
Facilitator Handbook to First Steps® ACP Conversations

INTRODUCTION AND PURPOSE

Introduction

Advance Care Planning (ACP) is a person-centered process that helps individuals plan and prepare for *future* healthcare decisions. To be effective, ACP Facilitators have a responsibility to ensure individuals have the time and information to understand, reflect upon, and discuss their future healthcare decisions.

Purpose of the *Facilitator Handbook to First Steps ACP Conversations*

This handbook is a resource for new Facilitators during the First Steps (FS) certification process and for Facilitators having ongoing FS ACP conversations. Respecting Choices recommends Facilitators use this handbook in their post-course practice conversations and ongoing conversations to improve communication skills and to deliver a standardized, reliable, and quality ACP service within their organizations and communities.

This handbook is divided into four parts:

- Part I: Preparation for the First Steps (FS) ACP Conversation
- Part II: Strategies to Facilitate the FS ACP Conversation
 - Using standardized role-play questions and additional frequently asked questions
- Part III: Follow-up Activities to ACP Conversations
 - Includes advance directive completion, strategies for documentation, communication, and coordination of care
- Part IV: Program-Specific Information
 - Note: This section intended to be customized to your ACP program

PART I: PREPARATION FOR THE FIRST STEPS (FS) ACP CONVERSATION

The Purpose of First Steps ACP Conversations

First Steps ACP conversations are intended to:

1. Motivate adults who have not started, or engaged in, a planning process by:
 - a. Exploring understanding of ACP, fears and concerns, experiences, and living well;
 - b. Assisting in the selection and preparation of a healthcare agent;
 - c. Identifying cultural and/or spiritual beliefs that may impact decision making; and
 - d. Identifying goals of care for a severe, permanent brain injury.
2. Prepare the healthcare agent for a future decision-making role. He/she will use this conversation to make decisions consistent with the individual's identified goals, values, and beliefs.
3. Complete (or revise) a written plan, if appropriate. An advance directive (AD) that appoints a healthcare agent is recommended. Facilitators will need to become familiar with, and competent to, completing the advance directive document relevant to the organization, community, or implementation team.
 - a. For some individuals, completing a statutory document does not meet their personal or cultural beliefs and needs. Be prepared to offer alternative options for documenting a plan, such as a letter to one's physician and family members.

Choosing a First Steps ACP Conversation Guide

There are two *First Steps ACP Conversation Guides*. Prior to the FS ACP conversation, the Facilitator will select the appropriate conversation guide.

1. **First Steps ACP Conversation Guide (RC 1143)**

This guide is used during FS ACP conversations with adults who have not started, or engaged in, a planning process AND 1) are accompanied by their chosen healthcare agent, OR 2) have not yet chosen a healthcare agent.

2. **First Steps ACP Conversation Guide: Adults with Chronic Illness (RC 1145)**

This guide is used during FS ACP conversations with adults who have an existing chronic illness AND 1) are accompanied by their chosen healthcare agent, OR 2) have not yet chosen a healthcare agent.

General Conversation Guidelines for Facilitators:

- Become familiar with the structure and format of the conversation guides. Each guide is divided into three phases: Exploration, Goals of Care, and Summary. Providing a person-centered and family-oriented approach to ACP conversations requires critical thinking and flexibility. While the flow of the questions in the conversation guides is helpful, there are times when the order of the questions can (or needs to) change.
- Include healthcare agents (if present) in the conversation to assess their understanding, affirm their roles and responsibilities, and promote more discussion.
- Use information from the FS ACP conversation to help the individuals identify and clarify their goals, values, and preferences for future healthcare decisions.
- Use the six communication skills and three communication techniques in the **Communication Skills (RC 0046)** card to deepen the conversation, promote dialogue, and develop trust.
 - Explore meaning of words/phrases
 - Paraphrase/clarify
 - Ask, “Anything else?”
 - Listen for and summarize themes
 - Affirm/reaffirm purpose of conversation
 - Verbalize empathy
 - Use the Ask-Teach-Ask technique
 - Remain value-neutral
 - Pay attention to nonverbal communication
- Use additional Respecting Choices tools or other organization-specific materials, for example:
 - ACP brochure, Information Card for Healthcare Agents, CPR Fact Sheet, the advance directive document used in your organization, and other educational materials as appropriate.
- Identify the need for further discussion with others, such as the physician/provider, other referrals, or other family. Make referrals and/or create a follow-up plan as appropriate.
- Find a quiet space for the conversation, prepare to be present, and actively listen to the individual’s goals, values, and beliefs.

Additional Guidelines for Facilitators in Clinical Settings:

- Ensure the individual has adequate decision-making capacity (DMC) to participate in the ACP conversation.
 - Only individuals who have DMC may create an advance directive.
 - Review and understand organizational policies for the assessment and documentation of decision-making capacity.
 - Some individuals who present with cognitive impairments or memory loss may still be able to participate in ACP conversations, even at a minimum level. This ability to participate is person-specific and will require the individual’s physician to determine the extent to which the individual may be present for, or participate in, an ACP conversation.
- Review existing advance directive or ACP information, if available.
- If the medical record is available to the Facilitator, review for pertinent history/current medical condition, and/or speak with individual’s physician or healthcare team member to prepare for meeting with adults who have an existing chronic illness.

PART II: STRATEGIES TO FACILITATE THE FS ACP CONVERSATION

Part II of the *Facilitator Handbook to First Steps Conversations* is intended to prepare Facilitators for the types of frequently asked questions (FAQs) that emerge during the various phases of the conversation: Exploration, Goals of Care, and Summary. Common FAQs are listed below, together with scripted responses and talking points. The Facilitator’s responses are suggestions and should be adapted as needed.

EXPLORATION

Facilitator Questions	Individual Responses	Suggested Responses and Critical-Thinking Talking Points for Facilitator
Introduction and Exploration of Understanding of ACP; Identification of Fears and Concerns		
“Tell me what you understand about this type of planning.”	“I think this is planning for a time when I am older and sick.”	<ul style="list-style-type: none"> • “Yes, this is a common response. Advance care planning is for all adults at any age who need to plan for a sudden event, such as a car accident or illness, in which they are unable to make their own healthcare decisions.” • <i>Read the description of Advance Care Planning in the First Steps ACP Conversation Guide.</i> • <i>Provide written information (e.g., ACP brochure).</i>
	“I don’t know why I need to do this. I am healthy.”	<ul style="list-style-type: none"> • “Even healthy individuals are at risk for a sudden event, such as a car accident or sudden illness.” • <i>Read the description of Advance Care Planning in the First Steps ACP Conversation Guide.</i>
	“I already filled out a Power of Attorney with my lawyer. Why do I need to do this again?”	<ul style="list-style-type: none"> • “That’s great that you have completed an advance directive. Can you tell me what you hope the advance directive that you have completed will do for you?” • “In our organization, we are trying to help individuals think more about the advance directives they have created. With this conversation, you will be able to review your existing plan, make sure it represents your current goals, values, and preferences and clarify anything that might be vague. This will help your healthcare agent and loved ones be better prepared to honor your choices.” • “Many people fill out the forms quickly without much discussion about their goals and values.”

		<ul style="list-style-type: none"> • <i>Optional: “We think that advance care planning is part of good healthcare and do not charge for this service.”</i> • <i>Ask the questions in the First Steps ACP Conversation Guide for individuals who have completed an advance directive document.</i> • <i>If needed, clarify the difference between financial power of attorney and healthcare power of attorney.</i>
“What fears or concerns, if any, do you have about planning?”	“What if I change my mind? How do I know what I want for something that may happen years from now?”	<ul style="list-style-type: none"> • “It is common for people to change their minds, if they get older, if they get sicker, or if they have experiences in life that change their goals and values. This is why we recommend you revisit your plan at key events in your life. Also, you can verbally change your plan at any time.” • <i>Explain the purpose of today’s conversation is to focus on making future healthcare decisions relevant to his/her current health status.</i>
“Can you tell me what you now understand about advance care planning?”	<i>(Add accurate response)</i>	<ul style="list-style-type: none"> • <i>This is the “teach-back” method to assess new understanding.</i>

Assess Understanding of Healthcare Agent Role

Ask Agent: “Tell me what you understand about this role.”	“I don’t know much about what’s involved. We’ve never talked about these things.”	<ul style="list-style-type: none"> • “That is one of the reasons why we offer a chance for you and [name of individual] to have this ACP conversation. It can be challenging to talk to a loved one without some support. I hope this will be helpful for both of you.” • <i>Provide written information on the role of the healthcare agent.</i> • <i>Review the four important qualities of a healthcare agent.</i> • <i>Use teach-back method to assess new understanding of the role of the healthcare agent and provide clarification if needed.</i>
“What questions do you have about the role of the healthcare agent?”	“So, I make decisions any time he/she is in the hospital?”	<ul style="list-style-type: none"> • “No, you will only make decisions if [name of individual] is unable to make his/her own decisions.” • <i>Explore additional questions or concerns.</i> • <i>Know the statutory/legal regulations and organization policies related to substitute decision making.</i>

**Explore and Listen for Experiences That Help the Individual Express Goals and Values
Related to Decision-Making; Promote Dialogue**

Role-Play Packet 1: First Steps ACP Conversation Guide (RC 1143) – GREEN

<p>“Tell me briefly about any experiences you have had with family or friends who became seriously ill or injured, like in a car accident.”</p>	<p>“My father had emphysema for many years. He kept smoking. The last time he was admitted to the hospital, he was on a breathing machine and never talked to us again. It was heartbreaking.”</p>	<ul style="list-style-type: none"> • “I’m sorry to hear of this experience. It sounds like it was challenging.” (<i>Verbalize empathy.</i>) • <i>Explore meaning of “heartbreaking” and “never talked to us again.”</i>
<p>“What did you learn from that experience?”</p>	<p>“I don’t want to die that way.”</p>	<ul style="list-style-type: none"> • <i>Explore meaning of “die that way.”</i>
<p>“What else did you learn?”</p> <p>“Anything else?”</p>	<p>“I don’t want to be a burden on my family.”</p> <p>“We argued over what my father would have wanted.”</p>	<ul style="list-style-type: none"> • <i>Explore meaning of “burden.”</i> • <i>Verbalize empathy.</i> • <i>Reaffirm the purpose of this conversation, e.g., “It is often true that family members disagree, especially when there have been no conversations. This is one reason why we encouraged this conversation today. In our summary, we will also talk about how to communicate decisions you may make today with other members of your family.”</i> • <i>Listen for the individual’s goals, values, and preferences.</i>
<p><i>Ask Agent:</i> “If you were present for these experiences, do you have anything to add?”</p>	<p>“I know that this was very hard for [individual’s name]. S/he didn’t talk to one sibling for a couple of years after their father died.”</p>	<ul style="list-style-type: none"> • <i>Verbalize empathy.</i> • <i>Reaffirm the purpose of ACP and the benefit of planning.</i>

Role-Play Packet 2: First Steps ACP Conversation Guide (RC 1145) – BLUE

<p>“Tell me briefly about any experiences you have had with family or friends who became seriously ill or injured, like in a car accident.”</p>	<p>“My uncle died in a horrific car accident. Didn’t even get to say goodbye to him.”</p> <p>“Things can happen suddenly.”</p> <p>“It was very sad.”</p>	<ul style="list-style-type: none"> • <i>Verbalize empathy.</i> • <i>Paraphrase and clarify, “So you learned that when there is a sudden death, there can be a lack of closure. What else did you learn?”</i> • <i>Explore meaning of words and phrases, as needed.</i> • <i>Realize that the experience of sudden loss does not allow people to learn about decision making. Verbalize empathy and proceed to exploring other experiences.</i>
<p>“Are there other experiences?”</p>	<p>“Yes, my aunt suffered for years with diabetes. She eventually had a leg amputated and needed kidney dialysis. She needed help around the clock for her personal care. Never was the same. She even had a heart attack and got CPR. Never talked to us again.”</p>	<ul style="list-style-type: none"> • <i>Verbalize empathy.</i> • <i>Explore meaning of “Never was the same” and “Never talked to us again.”</i> • <i>Paraphrase/clarify.</i>
<p>“What did you learn from that experience?”</p>	<p>“I learned that I want more control over my life than she had.”</p>	<ul style="list-style-type: none"> • “What would ‘control over life’ look like for you?”
<p>“What else did you learn?”</p>	<p>“I learned that my family should help make me comfortable if I was ever in that situation.”</p>	<ul style="list-style-type: none"> • <i>Paraphrase/clarify as you listen for the individual’s goals, values, and preferences.</i> • <i>Explore meaning of “help make me comfortable.”</i> • <i>Continue to ask, “What else did you learn?” (as appropriate).</i>
<p><i>Ask Agent:</i> “If you were present for these experiences, do you have anything to add?”</p>	<p>“With our aunt, it was just so sad to see her go from a vibrant woman to losing her dignity. She eventually died, but I don’t think she would have wanted all the treatments they continued to give her during the last years of her life.”</p>	<ul style="list-style-type: none"> • <i>Explore “losing her dignity.”</i> • <i>Summarize what you heard the individual and agent learn through this experience.</i>

**Explore ‘Living Well’ and Listen for Themes That Help the Individual Express
What is Important to Live Well**

<p>“What does ‘living well’ mean to you?”</p>	<p>“I like to be active. I do some sort of exercise almost every day. I like to play games and spend time with my family and friends.”</p>	<ul style="list-style-type: none"> • <i>Paraphrase and clarify, e.g., “It sounds like being active and spending time with family is important to you. Anything else?”</i> • <i>Explore meaning of “active” and “some sort of exercise” by asking, “What do you mean by ‘being active’ and what exercise do you like to do?”</i>
<p>“What else does ‘living well’ mean to you?”</p> <p>“Anything else?”</p>	<p>“I want to be independent for as long as possible.”</p>	<ul style="list-style-type: none"> • <i>Explore the meaning of “independent for as long as possible.”</i>

Explore Cultural and Spiritual Beliefs

<p>“What cultural beliefs do you have, if any?”</p>	<p>“What do you mean?”</p>	<ul style="list-style-type: none"> • “I will give you a few examples.” <ul style="list-style-type: none"> ○ “How are healthcare decisions made in your culture?” Or, “Who do you want included in such conversations?”
<p>“Who do you want included in such conversations?”</p>	<p>“Actually, I have two sons who I have not spoken to in years. How can I prevent them from being involved in any conversations if I become too ill to communicate?”</p>	<ul style="list-style-type: none"> • “I’m sorry about your relationship with your sons. Yes, you can indicate on an advance directive who you would <i>not</i> want included.”
<p>“What spiritual beliefs do you have, if any?”</p>	<p>“What do you mean? I’m not a religious sort of person.”</p>	<ul style="list-style-type: none"> • “Some examples may be your thoughts about prayer, meditation, or music.” • <i>Tell the individual if he/she thinks of something in the future to communicate it to the agent, doctor, and others who would benefit from knowing this information.</i>
<p>“How can we support your needs and/or practices?”</p>	<p>“My family and neighbors are supportive. I don’t really need any other type of support.”</p>	<ul style="list-style-type: none"> • <i>Customize to the individual’s response.</i>

First Steps ACP Conversation Guide: Adults with Chronic Illness (RC 1145) – BLUE
Explore Understanding of Medical Condition

<p>“Tell me what you understand about your medical condition(s).”</p>	<p>“I just had my yearly checkup and the doc says I’m doing great. I have high cholesterol and have been managing my diabetes for 10 years. They have me on meds to help with these things. I am doing good with diet.”</p>	<ul style="list-style-type: none"> • <i>Explore meaning of “I am doing great.”</i> • <i>Listen for and identify gaps in understanding.</i>
<p>“Have there been any change with your [medical condition(s)] in the past few months?”</p>	<p>“No, I just have many meds to remember to take each day. I worry I may forget.”</p>	<ul style="list-style-type: none"> • <i>Ask, “Would you like to review strategies to take your medications? I can write this down for you to remember to discuss with your nurse or other provider.”</i> • <i>Listen for and identify gaps in understanding.</i> • <i>Make a list of questions for doctor or nurse.</i>
<p>“What problems do you think you may have in the future from your [medical condition(s)]?”</p>	<p>“I know I could have a heart attack. Are there other problems I should be worried about?”</p>	<ul style="list-style-type: none"> • <i>Non-medical/community Facilitators:</i> <i>“I don’t know the answer for you, and it sounds like you have questions for your doctor. Should we write these down for you to discuss with your doctor or nurse?”</i> • <i>Facilitators with medical backgrounds may provide information within their scope of knowledge and area of expertise. Keep the information simple, yet accurate.</i>

GOALS OF CARE

The “Imagine This” scenario is a *goals of care* conversation. It allows individuals to discuss their goals in a situation of permanent and severe brain injury in which there is little chance they would recover the ability to know who they are and who they are with. This is a situation that many people fear. Facilitators first need to understand the scenario and be prepared to correct gaps in understanding and answer questions. The conversation guide provides a strategy for promoting understanding and discussion, as follows:

“There is one more decision every person should think about. Imagine this situation: a sudden event (such as a car accident or illness) left you unable to communicate. You are receiving all the care needed to keep you alive. The doctors believe there is little chance (for example, less than 5%) you will recover the ability to know who you are or who you are with.” Pause

“I want to make sure I explained this situation clearly. Can you tell me in your own words what you understand about this situation?”

Listen for gaps in understanding. Provide clarification on the meaning of the situation as needed.

“What questions do you have about this situation?”

Once the person can restate the situation accurately, ask: “In this situation, would you want to continue medical treatment? Or, would you want to stop medical treatment? In either case, you will still get the care you need to keep you comfortable.”

Ask agent, if present: “Do you have any questions about this situation and what [name of individual] has decided? Can you honor this decision?”

Facilitator Questions	Individual Responses	Suggested Responses and Critical-Thinking Talking Points for Facilitator
Explore Individual’s Goals of Care for a Severe, Permanent Brain Injury		
“I want to make sure I explained this situation clearly. Can you tell me in your own words what you understand about this situation?”	“I’ve had a sudden event and it’s unlikely that I’ll ever be able to talk.”	<ul style="list-style-type: none"> • “Let me clarify. Yes, you have had a sudden event and it is unlikely you will recover the ability to know who you are or who you are with.”
	“I would be miserable. I don’t want to be a vegetable.”	<ul style="list-style-type: none"> • “Tell us what you mean by ‘miserable’?” • “What does the word ‘vegetable’ mean to you?” • <i>Paraphrase/clarify as needed to promote additional conversation.</i> • <i>Continue listening for other words and phrases to explore to assist the individual in verbalizing what matters most.</i>
“What questions do you have about this situation?”	“How can they be sure that I won’t recover?”	<ul style="list-style-type: none"> • <i>Explore meaning of “won’t recover.”</i> • “For this situation, please assume the doctors have done the necessary tests and consulted specialists. They agree that this is the likely outcome. This situation gives you a chance to talk about this outcome and what is acceptable or unacceptable to you.”
	“What do you mean by little chance?”	<ul style="list-style-type: none"> • “In this situation, we describe ‘little chance’ as ‘less than five percent’; it is a low chance (but not zero).”
	“I would want a much better chance than that to recover.”	<ul style="list-style-type: none"> • “What does a ‘much better chance’ mean to you?”

	<p>“What do you mean by medical treatment?”</p>	<ul style="list-style-type: none"> • “Any treatment that is needed to keep you alive. These treatments may include intubation and mechanical ventilation (breathing machine), IV medications (such as antibiotics and fluids), surgery, and other interventions.”
<p><i>Ask Agent:</i> “Do you have any questions about this situation and what [name of individual] has decided?”</p>	<p>“I think I would feel the same way. Could we take him/her home?”</p>	<ul style="list-style-type: none"> • “[Agent’s name], it sounds like you would make a similar decision. However, your role as a healthcare agent is to make decisions that [individual’s name] would make, even if you disagreed.” • “It is unknown if he/she would be able to go home.” • <i>Ask individual,</i> “Would it be important to you to be able to go home?” • <i>Promote discussion. Ask the individual if this would be a goal or outcome the individual wants. Explore any questions or concerns.</i>
	<p>“Does that mean he/she would be brain dead?”</p>	<ul style="list-style-type: none"> • “No. If a person is declared brain dead, which is the definition of clinical death, then life-sustaining treatment would be stopped.” • <i>Clarify as needed, for example,</i> “The outcome we are talking about in this situation is that there is little chance you will be able to recover the ability to know who you are, or who you are with.”
<p>“In this situation, would you want to continue medical treatment to keep you alive? Or, would you want to stop medical treatment? In either case, you will still get the care you need to keep you comfortable.”</p>	<p>“This would not be living to me. I would not want to be kept alive unless I had a very good chance of having my mental abilities.”</p>	<ul style="list-style-type: none"> • <i>Explore meaning of “not living to me.”</i> • “What would be your definition of a ‘good chance’ of recovering your ability to know who you were, or who you were with? This would be helpful for your agent to understand.” • <i>Paraphrase/clarify as needed.</i> • <i>Repeat the situation as needed.</i> • <i>Note that this situation is NOT about “recovery” or “living”. Remember to focus on (and repeat) the key outcome in this situation, i.e., “...little chance you will recover the ability to know who you are, or who you are with.”</i> • <i>Discuss strategies to help communicate the decision to those who need to know.</i>

	<p>“I wouldn’t want to live this way, but could I get a second opinion?”</p>	<ul style="list-style-type: none"> • “This is helpful for your agent who, acting on your behalf, could ask for a second opinion.” • <i>Ask Agent:</i> “Do you have any questions about this request?” • <i>Explain that multiple specialists are involved in the assessment process.</i> • <i>Discuss strategies to help communicate the decision to those who need to know.</i>
	<p>“How would you keep me comfortable?”</p>	<ul style="list-style-type: none"> • “There are many strategies to help keep you comfortable. What does ‘comfort’ mean to you?” • “A plan would be developed to keep you as comfortable as possible.” • <i>Explore questions or concerns.</i> • <i>Make a list of questions for the doctor.</i>
<p><i>Ask Agent:</i> “Can you honor this decision?”</p>	<p>“Yes, but I just can’t imagine living without you.”</p>	<ul style="list-style-type: none"> • “Yes, these conversations do help people to reflect on how challenging it would be to live without someone they love. Are there other concerns you have about honoring this decision?” • <i>Verbalize empathy, as needed.</i> • <i>Offer support resources, as needed.</i>

Additional Frequently Asked Questions About the “Imagine This” Situation	Suggested Responses
<p>“What do you mean by unable to communicate? I’m unable to talk but can I blink or give a thumbs-up? Can I mouth words?”</p>	<ul style="list-style-type: none"> • “We mean unable to communicate and make your own decisions.”
<p>“Does this mean I am attached to machines?”</p>	<ul style="list-style-type: none"> • “In this situation, you are in the hospital and receiving all of the care/treatment needed to keep you alive. This includes machines.”
<p>“Will I have pain?”</p>	<ul style="list-style-type: none"> • “We cannot predict if you will have pain, but we know how to recognize and treat most symptoms and to keep you as comfortable as possible.” • “What worries you most about having pain?”

<p>“What if I want to keep medical treatment going and see if it would work?”</p>	<ul style="list-style-type: none"> • “What does ‘if it would work’ mean to you? What outcomes would you find acceptable?” • “This is called a trial of intervention and would need to be discussed with your doctor. It’s important to think and talk about your goals for treatment. Would you like to explore this option more?”
<p>“If these treatments do not work for me, can they be stopped?”</p>	<ul style="list-style-type: none"> • “Yes, treatments can be stopped. It will be important to discuss this preference with your agent and your doctor. In your advance directive document, we can include your preference to stop medical treatment and define what ‘does not work’ means to you.
<p>“How soon would I die if I decide not to have any more treatments?”</p>	<ul style="list-style-type: none"> • “This is unknown. What fears or concerns do you have about dying? What resources would be helpful to you?” • <i>Insert resource information that applies to your ACP program and/or community.</i>
<p>“What if my agent wants to override the decisions I’ve put down in writing? Can my agent override what I’ve said?”</p>	<ul style="list-style-type: none"> • “No, your healthcare agent cannot override a preference that you have clearly stated in your written advance directive. Your healthcare agent, doctors, and healthcare providers shall make decisions consistent with your stated goals, values, and preferences. If there is confusion or conflicts among your known values and goals, your agent will make a decision that best represents your values and preferences or is considered your best interest. This is why it is important for you and your healthcare agent to have ongoing discussions about your health and healthcare choices.” • <i>Discuss the benefits of designating alternate agents who will support the individual and the primary healthcare agent in honoring the individual’s preferences.</i>
<p>“I wouldn’t want to live like that permanently, but miracles do happen!”</p>	<ul style="list-style-type: none"> • “What would a ‘miracle’ look like for you?” • <i>Based on the individual’s response, consider asking follow-up questions for additional exploration:</i> <ul style="list-style-type: none"> – “What kind of outcome would be acceptable to you?” – “How would your healthcare agent know when it is time to stop treatments? For example, how would your healthcare agent know when burdens are outweighing benefits?” – “Would you like to talk about this with a religious advisor?”
<p>“Can I receive these treatments at home?”</p>	<ul style="list-style-type: none"> • “It depends on the type of medical treatment. Some treatments will require special nurses or others trained to manage the medical care required at home. You may be too ill or need skilled care that could impact the ability to return home. We can include your preference of where you wish to receive care in your advance directive document.”

THE DECISION-MAKING FRAMEWORK

The Facilitator helps individuals make informed decisions. Individuals with chronic illness will eventually be faced with a variety of decisions related to the progression of their illness and possible treatment complications. As with all treatment decisions, Respecting Choices uses the Decision-Making Framework (DMF) to facilitate a shared decision-making conversation.

- Explore *understanding of treatment decision* to uncover gaps in information
- Explore *understanding of benefits and burdens* and provide information as appropriate
- Explore *goals for treatment*: What would the person expect to happen? What would an unacceptable outcome be?
- Explore *fears and concerns*

THE CPR DECISION

Many people have limited knowledge about cardiopulmonary resuscitation (CPR). The CPR questions included on the ***First Steps ACP Conversation Guide for Adults with Chronic Illness*** and the ***CPR Fact Sheet*** are intended to assist individuals with *future* healthcare decision making. Individuals with lung disease (e.g., COPD, lung cancer) or individuals with heart disease (e.g., heart failure, cardiac myopathies) eventually will face decisions about whether or not they would want CPR attempted if their heart or breathing were to stop. The CPR conversation is intended to help individuals understand their options, gather necessary information, and begin this conversation proactively.

“One of the decisions you may be asked to make is whether you want attempts to restart your heart and breathing if they suddenly stopped. It is important to learn about CPR, so you can make a decision that fits your goals and values. I have a few questions for you.”

These questions slow the pace of the conversation, allowing for understanding, reflection, and discussion. Avoid reading the CPR options (or asking, “Do you want CPR if your heart or breathing were to stop?”) before exploration.

The question, “*What do you understand about the success of CPR?*” is an example of the Ask-Teach-Ask/Teach-back strategy. First, explore understanding. Listen for gaps in understanding. Ask permission to give information (e.g., “*Would you like to learn more?*”). Use the CPR Fact Sheet (or other educational materials) to provide factual, unbiased information. Remember to periodically stop and ask if there are any questions. Lastly, use “Teach Back” to assess new understanding, e.g., “*Tell me in your own words what you now understand about the success of CPR?*”

If the CPR discussion gets deferred to the individual’s physician/provider, remember to create specific questions for the individual to ask (e.g., “*What are the odds of CPR working for me?*”).

Facilitator Questions	Individual Responses	Suggested Responses and Critical-Thinking Talking Points for Facilitator
Help make informed decisions about CPR		
“What do you understand about CPR?”	“It’s what you do when someone’s heart stops to get it beating again.”	<ul style="list-style-type: none"> • “That’s right. CPR attempts to start the heart and breathing.” <i>(Proceed to next question.)</i>
“What has your doctor told you about CPR?”	“We haven’t talked about it. It hasn’t ever come up in an appointment.”	<ul style="list-style-type: none"> • “CPR is a treatment initiated automatically, if your preferences are not known. If we don’t ask people what they want, we assume they want CPR. It’s one of the reasons why we are talking about it today. What do you know about the success of CPR?”
“What do you know about the success rate of CPR?”	“I assume it works most of the time.”	<ul style="list-style-type: none"> • “That’s an important question. It is true that CPR works for some people; yet not as well for others. CPR is not as successful as most people think. Would you like to learn more?” • <i>If “yes, use the CPR Fact Sheet or information provided by your organization/ACP program.</i> • <i>If “no” say, “Thank you for taking time to think about the CPR choice as part of this planning conversation. This discussion may raise some questions that you may want to talk about with your doctor in the future.”</i>
“Tell me now what you understand about the success of CPR.”	“Well, it sounds like it doesn’t work as often as I thought. But if there’s a good chance of it working and I will leave the hospital, that sounds pretty good to me.”	<ul style="list-style-type: none"> • <i>This is the teach-back method to assess new understanding.</i> • “I’d like to continue to help you think about this. It is true that CPR works for some people; yet not as well for others. Can you tell me in your own words what ‘leave the hospital’ means to you?” • “It is certainly understandable why any person in good health or with a stable condition, such as yours, would consider CPR. What questions do you have about the outcomes for yourself?”

	<p>“What would happen if I don’t at least try CPR?”</p>	<ul style="list-style-type: none"> • <i>Provide factual information if CPR is not attempted: “If your heart or breathing stops, you will die.”</i> • <i>Proceed with next questions:</i> <ul style="list-style-type: none"> – “What outcome would you expect from CPR?” – “What fears or concerns do you have about making this decision?” • <i>Make a list of questions for doctor.</i>
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Additional Frequently Asked Questions About CPR	Suggested Responses	
<p>“Do I have to make this decision now?”</p>	<ul style="list-style-type: none"> • “No. The purpose is to provide information to help you make an informed decision about cardiopulmonary resuscitation (CPR). Your advance directive document may include a decision about CPR. Or, you may be asked about this decision at some point in your healthcare.” • “What fears or concerns, if any, do you have about making this decision?” 	
<p>“If I don’t try CPR, will I die?”</p>	<ul style="list-style-type: none"> • “Yes, if your heart or breathing stops, you will die. “ 	
<p>“Could my chance be better than these statistics?” “What are the odds of CPR working for me?”</p>	<ul style="list-style-type: none"> • “The statistic of leaving the hospital alive comes from research completed on CPR attempts for all patients in the hospital setting. You may have a better or lower chance than that percentage.” • “That would be a great question to ask your physician. I will write it down on this fact sheet, so you can remember to talk to <i>him/her</i> about this. Any other fears or concerns?” 	
<p>“Can we just try CPR and see if it would work?”</p>	<ul style="list-style-type: none"> • “Yes, but we will need to explore what “if it would work” means to you. What are your goals for CPR? What would be an unacceptable outcome?” • <i>One common unacceptable outcome of CPR is being in the “Imagine This” situation; not knowing who you are or who you are with. Help individuals make the connection between attempting CPR but stopping medical treatment if the outcome is there is little chance that they will recover the ability to know who they are, or who they are with.</i> 	
<p>“Can I leave this decision up to my agent and not make a decision now?”</p>	<ul style="list-style-type: none"> • “As we discussed, emergency life-saving treatment is automatically initiated, if your preferences are not known. If we don’t ask people what they want, we assume they want CPR. Your agent would make a decision about CPR in the future based on what <i>he/she</i> knows of your beliefs and values. It’s one of the reasons why we are talking about it today.” 	

Facilitating the CPR Decision: Position Paper

Facilitating the CPR decision with individuals and their loved ones can be challenging for many reasons.

Respecting Choices has written a position paper on the topic of cardiopulmonary resuscitation (CPR) to provide some clarity and guidance on this medical intervention.

The Facilitator role created by Respecting Choices requires a new level of skill and competence for health professionals (as part of a healthcare team) who assist individuals and their families in clarifying values and goals that help guide plans for future medical care and current medical decisions. Facilitators don't provide medical advice or specific information about diagnoses or prognoses; however, they do have some responsibility to provide general information about certain medical interventions, i.e., CPR.

This role has created some confusion and uncertainty among some health organizations and health professionals, therefore, Respecting Choices developed this position paper to address these concerns. This position paper is intended to make recommendations for those who facilitate conversations about the CPR decision and Instructors who teach the CPR content.

Facilitating the CPR Decision: Position Paper can be accessed at: respectingchoices.org/research-and-reports/quality-improvement-reports-and-white-papers/.

SUMMARY

Facilitators will provide a brief summary of the conversation and make recommendations for follow-up activities, including assisting with completion of a written advance directive document (or other alternative plans). Create individualized strategies for follow-up based on the individual's readiness and motivation to proceed, and the situation.

PART III: FOLLOW-UP ACTIVITIES TO ACP CONVERSATIONS

THE ADVANCE DIRECTIVE DOCUMENT

Goals for Advance Directive (AD) Documents:

- Appoints a healthcare agent (designated decision maker)
- Most fully meets the needs of the individual (legal advance directive document or alternative options for creating a plan, such as a letter to one's physician and family members)
- Is specific enough for the clinical situation
- Accurately reflects the individual's goals, values, and preferences
- Is clear, complete, and accurate
- Complies with legal, regulatory requirements

Common Problems with Written Plans:

- Technical errors or gaps (e.g., not properly executed according to state requirements)
- Ambiguous statements or phrases that are difficult to interpret in the clinical setting (e.g., "Don't use any tubes to keep me alive.")
- Lack of specific planning to honor an individual's preferences

Facilitators need to know the existing policies/guidelines, specific to their local community or organization, for completion of legal advance directive documents. Additional education and written information may be needed to prepare Facilitators to assist individuals to create legally binding advance directive documents.

TRANSFERRING INDIVIDUAL’S GOALS, VALUES, AND PREFERENCES TO WRITTEN PLAN

Facilitators are responsible for assisting in accurately transferring an individual’s goals, values, and preferences to a written plan (e.g., advance directive). This responsibility is focused on aligning the written instructions with the facilitated conversation.

One specific example of this responsibility is transferring the individual’s responses to the “Imagine This” situation to a written plan. The following table provides an example of an individual’s responses to the “Imagine This” situation, and how to document this on an advance directive. The suggested advance directive statement would need to be reviewed and discussed with the individual and added to the written plan under “Special Instructions” or another appropriate place.

Individual’s Goals	Advance Directive Statement
<ul style="list-style-type: none"> To have a quality life, to be active, aware, and independent To have a “good” chance of recovering the ability to know who he was, defined as greater than 50 percent. To stop medical treatment if less than a 5 percent chance of recovering his ability to know who he was, and if closer to 50 percent chance to recover, he would want to continue medical treatment. 	<ul style="list-style-type: none"> “If I am sick or injured and my doctors believe there is less than a 50 percent chance that I will recover the ability to know who I am, or who I am with, I want to refuse or stop all medical treatments.”

See Appendix I for sample language to document goals of care preferences on the advance directive document.

Additional Frequently Asked Questions About Advance Directives	Suggested Response
<p>“I already completed an advance directive. Why do I need a new one?”</p>	<ul style="list-style-type: none"> “This type of planning is ongoing. Goals, values, and preferences may change over time, so these plans should be revisited and updated to reflect your current goals, values, and preferences. If you choose to complete a new document, it will replace your old document. Later in our conversation, we will discuss strategies for providing copies of your document to your agents, family members, doctors, and others.” Ask, “What conversations did you have with your healthcare agent when you created your advance directive? Why do you think they clearly understand your goals, values, and preferences? Through our conversation, you may discover something new about your goals, values, and preferences that you will want to include in an updated version of your advance directive.”

<p>“What if I don’t have anyone who I trust to be my healthcare agent. Can I still complete an advance directive document?”</p>	<ul style="list-style-type: none"> • “First, let’s discuss options other than family members, such as a close friend, neighbor, or congregation member. Even without a person to name as healthcare agent, we recommend you express your goals, values, and preferences through an advance directive document to assist your doctors, healthcare team, or state-appointed guardian to guide medical decision making if you become unable to communicate your own decisions.”
<p>“Can my doctor be my healthcare agent?”</p>	<ul style="list-style-type: none"> • “No, in most states, a healthcare provider (or an employee of the healthcare provider) directly caring for you at the time cannot be your healthcare agent, unless the healthcare provider is related to you by blood, marriage, or adoption.” • <i>Review the qualities of a healthcare agent (use the First Steps ACP Conversation Guide or written information on the role of the healthcare agent).</i> • <i>Ask, “Do you know anyone who could do this?”</i> • <i>Discuss the benefits of designating alternate agents.</i>
<p>“Can I add personal notes to my loved ones into this advance directive document?”</p>	<ul style="list-style-type: none"> • “Yes, you may include personal notes or attach an addendum to communicate what’s important for others to know about your goals, values, and preferences.” • <i>Explore and provide guidance as needed.</i>

**STRATEGIES FOR DOCUMENTATION, COMMUNICATION, AND
COORDINATION OF CARE**

The ultimate impact of the ACP conversation is realized when the individual’s goals, values, and preferences are consistently integrated in the medical record, ongoing goals of care conversations, shared decision-making conversations, and coordination of care. Standardized systems should support the First Steps Facilitator’s role of documentation, communication, and coordination.

Documentation

■ **Facilitators with Access to the Medical Record**

- Document and summarize in a central location within the medical record, using a templated visit note. Notes should be individualized and use clear language. Use the individual’s own words in quotes, as appropriate. This helps healthcare agents and others “hear the voice” of their loved ones and better follow the individual’s goals, values, and preferences for care.
- Review documents for clarity, accuracy, and legality prior to including in the medical record.

■ **Facilitators without Access to the Medical Record**

- Create strategies to communicate the ACP conversation, such as providing a summary sheet of the conversation for the individual to take to his/her healthcare provider.

Communication

- If possible, communicate to healthcare provider the individuals' questions to support ongoing education, goals of care discussions, and shared decision making.
- Facilitators in community settings without access to the medical record will need to assist the individual in communicating his/her plan by making copies of the AD documents, providing fax numbers and mailing addresses of hospital medical records (health information management) departments, etc.

Coordination

- If need for additional care and resources is identified, provide timely referrals and access to support.
- Provide assistance in creating (or updating) a written AD document, for example:
 - Make recommendations to the individual for communication of plan, storage, and retrieval.
 - Provide individual with copies of the AD to give to agents and other family members, healthcare providers, and healthcare organizations.
 - Have individual review his/her healthcare preferences every time the individual has a physical exam or whenever any of the “Five Ds” occur:
 - Decade – at the start of each new decade of an individual’s life.
 - Death – whenever there is a death of a loved one.
 - Divorce – when the healthcare agent is a spouse, or domestic partner, and the marriage is annulled, or an individual gets divorced, or the domestic partnership is terminated after signing this document, the document is invalid. A new document must then be completed.
 - Diagnosis – when diagnosed with a serious health condition.
 - Decline – when there is a significant decline or deterioration of an existing health condition, especially when unable to live on own.
 - If preferences change, the individual needs to tell his/her healthcare agent, family, physician, and everyone who has copies of this advance directive. It would be necessary to complete a new advance directive to reflect current preferences.

PART IV: PROGRAM-SPECIFIC INFORMATION

There are some questions regarding the completion of advance directives and ACP program information that can only be answered by understanding the statutory and legal requirements, organizational policies, and/or community norms. Facilitators will need to become familiar with this program-specific information.

Appendix II provides a template for program-specific information that can be customized by the ACP program and provided as an additional resource for Facilitators.

APPENDIX I:

OPTIONAL ADDENDUM TO ADVANCE DIRECTIVE DOCUMENTS

Note: Individuals may want to add specific instructions to their advance directive document. This document is a sample of an advance directive addendum. It includes optional language to add to their advance directive. A goal for Facilitators is to help transfer what the person says during the conversation to a written plan that everyone can understand and fits with the advance directive document based on the laws of the state where the person resides.

Addendum to my advance directive document

Initial the box beside the one statement you agree with.

1. Treatments that may prolong life if I am in this situation

If I am sick or injured and my doctors believe there is little chance that I will recover the ability to know who I am, who my family and friends are, or where I am, this is my choice.

I want to refuse or stop all treatments. Some examples are a machine that breathes for me (respirator/ventilator), feeding tubes, blood products, antibiotics, or fluids given to me through an IV, treatments for chronic medical conditions, or other medications.

I want to receive all treatments to keep me alive, unless my doctor determines the treatments would harm me more than help me. With either choice, I understand I will be kept clean and comfortable. I will continue to receive pain and comfort medicines, and food and fluids by mouth if I can swallow safely.

2. Cardiopulmonary resuscitation (CPR)

Based on my current health, this is my choice about CPR if my heart or breathing stops.

I want CPR attempted unless my doctor determines:

- I have a medical condition and no reasonable chance of survival with CPR, **OR**
- CPR would harm me more than help me.

I do not want CPR. Let me die a natural death. (If you do not want emergency personnel to give you CPR, you will need to talk to your doctor about other documents you need.)

3. Including others when making decisions about my care (If there is time, try to include these people in my care decisions.):

4. If I am near death and cannot communicate, I want to give my friends and family these personal messages:

5. If I am near death, things I would want (for example, favorite music, rituals, dim lighting, a visit from the hospital chaplain or someone from my faith community):

Name _____ Date _____

Witness/Notary:

Name _____ Date _____

Name _____ Date _____

**APPENDIX II:
PROGRAM SPECIFIC INFORMATION
INSERT INFORMATION THAT APPLIES TO YOUR ACP PROGRAM**

Additional Questions That May Arise During FS ACP Conversations	Policies, Procedures, and Additional Information for Facilitators
<p>“What if I don’t have anyone who I trust to be my healthcare agent. Can I still complete an advance directive document?”</p>	<ul style="list-style-type: none"> • <i>A majority of states have adopted hierarchy surrogate consent laws for incapacitated individuals.</i> • <i>Insert information that applies to your state and/or organization policies.</i>
<p>“Who can witness my AD?”</p>	<ul style="list-style-type: none"> • <i>Insert information that applies to your state’s witness requirements.</i> • <i>Facilitators must be informed of witness and/or notary requirements specific to one’s state/local/organization to ensure the completion of legal, valid advance directives.</i> • <i>Create education opportunities or resource tools for Facilitators, e.g., State Statute Information Regarding Advance Directives (a sample document is included in the First Steps Facilitator Certification electronic folder for Instructors).</i>
<p>“Will my advance directive be honored in other states?”</p>	<ul style="list-style-type: none"> • <i>“Yes, there is some reciprocity, things that go from state to state. If you travel and need medical care in another state, your advance directive will be honored in other states, up to the point that it meets the laws of that state.”</i> • <i>“Later, we can talk about other ways to help make the document more portable.”</i> • <i>“If you were to move to another state, it would be recommended that you complete the advance directive from that state.”</i> • <i>Insert information that applies to your ACP program.</i>
<p>“What is the local system for out-of- hospital DNR?”</p>	<ul style="list-style-type: none"> • <i>Insert information that applies to your ACP program and local community.</i>
<p>“Who can help me if I want comfort-focused care, want to remain at home, and live alone?”</p>	<ul style="list-style-type: none"> • <i>Insert information that applies to your ACP program and local community.</i>

<p>“Does my state support <i>Death with Dignity</i> when I get closer to my end of life?”</p>	<ul style="list-style-type: none"> • <i>Insert information that applies to your ACP program and state.</i> • “Death with Dignity statutes require a person to have capacity and self-administer this lethal dose of medication. Would you want to talk with someone about this?” <i>Insert resource information that applies to your organization, such as ethics team, palliative care team, or chaplain.</i> • “Advance directives help guide care when individuals are able to direct their own care. Clearly documenting one’s desires (preferences) to maintain control, pain and comfort, and where and how you want to be cared for at the end of life are appropriate to include in an advance directive document.”
<p>“Does my healthcare agent need to sign the advance directive document?”</p>	<ul style="list-style-type: none"> • <i>Insert information that applies to your ACP program.</i>

Insert additional FAQs and information specific to organization, state, and/or local region.

Advance care planning Facilitators and Instructors will also need to become familiar with case law that may influence healthcare decision making. As an example, Wisconsin has two important state rulings that may impact the assistance and recommendations provided by a Facilitator. You will need to investigate the existence of such precedents in your own geographic area. This understanding assists with clarification of questions and misunderstandings and may guide the development of organizational policies and procedures.