Advance Care Planning at EHHOP

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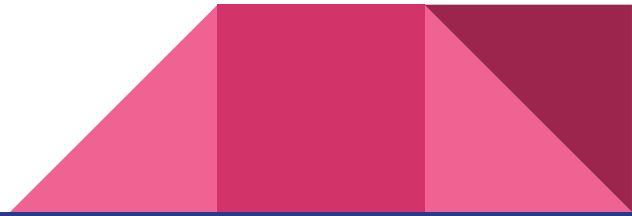
Pre-Workshop Survey

Objectives

- Define advance care planning
- Utilize various forms of ACP documentation, including a healthcare proxy form
- Reframe ACP conversations in the social, legal, and spiritual context that is applicable to the EHHOP patient population



Advance Care Planning

Advance care planning (ACP) is a process that supports adults at **any age or stage of health** in understanding and sharing their **personal values, life goals, and preferences** regarding future medical care [uptodate]

At EHHOP, we want to see if there is a way for all patients to have a space to talk about potential plans for medical care and people who they would want to be involved.

Terms to know:

- **Surrogate** - default medical decision maker if health care agent is not chosen, certain order of priority, 18+
- **Health Care Agent (HCA)** - designated by patient to make medical, non-financial decisions. Dictated on Health Care Proxy Form, 18+
- **Power of Attorney** - financial, legal, property decisions (NON-MEDICAL), can be the same as HPA.
- **Advanced Directives** (NY-Specific)
    - Health Care Proxy
    - Living Will
    - Nonhospital Order Not to Resuscitate (DNR)
    - Medical Order for Life Sustaining Treatment (MOLST)
- 5 Wishes, VALUE Statements, Serious Illness Conversations

If you are in a coma, vegetatitive state, or otherwise incapacitated, who would you want to make medical decisions for you?

Nobody: Consider a **Living Will** format/**5 Wishes** so that your medical instructions are clear and can be read by your caregivers when you are unable to communicate your wishes

Close family/friend: Consider a **Health Care Proxy** by appointing someone who can be your health care agent. They will be able to speak and decide for you when you are unable to do so.

5 Wishes Conversation

My Wish for:

- The person I want to make care decisions for me when I can’t
- The kind of medical treatment I want or don't want
- How comfortable I want to be
- How I want people to treat me
- What I want my loved ones to know

Even though you want someone you trust to make medical decisions for you, do you still have strongly held views about specific situations?

NO: Consider just a **Health Care Proxy.**

YES: Consider a **Health Care Proxy** and **Living Will** so that the appointment person can rely on your written instructions.

Health Care Proxy

- Completed by patient 18+
- Agent's authority to make decisions starts when doctor determines that patient has lost the capacity to make decisions for themselves.
  - If withdrawing or withholding treatment -> second doctor must confirm doctor's decision
- Type of decisions a HCA can make:
  - Artificial nutrition or hydration
  - Heartbeat restarted through CPR
  - Access to medical information and records
- **Patient can specify on Health Care Proxy what types of decisions HCA can make.**
- HCA is NOT financially responsible for cost of care
- People who **CANNOT** be HCA:
  - An operator, administrator, or employee of the hospital patient is admitted. (Unless related or appointed BEFORE admission)
  - Patient's doctor unless they are related to patient
- Two witnesses needed

HEALTH CARE PROXY

(1) I, Name of patient (18+) _____

hereby appoint Name of HCA (18+) _____

(name, home address and telephone number)

_____

_____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint _____

(name, home address and telephone number)

_____

_____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (*Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire *(specify date or conditions):*

_____

_____

(4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. *(If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.)* I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions *(attach additional pages as necessary):*

_____

_____

In order for your agent to make health care decisions for you about artificial nutrition and hydration *(nourishment and water provided by feeding tube and intravenous line),* your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification *(please print)*

Your Name _____

Your Signature _____ Date _____

Your Address _____

(6) Optional: Organ and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of:
(check any that apply)

☐ Any needed organs and/or tissues

☐ The following organs and/or tissues _____

_____

☐ Limitations _____

If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature _____ Date _____

(7) Statement by Witnesses *(Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)*

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1

Date _____

Name *(print)* _____

Signature _____

Address _____

_____

Witness 2

Date _____

Name *(print)* _____

Signature _____

Address _____

_____

Living Will

- There is **no** standard form for the living will in NYS.
  - They are, however, valid as long as they provide “clear and convincing” evidence
  - Templates are available
- **Evidence of your wishes**: contains specific instructions on medical treatments
  - CPR? Blood Transfusions? Dialysis?
- Must have the following:
  - Patient’s name
  - Date you created your living will
  - Statement regarding personal health care wishes
  - patient ‘s signature
  - Two witnesses’ signature and dates + statements from witnesses that patient’s signed the document willingly

This Living Will has been prepared to conform to the law in the State of New York, as set forth in the case In re Westchester County Medical Center, 72 N.Y. 2d 517 (1988). In that case the Court established the need for "clear and convincing" evidence of a patient's wishes and stated that the "ideal situation is one in which the patient's wishes were expressed in some form of writing, perhaps a 'Living Will'."

I, [1] Name of patient, being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below:

I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying, if I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, including but not limited to: (a) a terminal condition; (b) a permanently unconscious condition; or (c) a minimally conscious condition in which I am permanently unable to make decisions or express my wishes.

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment. While I understand that I am not legally required to be specific about future treatments **if I am in the condition(s) described above I feel especially strongly about the following forms of treatment**:

[2]

- ☐ I do not want cardiac resuscitation.
- ☐ I do not want mechanical respiration.
- ☐ I do not want artificial nutrition and hydration.
- ☐ I do not want antibiotics.

However, I **do want** maximum pain relief, even if it may hasten my death.

[3] Other directions:

These directions express my legal right to refuse treatment, under the law of New York. I intend my instructions to be carried out, unless I have rescinded them in a new writing or by clearly indicating that I have changed my mind.

Personal instructions AND If applicable, statement referring to HCA ("Any questions about how to apply my Living Will are to be decided by my health care agent.")

[4]

Signed _____ Date _____

Address _____

I declare that the person who signed this document appeared to execute the Living Will willingly and free from duress. He or she signed (or asked another to sign for him or her) this document in my presence.

[5]

Name of Witness 1 (please print, sign and date)

Signed _____ Date _____

Address _____

Name of Witness 2

Signed _____ Date _____

Address _____

MOLST

- Patients who have terminal illnesses and serious medical conditions.
- Doctor's written documentation on patient's preferences on:
  - CPR
  - Mechanical Intervention
  - Life Sustaining treatments
- **Must** be completed by HCP and signed by NYS licensed physician to be valid

MOLST translates your **current medical treatment preferences into physician orders, while HCP and/or Living Will guides **future** medical care**

NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN OR NURSE PRACTITIONER KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

ADDRESS

CITY/STATE/ZIP

DATE OF BIRTH (MM/DD/YYYY) ☐ Male ☐ Female eMOLST NUMBER (THIS IS NOT AN eMOLST FORM)

Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form based on the patient's current medical condition, values, wishes, and MOLST Instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician or nurse practitioner must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician or nurse practitioner examines the patient, reviews the orders, and changes them.

MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician or nurse practitioner and consider asking the physician or nurse practitioner to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

If the patient has an intellectual or developmental disability (I/DD) and lacks the capacity to decide, the doctor (not a nurse practitioner) must follow special procedures and attach the completed Office for People with Developmental Disabilities (OPWDD) legal requirements checklist before signing the MOLST. See page 4.

SECTION A Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing

Check **one**:

☐ **CPR Order: Attempt Cardio-Pulmonary Resuscitation**
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

☐ **DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

SECTION B Consent for Resuscitation Instructions (Section A)

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law. Individuals with I/DD who do not have capacity and do not have a health care proxy must follow SCPA 1750-b.

_____ ☐ Check if verbal consent (Leave signature line blank) _____
SIGNATURE DATE/TIME

_____
PRINT NAME OF DECISION-MAKER

_____ _____
PRINT FIRST WITNESS NAME PRINT SECOND WITNESS NAME

Who made the decisions? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate*

SECTION C Physician or Nurse Practitioner Signature for Sections A and B

_____ _____ _____
PHYSICIAN OR NURSE PRACTITIONER SIGNATURE* PRINT PHYSICIAN OR NURSE PRACTITIONER NAME DATE/TIME

_____ _____
PHYSICIAN OR NURSE PRACTITIONER LICENSE NUMBER PHYSICIAN OR NURSE PRACTITIONER PHONE/PAGER NUMBER

SECTION D Advance Directives

Check all advance directives known to have been completed:

☐ Health Care Proxy ☐ Living Will ☐ Organ Donation ☐ Documentation of Oral Advance Directive

***If this decision is being made by a 1750-b surrogate, a physician must sign the MOLST.**

SECTION E — Orders For Other Life-Sustaining Treatment and Future Hospitalization When the Patient has a Pulse and the Patient is Breathing

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. **If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped. Before stopping treatment, additional procedures may be needed as indicated on page 4.**

Treatment Guidelines No matter what else is chosen, the patient will be treated with dignity and respect, and health care providers will offer comfort measures. *Check one:*

- ☐ **Comfort measures only** Comfort measures are medical care and treatment provided with the primary goal of relieving pain and other symptoms and reducing suffering. Reasonable measures will be made to offer food and fluids by mouth. Medication, turning in bed, wound care and other measures will be used to relieve pain and suffering. Oxygen, suctioning and manual treatment of airway obstruction will be used as needed for comfort.
- ☐ **Limited medical interventions** The patient will receive medication by mouth or through a vein, heart monitoring and all other necessary treatment, based on MOLST orders.
- ☐ **No limitations on medical interventions** The patient will receive all needed treatments.

Instructions for Intubation and Mechanical Ventilation *Check one:*

- ☐ **Do not intubate (DNI)** Do not place a tube down the patient's throat or connect to a breathing machine that pumps air into and out of lungs. Treatments are available for symptoms of shortness of breath, such as oxygen and morphine. (This box should not be checked if full CPR is checked in Section A.)
- ☐ **A trial period** *Check one or both:*
  - ☐ **Intubation and mechanical ventilation**
  - ☐ **Noninvasive ventilation (e.g. BIPAP), if the health care professional agrees that it is appropriate**
- ☐ **Intubation and long-term mechanical ventilation, if needed** Place a tube down the patient's throat and connect to a breathing machine as long as it is medically needed.

Future Hospitalization/Transfer *Check one:*

- ☐ **Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled.**
- ☐ **Send to the hospital, if necessary, based on MOLST orders.**

Artificially Administered Fluids and Nutrition When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have either a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. **Additional procedures may be needed as indicated on page 4.**
Check one each for feeding tube and IV fluids:

- ☐ **No feeding tube**
- ☐ **A trial period of feeding tube**
- ☐ **Long-term feeding tube, if needed**
- ☐ **No IV fluids**
- ☐ **A trial period of IV fluids**

Antibiotics *Check one:*

- ☐ **Do not use antibiotics.** Use other comfort measures to relieve symptoms.
- ☐ **Determine use or limitation of antibiotics when infection occurs.**
- ☐ **Use antibiotics** to treat infections, if medically indicated.

SECTION F Review and Renewal of MOLST Orders on this MOLST Form

The physician or nurse practitioner must review the form from time to time as the law requires, and also:

- If the patient moves from one location to another to receive care; or
- If the patient has a major change in health status (for better or worse); or
- If the patient or other decision-maker changes his or her mind about treatment.

Date/Time	Reviewer's Name and Signature	Location of Review (e.g., Hospital, NH, Physician's or Nurse Practitioner's Office)	Outcome of Review
			☐ No change ☐ Form voided, new form completed ☐ Form voided, **no** new form
			☐ No change ☐ Form voided, new form completed ☐ Form voided, **no** new form
			☐ No change ☐ Form voided, new form completed ☐ Form voided, **no** new form

MOLST translates your **current medical treatment preferences into physician orders, while HCP and/or Living Will guides **future** medical care**

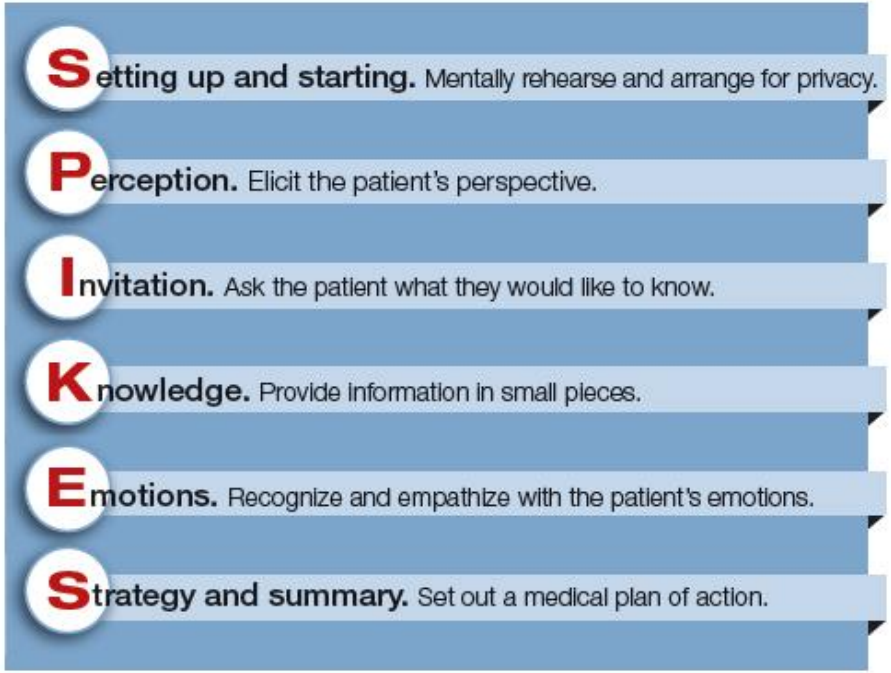
Case

Patient TA is a 50 year-old cis-gender male with a PMHx significant for advanced chronic instertitial lung disease (requiring 4L NC O2), hypertension, and CKD3 presenting for routine primary care follow up.

Social History: The patient lives in shared housing in East Harlem. He does not work due to his limited mobility secondary to his medical conditions. His social support network consists of his brother and a few close friends in New York. The patient is an immigrant from Ivory Coast (moved 10 years ago), and does not meet current US residency requirements.

How will we introduce ACP to our patient?

Conduct a family meeting with the patient and caregivers present.



How do I continue the conversation with the family?

V.A.L.U.E.

A 5-step mnemonic to improve ICU clinician communication with families

- V = Value comments made by the family
- A = Acknowledge family emotions
- L = Listen
- U = Understand the patient as a person
- E = Elicit family questions

Set the Stage

Steps	What To Say
1. Ask the patient who else they would like present.	Is there anyone else you would like to include in our discussion of your long term medical plans?
2. Seek permission to discuss ACP.	Is it okay if we discuss your goals of medical care?
3. Go over the patient's communication preferences.	Do you like to hear details or hear more about the big picture?
4. Normalize the content.	We speak to all of our patients about planning for the future. Have you thought about who you would want to make medical decisions for you in the future if you are unable to do so yourself?

Get into the ACP Details

Steps	What To Say
5. Understand the patient's perspective of their illness.	Tell me what you believe is going on with your health
6. Discuss the patient's hopes, purpose in life.	What are your hopes for treatment? What parts of life are most important to you?
7. Explore patient's thoughts on quality of life.	If you were unable to care for yourself and needed others to care for your, how would that be for you?
8. Address patient's worries and fears.	What are your concerns? What worries you about your health in the future?
9. Talk through the patient's strengths. *Bring up spirituality and religious values here	Where do you get support? Do you have any cultural or spiritual beliefs that are important to you?
10. Ask about healthcare proxy/other documents.	**If you couldn't speak for yourself, who would you like to make medical decisions for you? Have you talked with that person about what you would want and not want? What did you say?**

Counseling on how to choose health care agent

- Will the person make decisions that are in line with your wishes?
  - Even if the your wishes and theirs differ?
- Will the person be comfortable speaking up on your behalf?
  - Will they be okay asking questions of doctors/medical providers?
- Will the person be good at making decisions in changing circumstances (“under pressure”)?
- Who might be a good choice?
  - Parent, spouse/partner, child, sibling, friend, cousin, trusted neighbor
  - CANNOT be a member of your current medical team
  - In NYS the role legally falls to spouse if there is no proxy selected
- Make sure the person is willing to take on the role and understands their responsibilities, along with your wishes.

Partner with the Patient

Steps	What To Say
11. Identify and normalize uncertainty.	We don't know exactly what the future holds. It's okay to feel some anxiety surrounding this topic.
12. Depending on health literacy and patient desire, offer evidence relating to life expectancy, disease prognosis, etc.	*Dependent on disease course*
13. Make recommendations given your goals as a clinician.	I hope to treat you with XY so that we can extend your lifespan to meet your goals. We do want to have a plan in place in case things do not go as we hope.

Feedback & Wrap-Up

Steps	What To Say
14. Invite the patient to ask questions.	What questions can I answer for you? You seem uncertain about XY; how can I help clarify?
15. Summarize goals and next steps.	Today we've discussed XY. It sounds like your goals are XY. Based on that we will sign XY forms/discuss again at your next visit.
16. Document in EMR and communicate with the rest of the treatment team.	I'm going to let your other doctors know we had this conversation by including this document in your medical record. Is that okay?

Specific to EHHOP

- Undocumented population
- Non-native English speakers
- Spirituality and/or religion may play large role in medical decisions

Undocumented

What are some barriers you can think of that would specifically affect patients who are undocumented's ability to participate in proper ACP conversations?

Legality

- In NYS, **NO** forms discussed above need to be notarized.
- Documents are only seen by health care providers, witnesses, patient, and anyone patients shows it too. **No public officers/government officials need to be provided this information.**

Special Considerations

- People at home overseas - is there anyone they would like to call if they do lose capacity? - **living wills document**
- Are there any rituals/beliefs/practices the patient would like to occur if they lose capacity - **living wills document**

Cultural Differences (Language, Spirituality/Religion)

- Forms
  - HCP: English, Spanish, Chinese, Haitian Creole, Italian, Korean, and Russian
  - Living Will: Can be written in the patient's primary language
  - MOLST: Spanish and English
- Aid your interpreter in translating the conversation within the appropriate cultural context by
  - 1) Doing research on the culture of palliative care conversations for each of your patients
  - 2) Conducting pre meetings with interpreters to prepare and discuss cultural humility
  - 3) Conducting post meetings with interpreters to debrief and clarify language
- Spirituality/Religion
  - "What beliefs and what values do you have?"
  - "Wow does religion/spirituality impact how you want to be cared for at EOL?"

Breakout Case

Take turns setting the tone for and completing an advance care planning conversation with your EHHOP patient. Each person will have 30 seconds before the next person jumps in (from where the previous left off). Groups will last about 10 minutes.

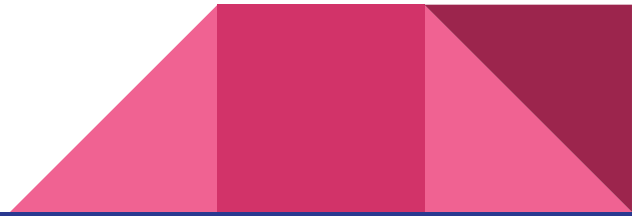
Patient: Patient Z is a 45yo cis-gender female with a PMHx significant for type 2 diabetes (insulin dependent with wavering adherence, uncontrolled A1c 9.5, diagnosed 4 years ago), hypertension, hyperlipidemia, asthma, and housing instability. She lives in an apartment in East Harlem with her husband, parents, and four children (ages 20, 16, 14, and 7). She has never heard the term advance care planning or healthcare proxy before and has never been hospitalized.

Flow in EHHOP

1. Section in sign-in will be dedicated to advanced care planning.
    a. ESIP interpreter notified about ACP conversation and terms that may be used
    b. Patient notified by TS/CCS/CCJ over telephone week before clinic; can ask patient if they want to bring family member
2. Ask patient to complete ACP survey at start of discussion.
3. All patients to complete *at least* a healthcare proxy form + brief conversation on goals of care (can consider further documents when appropriate).
    a. Chronic Care Seniors and TSs should decide (in advance of next full visit) if other documentation is appropriate.
    b. EHHApp links with access to blank copies of all documents in Spanish & English.
4. Upload to patient's Epic chart via media section (search for document type → advanced care planning) and .EHHOPACP note.
5. Ask patient to complete ACP survey at conclusion of discussion.

Every 3 month check in should include brief mention of ACP and if goals of care or HCA has changed.

Thank you for your attention! Questions?



Post-Workshop Survey

Resources

Prepareforyourcare.org

- More comprehensive advanced directive here (Spanish and English available)

https://cvquality.acc.org/docs/default-source/default-document-library/b17214-pinnacle-acp-toolkit_final_termsb213e869f23c6a89922dff0000b52e5f.pdf?sfvrsn=a12f82bf_0

https://ag.ny.gov/sites/default/files/advancedirectives.pdf -> good for understanding ACP terms!