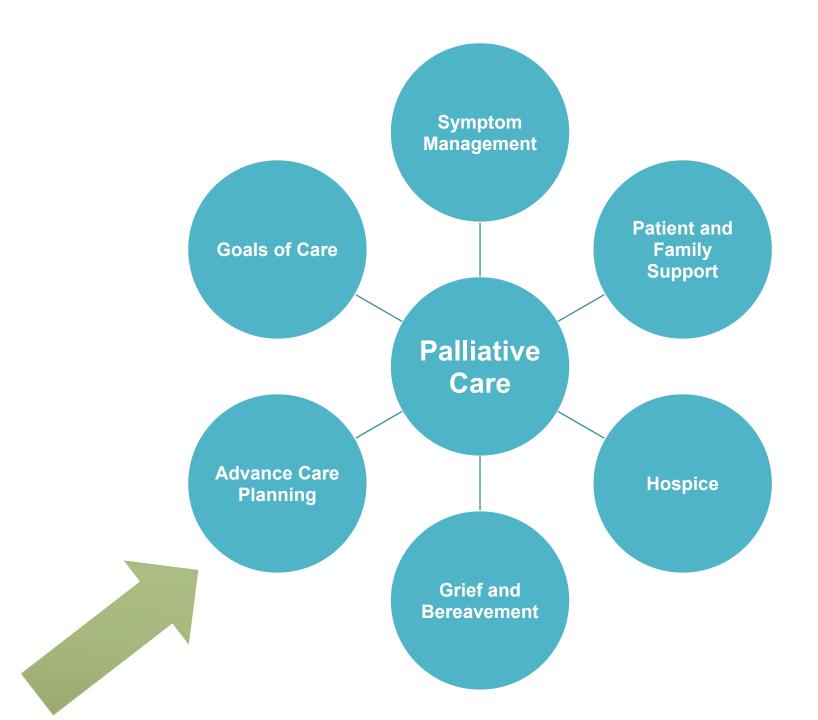
Approach to Advance Care Planning

> Maie El-Sourady, MD MS Palliative Care PCEC Program



# Goals and Objectives

Define Advance Care Planning

Review a practical approach to advance care planning

Discuss barriers and challenges with Advance Care Planning

Discuss which ACP documentation is most helpful at different stages of ACP

What is Advance Care Planning?

Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know about your preferences, often by putting them into an advance directive.

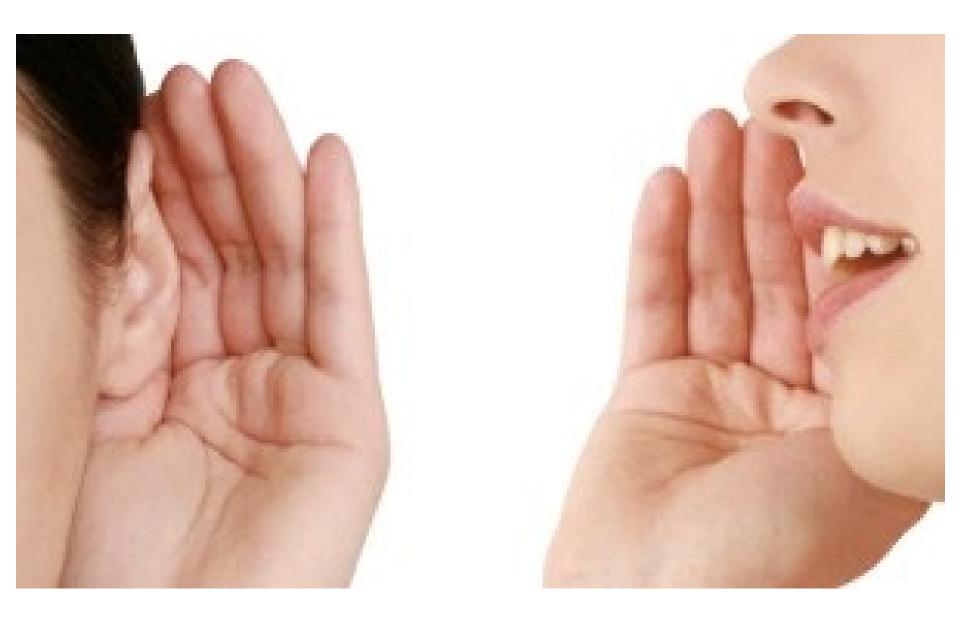
### Advance Care Planning Advance Directive

Discussion

Documentation

# Do Advance Directives change outcomes?

The presence of an advance directive does not seem to change how people die.



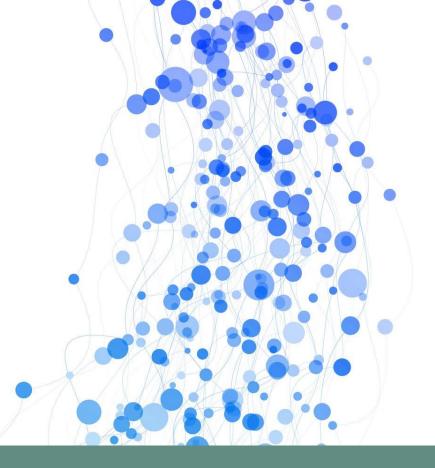
## The Point of ACP

### What it should be

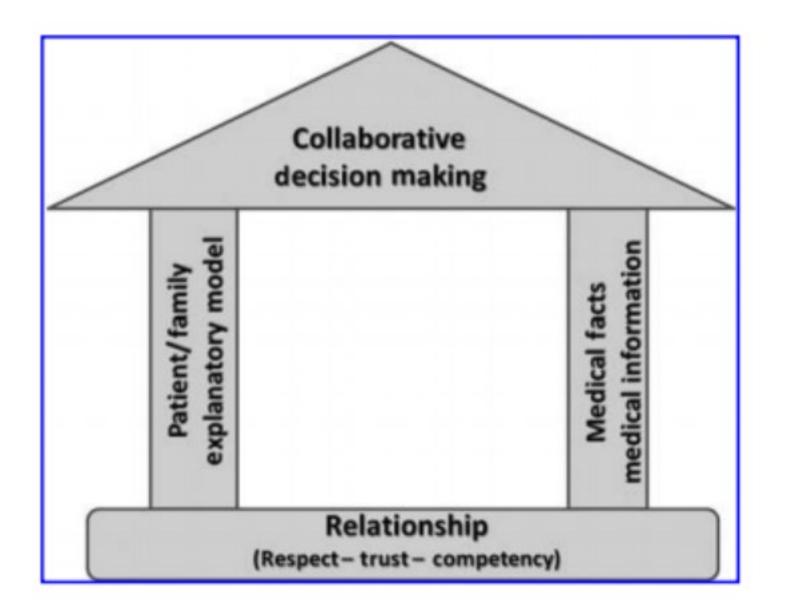
 Allow a patient to participate in medical decision-making if they lose capacity to do so

### How its used

 A way to help patients and their surrogates communicate medical preferences (usually at the end-of-life) to the healthcare system



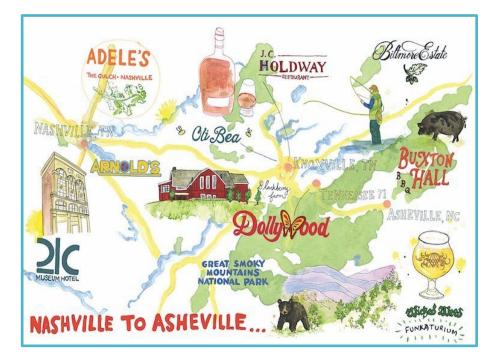
# An Approach to Advance Care Planning



Bhang TN and Iregui JC. Creating a Climate of Healing: A visual model for Goals of Care Discussions. JPM (2013)718-19.

### HOW WE THINK

### HOW WE MUST SPEAK



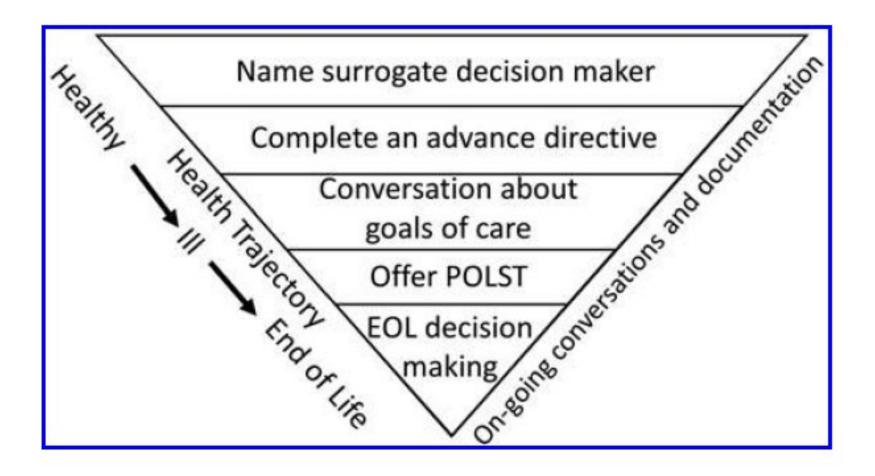




TRANSLATE THE ROAD MAP INTO DRIVING DIRECTIONS



Prognosis is what you think will happen translated into what you think the patient will experience



Izumi and Fromme – Journal Pall Med – (2017)20:220

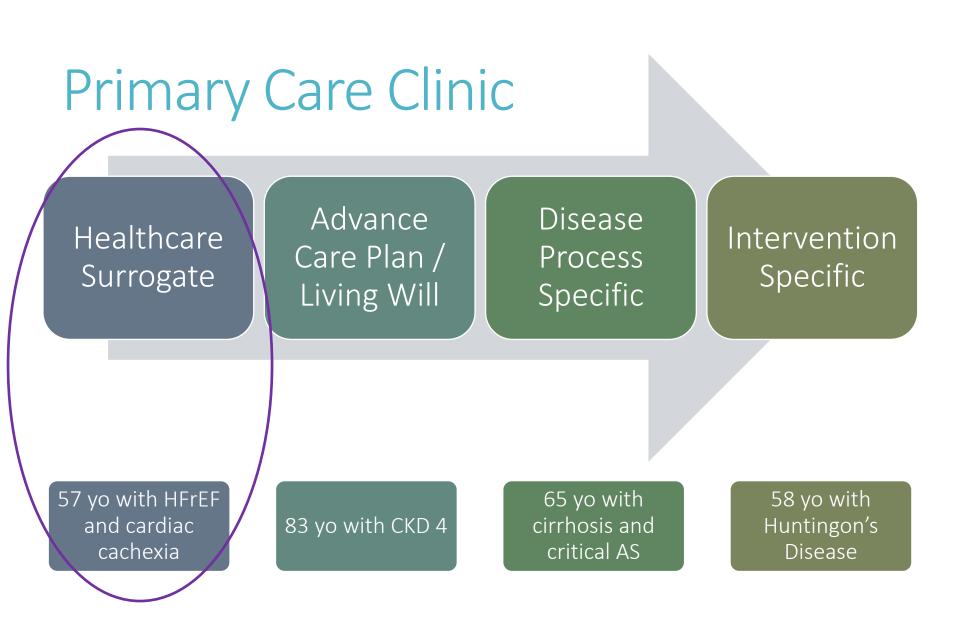
### Healthcare Surrogate

### Advance Care Plan / Living Will

### Disease Process Specific

### Intervention Specific

### **Illness Progression**



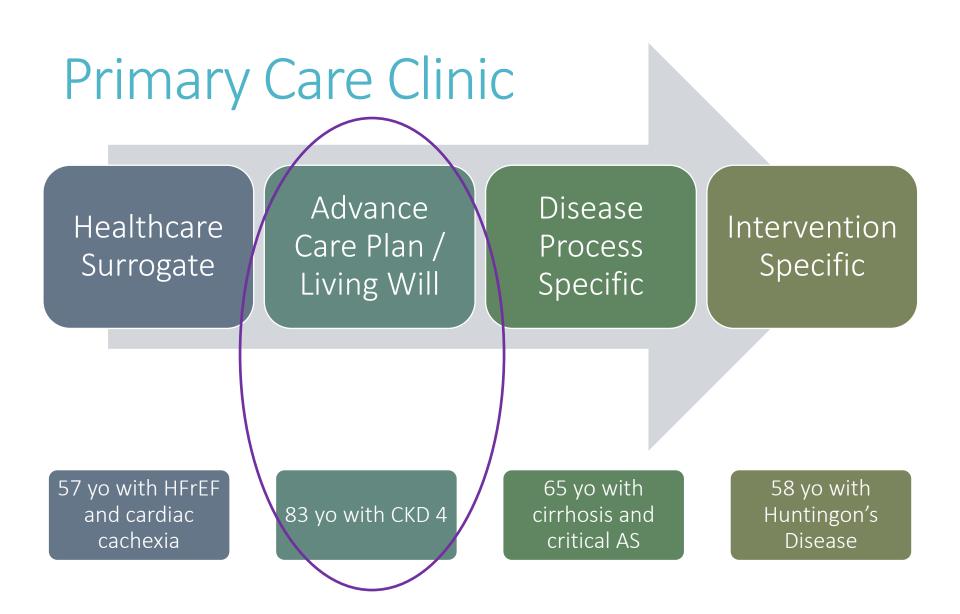
Health Care Surrogate Healthcare Agent / Healthcare Surrogate / Durable Power of Attorney for Healthcare / Medical Power of Attorney

An adult or emancipated minor who is appointed by another person to make health care decisions for that person

Usually becomes effective if the person lacks capacity and is no longer effective if person regains capacity

Should be a person that can apply the principle of "substituted judgment"

"Who could speak for you if you were unable to speak for yourself?"



Living Wills and Advance Care Plans Living wills are often drawn up by attorneys, so often not medically specific

Advance Care Plans can be downloaded by state and can be confusing

It is best to fill out your state's form, although most states will honor an advance care directive written in another state

Are designed to give permission to withhold or withdraw life-prolonging measures in end-stage medical conditions

DO NOT APPLY UNLESS PROGNOSIS IS CLEAR



### Creating an Advance Care Plan

Discuss what a patient enjoys doing and what makes their life worth living

Discuss minimal quality of life measures

Discuss any intervention that they might consider acceptable or unacceptable, both in the short or long term

Discuss if they would put up with potentially burdensome interventions or prolonged timeline to possibly achieve an acceptable quality of life

2 QUESTIONS for patients and families What do you hope for? What is off limits?

#### Tennessee

, hereby give 🗲

these advance instructions on how I want to be treated by my doctors and other health care providers when I can no longer make those treatment decisions myself.

#### Agent -

I want the following person to make health care decisions for me. This includes any health care decision I could have made for myself if able, except that my agent must follow my instructions below.

Name:	
T ACCUTOC:	

Phone number: Relation:

Address:

#### Alternate Agent

If the person named above is unable or unwilling to make health care decisions for me, I appoint as alternate the following person to make health care decisions for me. This includes any health care decision I could have made for myself if able, except that my agent must follow my instructions below.

N	2101	0
1.1	an	<b>C</b> .

Phone number: Relation:

Address:

My agent is also my personal representative for purposes of federal and state privacy laws, including HIPAA.

#### When Effective (mark one)

- I give my agent permission to make health care decisions for me at any time, even if I have capacity to make decisions for myself.
- I do not give such permission (this form applies only when I no longer have capacity).

#### Quality of Life-

By marking "Yes" below, I have indicated conditions I would be willing to live with if given adequate comfort care and pain management.

By marking "No" below, I have indicated conditions I would *not* be willing to live with (that to me would create an unacceptable quality of life).

#### Permanent Unconscious Condition

□ Yes □ No I become totally unaware of people or surroundings with little chance of ever waking up from the coma.

# ١F

Permanent Confusion				
□ Yes □ No	I become unable to remember, understand, or make decisions. I do not recognize loved ones or cannot have a clear conversation with them.			
Dependent in All Activities of Daily Living				
□ Yes □ No	I am no longer able to talk or communicate clearly or move by myself. I depend on others for feeding, bathing, dressing, and walking. Rehabilitation or any other restorative treatment will not help.			
End-Stage Illnesses				
□ Yes □ No	I have an illness that has reached its final stages in spite of full treatment. Examples: Widespread cancer that no longer responds to treatment; chronic and/or damaged heart and lungs, where oxygen is needed most of the time and activities are limited due to the feeling of suffocation.			

#### Treatment-

If my quality of life becomes unacceptable to me (as indicated by one or more of the conditions marked "No" on the previous page) and my condition is irreversible (that is, it will not improve), I direct that medically appropriate treatment be provided as follows. By marking "Yes" below, I have indicated treatment I want. By marking "No" below, I have indicated treatment I do *not* want.

#### CPR (Cardiopulmonary Resuscitation)-

Yes Do To make the heart beat again and restore breathing after it has stopped. Usually this involves electric shock, chest compressions, and breathing assistance.

#### Life Support / Other Artificial Support-

Yes D No Continuous use of breathing machine, IV fluids, medications, and other equipment that helps the lungs, heart, kidneys, and other organs to continue to work.

#### Treatment of New Conditions-

Yes Do Use of surgery, blood transfusions, or antibiotics that will deal with a new condition but will not help the main illness.

#### Tube Feeding / IV Fluids

□ Yes □ No Use of tubes to deliver food and water to a patient's stomach or use of IV fluids into a vein, which would include artificially delivered nutrition and hydration.

# THEN

#### Quality of Life

By marking "Yes" below, I have indicated conditions I would be willing to live with if given adequate comfort care and pain management.

By marking "No" below, I have indicated conditions I would *not* be willing to live with (that to me would create an unacceptable quality of life).

#### Permanent Unconscious Condition



I become totally unaware of people or surroundings with little chance of ever waking up from the coma.

#### Permanent Confusion

🗆 Yes 🎽 No

I become unable to remember, understand, or make decisions. I do not recognize loved ones or cannot have a clear conversation with them.

#### Dependent in All Activities of Daily Living-



I am no longer able to talk or communicate clearly or move by myself. I depend on others for feeding, bathing, dressing, and walking. Rehabilitation or any other restorative treatment will not help.

#### End-Stage Illnesses



I have an illness that has reached its final stages in spite of full treatment. Examples: Widespread cancer that no longer responds to treatment; chronic and/or damaged heart and lungs, where oxygen is needed most of the time and activities are limited due to the feeling of suffocation.

Applies to all unacceptable conditions checked on previous page

#### Treatment

If my quality of life becomes unacceptable to me (as indicated by one or more of the conditions marked "No" on the previous page) and my condition is irreversible (that is, it will not improve), I direct that medically appropriate treatment be provided as follows. By marking "Yes" below, I have indicated treatment I want. By marking "No" below, I have indicated treatment I do *not* want.

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- Continuous use of breathing machine, IV fluids, medications, and other equipment that helps the lungs, heart, kidneys, and other organs to continue to work.

#### Treatment of New Conditions-

- 🗆 Yes 🎽 No
- Use of surgery, blood transfusions, or antibiotics that will deal with a new condition but will not help the main illness.

#### Tube Feeding / IV Fluids



Use of tubes to deliver food and water to a patient's stomach or use of IV fluids into a vein, which would include artificially delivered nutrition and hydration.

#### Quality of Life

By marking "Yes" below, I have indicated conditions I would be willing to live with if given adequate comfort care and pain management.

By marking "No" below, I have indicated conditions I would *not* be willing to live with (that to me would create an unacceptable quality of life).

#### Permanent Unconscious Condition



I become totally unaware of people or surroundings with little chance of ever waking up from the coma.

#### Permanent Confusion



I become unable to remember, understand, or make decisions. I do not recognize loved ones or cannot have a clear conversation with them.

#### Dependent in All Activities of Daily Living-



I am no longer able to talk or communicate clearly or move by myself. I depend on others for feeding, bathing, dressing, and walking. Rehabilitation or any other restorative treatment will not help.

#### End-Stage Illnesses



I have an illness that has reached its final stages in spite of full treatment. Examples: Widespread cancer that no longer responds to treatment; chronic and/or damaged heart and lungs, where oxygen is needed most of the time and activities are limited due to the feeling of suffocation.

Applies ONLY to unacceptable conditions (permanent unconscious condition and permanent confusion)

#### Treatment

If my quality of life becomes unacceptable to me (as indicated by one or more of the conditions marked "No" on the previous page) and my condition is irreversible (that is, it will not improve), I direct that medically appropriate treatment be provided as follows. By marking "Yes" below, I have indicated treatment I want. By marking "No" below, I have indicated treatment I do *not* want.

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Use of surgery, blood transfusions, or antibiotics that will deal with a new condition but will not help the main illness.

#### Tube Feeding / IV Fluids



Use of tubes to deliver food and water to a patient's stomach or use of IV fluids into a vein, which would include artificially delivered nutrition and hydration.

#### Quality of Life

By marking "Yes" below, I have indicated conditions I would be willing to live with if given adequate comfort care and pain management.

By marking "No" below, I have indicated conditions I would *not* be willing to live with (that to me would create an unacceptable quality of life).

#### Permanent Unconscious Condition

🗙 Yes 🗆 No

I become totally unaware of people or surroundings with little chance of ever waking up from the coma.

#### Permanent Confusion

¥Yes □ No

I become unable to remember, understand, or make decisions. I do not recognize loved ones or cannot have a clear conversation with them.

#### Dependent in All Activities of Daily Living-



I am no longer able to talk or communicate clearly or move by myself. I depend on others for feeding, bathing, dressing, and walking. Rehabilitation or any other restorative treatment will not help.

#### End-Stage Illnesses



I have an illness that has reached its final stages in spite of full treatment. Examples: Widespread cancer that no longer responds to treatment; chronic and/or damaged heart and lungs, where oxygen is needed most of the time and activities are limited due to the feeling of suffocation.

None of these apply because they did not mark any unacceptable conditions

#### Treatment-

If my quality of life becomes unacceptable to me (as indicated by one or more of the conditions marked "No" on the previous page) and my condition is irreversible (that is, it will not improve), I direct that medically appropriate treatment be provided as follows. By marking "Yes" below, I have indicated treatment I want. By marking "No" below, I have indicated treatment I do not want.

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#### Life Support / Other Artificial Support-

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#### Treatment of New Conditions-



Use of surgery, blood transfusions, or antibiotics that will deal with a new condition but will not help the main illness.

#### Tube Feeding / IV Fluids



Use of tubes to deliver food and water to a patient's stomach or use of IV fluids into a vein, which would include artificially delivered nutrition and hydration.

### Applying an Living Will

Example: 78 year old with acute right sided MCA stroke.

Patient has a living will that says that he would not want to be maintained on machinery *if he had a terminal condition that could not be improved and would want to be allowed a natural death* 

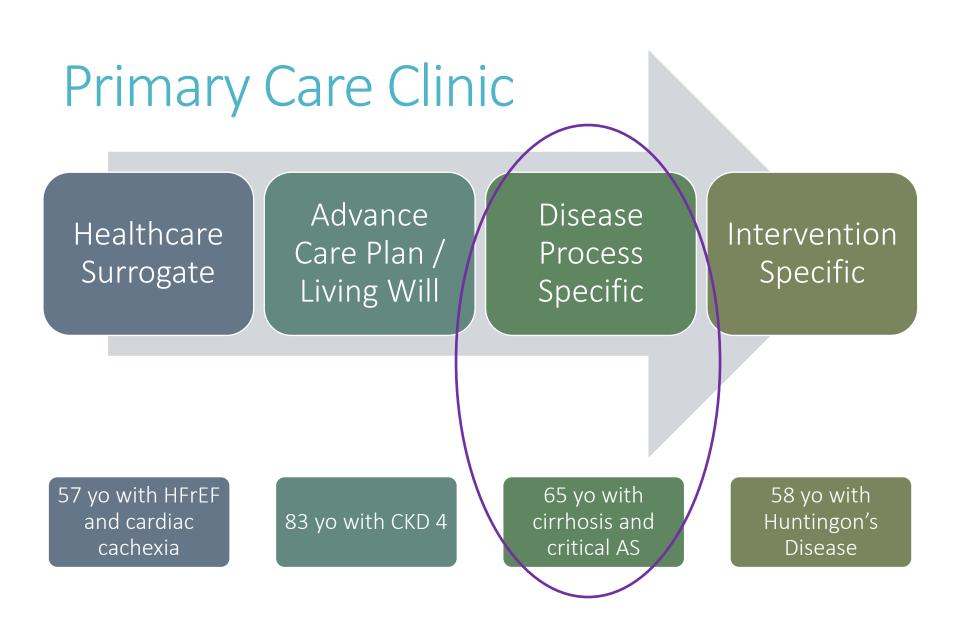
Does his living will apply in this situation?

Would you change is code status to DNR/DNI?

Would you discuss PEG with this family?

# What it can feel like when creating an ACP

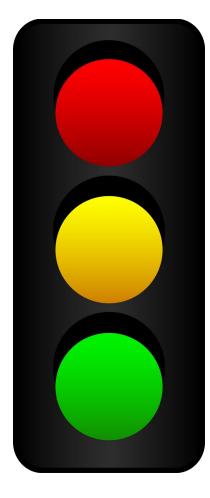




For the patient or family who wants "everything"

Most people mean "Everything that will help me get better (or at least stay the same)."

Our job is to help define which interventions fall into those categories.



### Interventions that WILL NOT help

### Interventions that MAY help

Interventions that WILL help

# Primary Care Clinic

### Healthcare Surrogate

Advance Care Plan / Living Will

Disease Process Specific

### Intervention Specific

57 yo with HFrEF and cardiac cachexia

### 83 yo with CKD 4

65 yo with cirrhosis and critical AS 58 yo with Huntingon's Disease

### Tracheostomy and PEG

Maintaining a quality of life that may be unacceptable

- Advanced dementia
- •Neurologic condition without acceptable improvement (stroke, traumatic brain injury)
- Maintaining a quality of life that may be acceptable
- •Advanced ALS or Muscular Dystrophy
- •Head and Neck Cancer
- •Neurologic condition with acceptable improvement

## Code Status Discussions

DNR (Do Not Resuscitate)

• Do not perform CPR in the event of a Pulseless Arrest

#### DNI (Do not Intubate)

- Do not place an endotracheal tube
- Does not apply to other respiratory support such as BiPAP

Should not be extrapolated to an overall "goals of care" discussion

Can have full aggressive treatment (chemo, pressors, ICU care) but draw the line at intubation and CPR

A COPY OF THIS FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED			
Tennessee Physician Orders for Scope of Treatment (POST, sometime called "POLST)		Patient's Last Name	
This is a Physician Order Sheet based on the medical conditions and wishes of the person identified at right ("patient"). Any section not completed indicates full treatment for that section. When need		First Name/Middle Initial	
occurs, <u>first</u> follow these orders, <u>then</u> contact physician.		Date of Birth	
Section	CARDIOPULMONARY RESUSCITATION (CP	R): Patient has no pulse <u>and</u> is not breathing.	
A Check One	□ <u>R</u> esuscitate (CPR) □ <u>D</u> o <u>N</u> ot	Attempt <u>Resuscitation</u> (DNR / no CPR) ( <u>A</u> llow <u>N</u> atural <u>D</u> eath)	
Box Only	When not in cardiopulmonary arrest, follow orders in I	B, C, and D.	

Section	MEDICAL INTERVENTIONS. Patient has pulse and/or is breathing.
B Check One Box	Comfort Measures. Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management.
Only	Limited Additional Interventions. In addition to care described in Comfort Measures Only above, use medical treatment, antibiotics, IV fluids and cardiac monitoring as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: basic medical treatment.
	<ul> <li>Full Treatment. In addition to care described in Comfort Measures Only and Limited Additional Interventions above, use intubation, advanced airway interventions mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. Treatment Plan: Full treatment including in the intensive care unit.</li> <li>Other Instructions:</li> </ul>

Section C Check One	ARTIFICIALLY ADMINISTERED N <ul> <li>No artificial nutrition by tube.</li> <li>Defined trial period of artificial r</li> <li>Long-term artificial nutrition by</li> </ul> Other Instructions:	•
Section D Must be Completed	Discussed with: Patient/Resident Health care agent Court-appointed guardian Health care surrogate Parent of minor Other:(Specify)	The Basis for These Orders Is: (Must be completed)      Patient's preferences     Patient's best interest (patient lacks capacity or preferences unknown)     Medical indications     (Other)

Physician/NP/CNS/PA Name (Print)	Phys	ician/NP/CNS/PA Signature	Date	MD/NP/CNS/PA Phone Number:
	NP/CNS	/PA (Signature at Discharge)		( )
Signature of Patient, F	arent of	Minor, or Guardian/Health C	are Representative	
Preferences have been expressed to a physician and /or health care professional. It can be reviewed and updated at any time if your preferences change. If you are unable to make your own health care decisions, the orders should reflect your preferences as best understood by your surrogate.				
Name (Print)	Signa	ature	Relationship (write	"self" if patient)
Agent/Surrogate		Relationship	Phone Number (	)
Health Care Professional Preparing Form		Preparer Title	Phone Number ( )	Date Prepared

A COPY OF THIS FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED			
Tennessee Physician Orders for Scope of Treatment (POST, sometime called "POLST)		Patient's Last Name	
This is a Physician Order Sheet based on the medical conditions and wishes of the person identified at right ("patient"). Any section not completed indicates full treatment for that section. When need		First Name/Middle Initial	
occurs, <u>first</u> follow these orders, <u>then</u> contact physician.		Date of Birth	
Section	•	R): Patient has no pulse <u>and</u> is not breathing.	
A Check One	☐ <u>R</u> esuscitate (CPR)	Attempt <u>Resuscitation (DNR / no CPR) (Allow Natural D</u> eath)	
Box Only	When not in cardiopulmonary arrest, follow orders in E		

## POST Form (Example 1) A patient with advanced illness does not want CPR or advanced interventions, and only wants treatments of symptoms

Section B	MEDICAL INTERVENTIONS. Patient has pulse and/or is breathing.		
Check One Box	X	<b>Comfort Measures.</b> Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management.	
Only		Limited Additional Interventions. In addition to care described in Comfort Measures Only above, use medical treatment, antibiotics, IV fluids and cardiac monitoring as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: basic medical treatment.	
	□ Oth	Full Treatment. In addition to care described in Comfort Measures Only and Limited Additional Interventions above, use intubation, advanced airway interventions mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. Treatment Plan: Full treatment including in the intensive care unit.	

## POST Form (Example 1) A patient with advanced illness does not want CPR or advanced interventions, and only wants treatments of symptoms

A COPY OF THIS FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED			
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Section	· · · · ·	R): Patient has no pulse <u>and</u> is not breathing.	
A Check One	□ <u>R</u> esuscitate (CPR) X <u>D</u> o <u>N</u> ot	Attempt <u>R</u> esuscitation (DNR / no CPR) ( <u>A</u> llow <u>N</u> atural <u>D</u> eath)	
Box Only	When not in cardiopulmonary arrest, follow orders in I		

# POST Form (Example 2)

A patient with lung disease who does not want CPR but would want to be intubated and placed on mechanical ventilation

Section B	ME	DICAL INTERVENTIONS. Patient has pulse and/ <u>or</u> is breathing.
Check One Box		<b>Comfort Measures.</b> Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management.
Only		Limited Additional Interventions. In addition to care described in Comfort Measures Only above, use medical treatment, antibiotics, IV fluids and cardiac monitoring as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: basic medical treatment.
	X	<b>Full Treatment.</b> In addition to care described in Comfort Measures Only and Limited Additional Interventions above, use intubation, advanced airway interventions mechanical ventilation as indicated. <b>Transfer</b> to hospital and/or intensive care unit if indicated. <b>Treatment Plan: Full treatment including in the intensive care unit.</b>
	Otl	the Intensive care unit.

# POST Form (Example 2)

A patient with lung disease who does not want CPR but would want to be intubated and placed on mechanical ventilation

# For every patient

### Identify a surrogate

 Who do you trust to speak for you if you were unable to speak for yourself?

#### Address medical limitations

•Have you spoken with [healthcare surrogate] about what you would or would not want done if you were to get really sick?

•Are there any medical interventions that you would consider off limits?

# Helpful Resources

Advance Care Plans by state: <a href="http://www.caringinfo.org">http://www.caringinfo.org</a>

NIH National Institute on Aging: <u>http://www.nia.nih.gov/health/publication/advan</u> <u>ce-care-planning</u>

Tennessee Department of Health: <u>https://tn.gov/health/article/advance-directives</u>

Murray S, Kendall M, Boyd K and Sheikh A. Illness trajectories and palliative care. BMJ 2005; 330; 1007-1011

Lang F and Quill T. Making Decisions with Families at the End of Life. **American Family Physician.** (2004) 70:719.

Rosenfeld KE, Wenger NS, and Kagawa-Singer M. End-of-Life Decision-Making: A Qualitative Study of Elderly Individuals. J Gen Intern Med (2000)15:620.



Opioids Dosage Conversion 17\* Chris Marcellino MD LLC

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VitalTalk Tips (4+) Vital Talk \*\*\*\*\* 4.9 · 12 Ratings Free

James Tulsky Mastering Communication with Seriously III Patients Balancing Honesty with Empathy and Hope

**Anthony Back** 

**Robert Arnold** 





Palliative Care Fast Facts 17\* HAIPENG ZHANG

**Useful Resources** 

Thank you!

Feedback for this lecture 5 questions (3 minutes)

