Having Conversations That Matter
Sydney Phillips, LMSW
Objectives

• To understand the importance of Advance Care Planning
• To think about health care choices that reflect your values and beliefs
• To make plans to talk about your decisions with loved ones
• To understand the Health Care Power of Attorney Document
What is Advance Care Planning (ACP)?

ACP is a process that enables individuals to make plans about their future health care choices. It allows individuals to take part and be in charge of their health care plan.
What is Advance Care Planning?

Advance Care Planning is about preplanning the following:

➢ **Knowing** available future treatment plan for individuals

➢ **Determining** an individual’s future treatment plan goals that align with his/her values

➢ **Sharing** their decision with their physicians and loved ones

➢ **Completing** Advance Directive for future reference
Everyone **over the age of 18-years-old** should have ACP conversations and an advance directive completed.
Why is Advance Care Planning Important?

➢ The completed Advance Directive will be an individual’s voice

➢ The completed Advance Directive will guide clinicians and families to honor a person’s wishes regarding treatment plans when he/she is too ill to make decisions

➢ It is a gift for loved ones, as it will ease the burden of decision-making
Advance Directives available in South Carolina

(1) South Carolina Health Care Power of Attorney (HCPOA)
(2) Living Will (Declaration of a Desire for a natural death)
(3) Five Wishes
(4) EMS DNR (Do Not Resuscitate) Order
(5) POST (not active yet)

*Adult Health Care Consent: If you did not have one or any of the advance directives listed above your health care professionals would then move to the health care consent act to guide the clinician for decision making.
Who makes Health Care decisions for you, when you cannot provide consent?

(1) A **Guardian** appointed by the court
(2) An **attorney-in-fact** appointed by the patient in a durable power of attorney, if the decision is within the scope of his/her authority
(3) Appointed Health Care Power Of Attorney (HCPOA)
(4) A **spouse** of the patient
(5) An **adult child** of the patient
(6) A **parent** of the patient
(7) An **adult sibling** of the patient
(8) A **grandparent** of the patient
(9) Any other **adult relative** by blood or marriage
South Carolina Health Care Power of Attorney (HCPOA)

This document only comes into effect if, and only if, a person is unable to make decisions for themselves.

The HCPOA document allows a person to make 4 important decisions:

1. The first decision that will be made is about appointing an agent
2. The second decision is about organ donation

The third and fourth decisions pertain to a situation where an individual's life expectancy is limited or they are permanently unconscious.

3. The third decision is about life-sustaining treatment
4. The final decision is about artificial nutrition and hydration

This document may be altered or changed at ANY TIME. We suggest that you review this document each year with your loved ones and health care providers because your values, beliefs and wishes may change. You may complete a new document at any time and dispose of the previous one.
Evidence-Based Benefits of Advance Care Planning Conversations

➢ Adequate time to make informed decisions and fulfill personal goals

➢ Higher patient satisfaction

➢ Enhanced goal-oriented care

➢ Fewer hospitalizations

➢ Increased and earlier hospice care

➢ Improved quality of life

➢ Better patient and family coping

➢ Improved bereavement outcomes
Choosing an Agent

• What should you think about when choosing an agent?
  • Will this person put my values, beliefs and wishes above their own
  • Do they know me well and understand what is important to me
  • Could they handle this responsibility
  • Will they be readily available if something happens/will they be able to get to me in a timely manner

• Who can be an agent?
  • Anyone may be your agent if they are over the age of 18. Ex: Neighbors whom you are close too, Long-Term Partners, Family or Friends
  • Doctors or Health Care Providers who are currently providing you treatment MAY NOT be your agent (Page 2 Section 7)

• What is the agent’s role?
  • The agent’s role is to ultimately act as if they are you when making medical decisions for you
  • The agent will speak for you if you are unable to speak for yourself for whatever reason
Choosing an Agent
Continued

• When does this come into effect?
  • The Health Care Power of Attorney only comes into effect if you do not have the capacity to make decisions for yourself EX: Coma

• When should I tell that person they are my Health Care Agent?
  • Before you make them your Health Care Agent
  • That person may not feel comfortable making those decisions or they may feel like their value system does not align with what you want
ACP is appropriate for which of the following people?

A. A 22 year old female healthy new college graduate who comes to your clinic for birth control and annual physical.
B. An 88 year old male with end stage COPD who comes to your clinic for medication refills.
C. A 45 year old female with hypothyroid, obesity, and diabetes who comes to your clinic for routine follow-ups.
D. All of the above
ACP is appropriate for which of the following people?

A. A 22 year old female healthy new college graduate who comes to your clinic for birth control and annual physical.

B. An 88 year old male with end stage COPD who comes to your clinic for medication refills.

C. A 45 year old female with hypothyroid, obesity, and diabetes who comes to your clinic for routine follow-ups.

D. All of the above
Who would be the legal health care proxy for an unconscious, unmarried patient with no advanced directive or legal guardian and five adult children?

A. Live in girlfriend for two years
B. The majority of his adult children
C. Eldest son who is 40 years old from out of town
D. Youngest daughter, who lives locally and goes to all of the patient’s appointments and has the most knowledge about his health
E. Ex-wife
Who would be the legal health care proxy for an unconscious, unmarried patient with no advanced directive or legal guardian and five adult children?

A. Live in girlfriend for two years

B. The majority of his adult children

C. Eldest son who is 40 years old from out of town

D. Youngest daughter, who lives locally and goes to all of the patient’s appointments and has the most knowledge about his health

E. Ex-wife
Who would be the legal health care proxy for an unconscious, married patient with no advanced directive or legal guardian and two adult children?

A. Live in girlfriend for two years
B. Spouse, from whom he has been separated for four years
C. Eldest son, who is 40 years old from out of town
D. Youngest daughter
E. Sister, who lives locally and goes to all of patient’s appointments and has the most knowledge about his health
Who would be the legal health care proxy for an unconscious, married patient with no advanced directive or legal guardian and two adult children?

A. Live in girlfriend for two years
B. Spouse, from whom he has been separated for four years
C. Eldest son, who is 40 years old from out of town
D. Youngest daughter
E. Sister, who lives locally and goes to all of patient’s appointments and has the most knowledge about his health
Skills Practice
ACP Conversation Guide for a Healthy Individual

The Patient is.....

➢ A 25-year-old married artist
➢ Has had no hospitalization within last 5 years
➢ Comes in for outpatient appointment for an Annual Wellness Visit
Demonstration of ACP Conversation Guide

You…….

➢ A Social Worker

➢ The goals of the conversation today are:
  • To explore patient’s values
  • To align the care plan to reflect patient’s values using the conversation guide
  • To focus on future care plan goals rather than specific procedures and detailed treatment
Advance Care Planning Discussion Guide for Individual

Introduction of Advance Care Planning, Ask for permission

I would like to speak with you about Advance Care Planning and the importance of Advance Care Planning discussions as it relates to your future treatment goals. Is that alright?

Evaluate the Understanding of Advance Care Planning

Do you know what Advance Care planning is?

Explain Advance Care Planning and the Benefits

Advance Care Planning is a process that enables individuals to make plans about their future health care. It allows individual to take part and be in charge of their health care plan.

Advance Care Planning Involves:

- Knowing possible future treatment plans and how they align with your values and beliefs
- Determining your treatment plan goals that align with your values and beliefs
- Sharing your decisions with your physicians and families/friends
- Completing an Advance Directive for future treatment plans

Everyone over the age of 18-years-old should have advance care planning documentation and conversations.
Four Steps of the Health Care Power of Attorney (HCPOA) document

There are many legal Advance Care Planning Documents available in South Carolina. The Health Care Power of Attorney (HCPOA) document is one of them. This document does not have to be notarized.

The HCPOA document allows you to make 4 important decisions. This document only comes into effect if, and only if, you are unable to make decisions for yourself.

- The first decision you will have to make is determining “who do you want to appoint as your health care agent”. The agent’s responsibility is to advocate for the treatments/goals you would want for yourself.
- The second decision you will need to make is about organ donation.

The third and fourth decisions pertain to a situation where your life expectancy is limited or you are permanently unconscious.

- The third decision you will need to make is whether you desire to have life-sustaining treatment, such as a breathing machine or chest compressions, if your heart or breathing stops and you will not have a meaningful recovery.
- The final decision you will have to make is whether you would like artificial nutrition and hydration, for example, a feeding tube or IV fluids.
Inquire About Goals/Values/ Fears/ Strengths/ Critical Abilities / Family Awareness

I think it would be helpful for me to understand what is most important to you:

1.) Would you mind sharing any cultural, family, religious, spiritual, or personal beliefs that might help you choose the care you want or do not want?

2.) What are your worries/fears/concerns about your future health?

3.) What brings you strength during difficult times?

4.) What abilities are so critical to your life that you can’t imagine living without them?

5.) How much does your family know about your values and wishes?

Summarize the conversation (overall goals) and Recommend the Plan

Keeping in mind the values you shared with me and your current health, I recommend that we complete/update your Advance Care Planning Document. This will help to make sure that your treatment plans reflect what is most important to you.

How does that sound?
Reassure Commitment

“[I/our medical team] will be with you to help you.”

Respond to Emotion appropriately

Non-verbal

- Provide Tissues and Utilize Silence
- Appropriate Physical Reassurance (ex. hand on shoulder)
- Active Listening and Consistent Eye Contact

Verbal (Name Emotion)

- “It would be fine for someone in your situation to feel [sad/angry/frustrated.]”
- “I cannot imagine how hard it is for you [to lose your independence.]”
- (Name Emotion) “I sense how upset you are feeling about ----“
- (Name Emotion) “It sounds like you are worried that the illness might shorten your life.”
Why do we use the Conversation Guide?

➢ Help ACP Conversation flow smoothly

➢ Help to initiate compassionate and effective conversations with patients about values, goals, and preferences.

➢ Ensure you complete key steps in an intentional sequence

➢ Ensure a meaningful and successful conversation is accomplished

➢ Patient-Tested Language
Demonstration of Serious Illness
Conversation Guide

The Patient is.....
• 71 years old married retired office manager
• Parkinson's Disease
• 4 hospitalizations, multiple Rehab stays, 1 ER visit this year
• Symptoms:
  - worsening shortness of breath
  - Increase weakness
  - Worsening functional status, weight fluctuate with diuretics
• Receiving homecare /PATH service after hospitalization
Demonstration of Serious Illness Conversation Guide

You......

• Social Worker

• The goals of the conversation today is:

- Explain your patient the benefit of Advance Care Planning
- Explore patient’s value:
- Align care plan reflecting patient’s value when illness progress using conversation guide
- Focus should be on future care plan goals (advance directive) rather than procedures and detail treatment
Advance Care Planning Discussion Guide for Individual with Serious Illness

Set up and Start Advance Care Planning Conversation

I would like to talk to you about what you can anticipate with your illness moving forward and discuss future treatment plans that align with your values to ensure that you get the best care possible. May I discuss this with you today?

Assess patient’s perception of current illness

To make sure we are on the same page, can you tell me what your understanding is of your illness (correct any misunderstanding using the language that match patient’s level of education. After correction, confirm patient’s understanding) *(Use Ask-Tell-Ask principle)*

Invite patient to share his/ her information Preference

How much information about what is likely ahead with your illness would you like me to share with you?
Share Knowledge related to prognosis and medical treatment
(in term of Time / Function / Uncertainty)

Time: I understand this is a difficult situation for you, but I am worried that your time may be as short as ... (days, weeks, months, years, etc.).

Function: I hope that this is not the case, but I am worried:
- That your current ability to function might be your “new normal.”
- That this may be as strong as you will feel.
- That things may get more difficult for you moving forward.

Uncertain: It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time. However, I am worried that you could get sick quickly, and I think it is important to prepare for the unexpected. (use hope & worry principle)
Respond to Emotion empathically

Non-verbal
- Provide Tissues and Utilize Silence
- Appropriate physical reassurance (ex. hand on shoulder)
- Active listening and Consistent Eye Contact

Verbal (Using “N-U-R-S-E”)
- N-ame “You seem like you are frustrated”, “It would be fine for someone in your situation to feel [sad/angry/frustrated.]”
- U-nderstand “I cannot imagine how hard this is for you and your family.”
- R-espect “I can see how much you are trying to honor your Dad’s wishes.” “You are asking a lot of really good questions.” “I am very impressed with how well you’ve cared for your mother during this long illness.”
- S-upport “We will be there to help advise you. We can talk again tomorrow.”
- E-xplore “Tell me more about what you are thinking/feeling.”
Explore Patient’s values
(Goals/ Fears/ Strengths/ Critical Abilities/ Trade-Offs/ Family Awareness)

I think it would be helpful for me to understand what is most important to you:

1.) Given what we know about your illness, what are your treatment **goals**?

2.) What are your **worries** and **fears** about your illness?

3.) You have been through so much. What has kept you going? From where do you
gather your **strength**?

4.) What **abilities** are so critical to your life that you can’t imagine living without them?”

5.) What is your line in the sand where you would say “enough is enough”?
   How much are you willing to go through to gain more time?

6.) How much does your **family** know about your values and wishes?

7.) **For incapacitated patients:**
   
   a. Tell me a few things about your loved one. (What he/she enjoyed doing, his/her
      work and passion, what is important for him/her, etc.)
   
   b. “Have you ever talk with your loved one about his/her treatment wishes and
      priorities when he/she faced serious illness?”
Strategize specific decisions & Summarize the conversation

Keeping in mind the values you shared with me and the course of your illness, I recommend that we _____. This will help us make sure that your treatment plans reflect what is most important to you.

How does that sound?

Affirm continued Support

“[I/our medical team] will be with you during this illness, no matter what happens.”

OR

For patient with life limiting illness

“As a cure for your illness is not possible at this point in time, we will help you to live as FULL a life as possible.”

Adapted from Ariadne Labs’ serious illness conversation guide
Group Debriefing
Scenario 1- ICU Patient

- You are caring for a patient who is unconscious on the ventilator in the ICU.
- She had an out-of-hospital cardiac arrest
- Remains unresponsive 72 hours
- She has no cough/corneal/gag reflexes but breathes occasionally over the ventilator.
- Healthcare team does not believe she has a chance at neurologic recovery
- She has no advanced directive
- Her husband is her surrogate decision-maker
- You arrange a family meeting to discuss next-steps
- Her husband, parents, brother, and uncle are there
After finding an appropriate location and making introductions, what is the best next step?

A.) Give an update on patient’s medical condition including updated tests and consultant opinions.
B.) Recommend extubation, as the patient will not recover.
C.) Ask the patient’s husband to tell the team his understanding of his wife’s current medical condition.
D.) Go around the room and have each of the clinicians introduce themselves and give a medical update.
E.) Ask the patient’s mom’s opinion about her daughter’s condition since she is the most emotional.
After finding an appropriate location and making introductions, what is the best next step?

A.) Give an update on patient’s medical condition including updated tests and consultant opinions.
B.) Recommend extubation, as the patient will not recover.
C.) Ask the patient’s husband to tell the team his understanding of his wife’s current medical condition.
D.) Go around the room and have each of the clinicians introduce themselves and give a medical update.
E.) Ask the patient’s mom’s opinion about her daughter’s condition since she is the most emotional.
Throughout the course of the family meeting, the patient’s husband states he is “hoping for a miracle.” What is the best response?

A.) I know you are, but that is not possible at this time.
B.) What kind of miracle are you hoping for?
C.) A miracle COULD happen. It is up to God.
D.) Let’s just give her more time. She might wake up.
Throughout the course of the family meeting, the patient’s husband states he is “hoping for a miracle.” What is the best response?

A.) I know you are, but that is not possible at this time.
B.) What kind of miracle are you hoping for?
C.) A miracle COULD happen. It is up to God.
D.) Let’s just give her more time. She might wake up.
While addressing prognosis and discussing treatment options, including extubation, the patient’s uncle becomes angry stating that “I see how full the ER is. You just want her to be gone so you can have her room.” What should you do next?

A.) Excuse yourself from the meeting to call risk management.
B.) Ask the chaplain for prayer.
C.) Say, “That’s not true. We want to help her.”
D.) Say, “I’m so sorry you are frustrated. Help us understand why you feel this way.
E.) Say, “It’s not about having her room. We are talking about extubation because your niece wouldn’t want to live like this.”
While addressing prognosis and discussing treatment options, including extubation, the patient’s uncle becomes angry stating that “I see how full the ER is. You just want her to be gone so you can have her room.” What should you do next?

A.) Excuse yourself from the meeting to call risk management.
B.) Ask the chaplain for prayer.
C.) Say, “That’s not true. We want to help her.”
D.) Say, “I’m so sorry you are frustrated. Help us understand why you feel this way.
E.) Say, “Its not about having her room. We are talking about extubation because your niece wouldn’t want to live like this.”
Tips and Tricks:

➢ Remember that you will move onto your next patient. This family has to live with their decision forever. Be kind. Reserve judgement.
➢ These discussions are an ongoing process, not a one time event.
➢ Remember Ask-Tell-Ask.
➢ Remember hope/worry, wish/worry language.
➢ “Tell me more.”
➢ Warning shots: “I have some serious news to tell you.”
➢ Do not to give more than three pieces of information at a time.
➢ You are not responsible for the outcome, only how you show up.
Communication is KEY
• Having these conversations with your loved ones and health care providers are extremely important!
• These conversations can help bridge the gap between what is important to YOU and what is important to your loved ones!
• We understand these conversations are hard and we can assist with having these conversations if you are uncomfortable!

Where should I keep my HCPOA Document?
• File Cabinet
• Give one to your primary doctor and if you go to the hospital have them scan a copy into your chart
• Give a copy to your HCPOA
• You could keep one in the glove box of your car
• Keep a copy in a book or a bible

Do NOT
• Keep a copy in a safe that only you know the password too
• Do not keep it in a safety deposit box at the bank
Questions

End of Presentation

ANY QUESTIONS?
Contact Information:

• Prisma Health Home Health and Prisma Health Hospice
• Please Contact: Sydney Phillips, LMSW
• sydney.phillips@prismahealth.org
• 803-296-3353