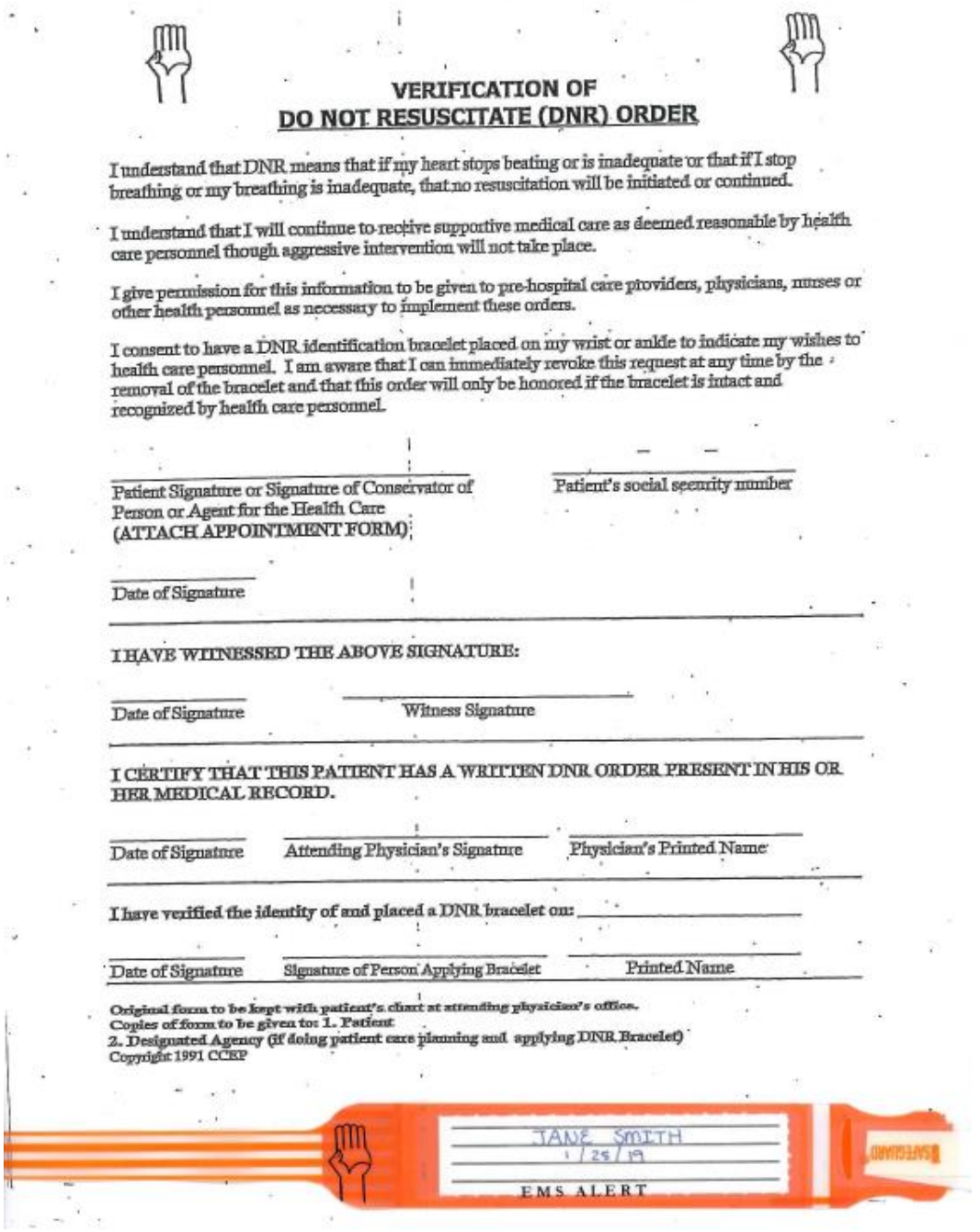
	Provide	Withhold
Cardiopulr		X
Artificial R		X
Artificial means of providing nutrition and hydration		X

Other specific requests: **I am A DNR/DNI, at no time do I want resuscitation efforts – no ventilators, no CPR, no defibrillation.**

HOW TO ENSURE DNR HONORED AT HOME:

- DNR Bracelet
- MOLST Forms

- Both Plastic or Metal Bracelets can be used in Connecticut
- Need to be provided by your doctor – through the CT College of Emergency Physicians



VERIFICATION OF
DO NOT RESUSCITATE (DNR) ORDER

I understand that DNR means that if my heart stops beating or is inadequate or that if I stop breathing or my breathing is inadequate, that no resuscitation will be initiated or continued.

I understand that I will continue to receive supportive medical care as deemed reasonable by health care personnel though aggressive intervention will not take place.

I give permission for this information to be given to pre-hospital care providers, physicians, nurses or other health personnel as necessary to implement these orders.

I consent to have a DNR identification bracelet placed on my wrist or ankle to indicate my wishes to health care personnel. I am aware that I can immediately revoke this request at any time by the removal of the bracelet and that this order will only be honored if the bracelet is intact and recognized by health care personnel.

Patient Signature or Signature of Conservator of Person or Agent for the Health Care (ATTACH APPOINTMENT FORM)

Patient's social security number

Date of Signature

I HAVE WITNESSED THE ABOVE SIGNATURE:

Date of Signature

Witness Signature

I CERTIFY THAT THIS PATIENT HAS A WRITTEN DNR ORDER PRESENT IN HIS OR HER MEDICAL RECORD.

Date of Signature

Attending Physician's Signature

Physician's Printed Name

I have verified the identity of and placed a DNR bracelet on:

Date of Signature

Signature of Person Applying Bracelet

Printed Name

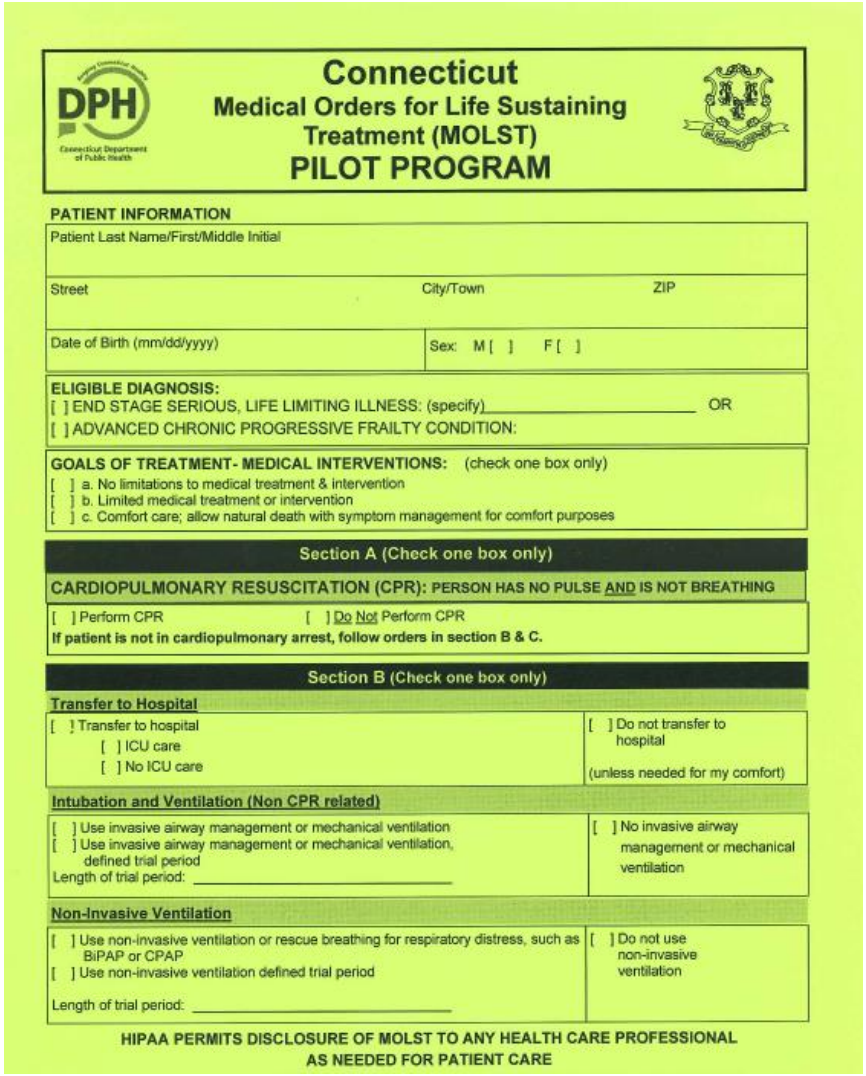
Original form to be kept with patient's chart at attending physician's office.
Copies of form to be given to: 1. Patient
2. Designated Agency (if doing patient care planning and applying DNR Bracelet)
Copyright 1991 CCEP

JANE SMITH
1/25/19
EMS ALERT

MOLST

- Connecticut MOLST form-fairly new document
  - -Medical Orders for Life Sustaining Treatment
  - Addresses many other treatment options besides CPR, resuscitation, intubation, artificial nutrition and hydration
  - SIGNED BY A PHYSICIAN OR APRN-they are actual orders that travel with patient from MD office to MD office, or MD office to Hospital

MOLST FORM



Connecticut
Medical Orders for Life Sustaining Treatment (MOLST)
PILOT PROGRAM

PATIENT INFORMATION

Patient Last Name/First/Middle Initial

Street | City/Town | ZIP

Date of Birth (mm/dd/yyyy) | Sex: M [ ] F [ ]

ELIGIBLE DIAGNOSIS:
[ ] END STAGE SERIOUS, LIFE LIMITING ILLNESS: (specify)_____ OR
[ ] ADVANCED CHRONIC PROGRESSIVE FRAILTY CONDITION:

GOALS OF TREATMENT- MEDICAL INTERVENTIONS: (check one box only)
[ ] a. No limitations to medical treatment & intervention
[ ] b. Limited medical treatment or intervention
[ ] c. Comfort care; allow natural death with symptom management for comfort purposes

Section A (Check one box only)

CARDIOPULMONARY RESUSCITATION (CPR): PERSON HAS NO PULSE AND IS NOT BREATHING

[ ] Perform CPR [ ] Do Not Perform CPR
If patient is not in cardiopulmonary arrest, follow orders in section B & C.

Section B (Check one box only)

Transfer to Hospital

[ ] Transfer to hospital
[ ] ICU care
[ ] No ICU care

[ ] Do not transfer to hospital
(unless needed for my comfort)

Intubation and Ventilation (Non CPR related)

[ ] Use invasive airway management or mechanical ventilation
[ ] Use invasive airway management or mechanical ventilation, defined trial period
Length of trial period: _____

[ ] No invasive airway management or mechanical ventilation

Non-Invasive Ventilation

[ ] Use non-invasive ventilation or rescue breathing for respiratory distress, such as BiPAP or CPAP
[ ] Use non-invasive ventilation defined trial period
Length of trial period: _____

[ ] Do not use non-invasive ventilation

HIPAA PERMITS DISCLOSURE OF MOLST TO ANY HEALTH CARE PROFESSIONAL AS NEEDED FOR PATIENT CARE

Section C (Check one box only)

Medically Administered Hydration (oral or by mouth hydration will always be offered if feasible)

[ ] Use medically administered hydration
[ ] Use medically administered hydration, defined trial period
Length of trial period: _____

[ ] No medically administered hydration

[ ] Undecided
[ ] Did not discuss

Medically Administered Nutrition (oral or by mouth nutrition will always be offered if feasible)

[ ] Use medically administered nutrition, such as total parenteral nutrition or tube feedings
[ ] Use medically administered nutrition defined trial period
Length of trial period: _____

[ ] No medically administered nutrition

[ ] Undecided
[ ] Did not discuss

Dialysis

[ ] Use dialysis
[ ] Use dialysis, defined trial period
Length of trial period: _____

[ ] No dialysis

[ ] Undecided
[ ] Did not discuss

Other treatment preferences specific to the patient's medical condition, e.g. vasopressors, medications, antibiotics, etc.

Section D

For this form to be valid: The form must be a lime green original MOLST form and the provider signing must ensure the form is thoroughly completed and signed by the patient or patient's legally authorized representative, provider and witness. A form that is incomplete, improperly completed or amended, except as permitted in Section E shall be deemed invalid and of no effect.

Discussed with:
[ ] Patient
[ ] Legally Authorized Representative (specify) _____

Signature below confirms this form was signed by the patient or Legally Authorized Representative **voluntarily** and reflects his/her wishes and goals of treatment as expressed to the provider signing below. Signature by a patient representative as indicated above confirms the form reflects his/her assessment of the patient's preferences or goals of care, or if those preferences are unknown, his/her understanding of the patient's best interests.

Signature of Patient or Legally Authorized Representative: | Date:

Printed Name of Patient or Legally Authorized Representative:

Signature of Provider: [ ] MD/DO [ ] APRN [ ] PA

Printed Name of Provider: | Date:

Provider Phone Number:

Signature of Witness:

Printed Name of Witness: | Date:

Interpreter Name or ID# and/or Service | Date:

Connecticut Department of Public Health, 410 Capitol Avenue, PO Box 304308, Hartford, CT 06134

BEYOND THE LEGAL SPEAK…

What are your goals and wishes?

- The "conversation" isn't only about completing an Advance Directive, rather it's about an individual's goals and wishes regarding "what matters" and their treatment preferences.

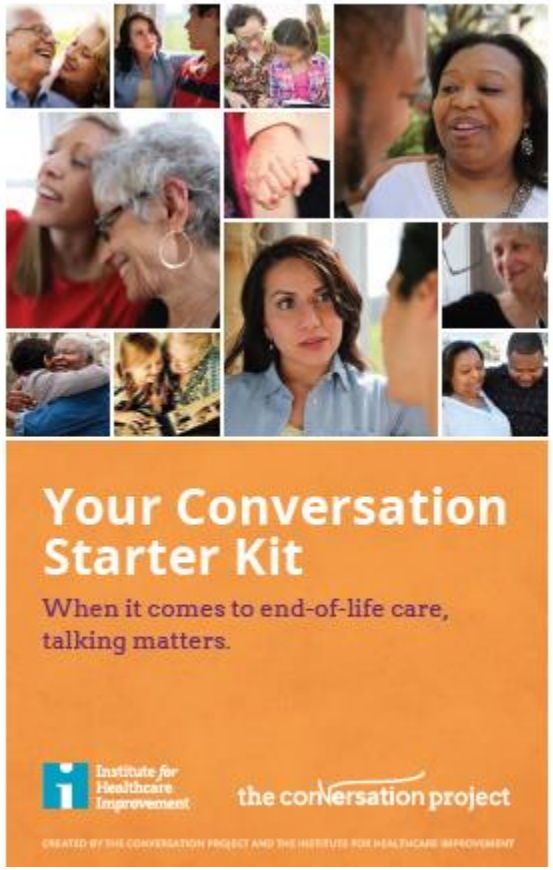
5 'SIMPLE' QUESTIONS

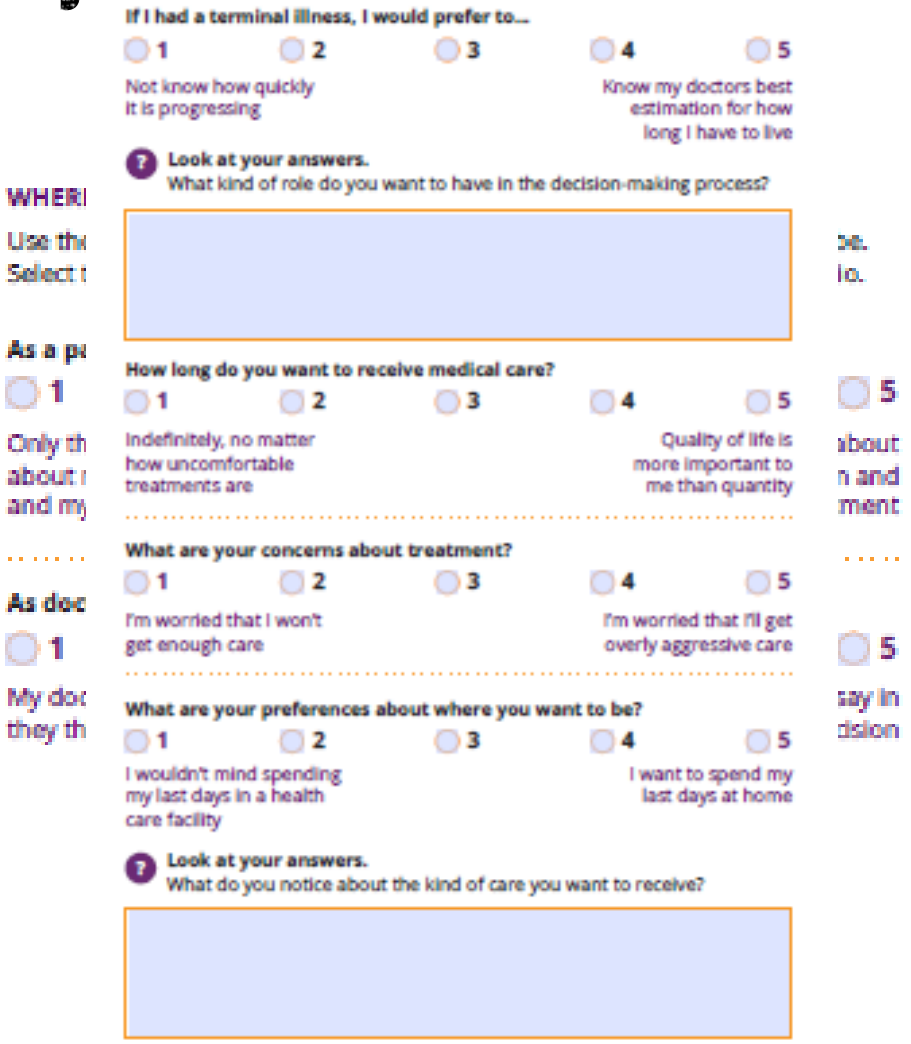
1. What is your understanding of where you are with your illness?
2. What are your fears or worries for the future?
3. What are your goals and priorities?
4. What outcomes are unacceptable to you? What are you willing to sacrifice and not?
5. What would a good day look like?

THE CONVERSATION PROJECT

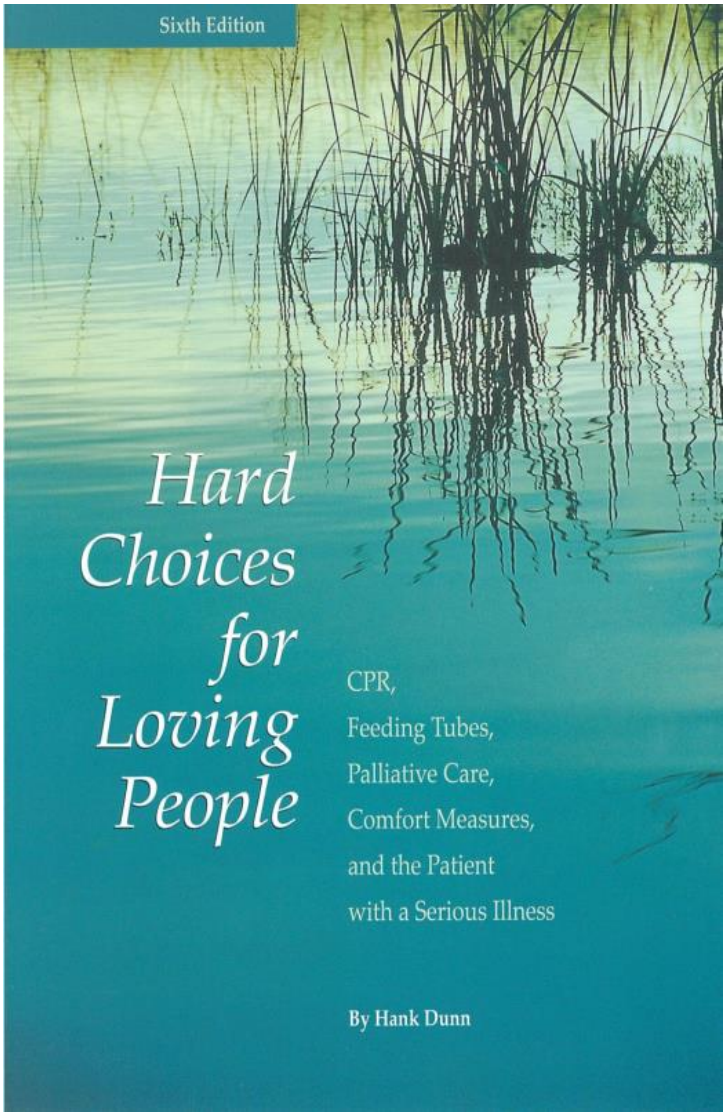
- National Initiative started in 2010 by Ellen Goodman
- Dedicated to encourage discussion about their wishes for end of life care
- Works in collaboration with the IHI-Institute for Healthcare Improvement
- TCP Starter Kit-asks questions about values/goals-www.theconversationproject.org

TOOLS TO ELICIT PATIENT GOALS: THE CONVERSATION PROJECT





HARD CHOICES FOR LOVING PEOPLE



KEY TAKE-AWAYS

Palliative Care Specialists can help you navigate acute serious or chronic progressive illness to optimize quality of life, and help identify when its time to transition to hospice care.

Medical Care should be customized for each person, based on their values – it's your legal right.

Completing Advance Care Planning Documents provides a road map for what medical treatments you want.

Clarity around your values to your HC Proxy – empowers them to speak on your behalf, your voice is heard even if you can't talk.

Talk to your doctor or request palliative care support to assist with Advance Care Planning and Goals of Care discussions.

THANK YOU!