Respecting Choices®
PERSON-CENTERED CARE

First Steps® ACP Conversation Guide

Meeting with individual (and agent, if present)

This conversation guide is intended for 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.

Prior to beginning this conversation, assess for the following:

1. **Is the individual accompanied by his/her healthcare agent? If not, can agent participate by phone/video?**
2. **Has the individual previously completed a written plan, such as an advance directive (AD)?**
3. **Does the individual have a chronic illness? If yes, use the First Steps ACP Conversation Guide for Adults with Chronic Illness (RC 1145).**

Note to Facilitator: *The text in bold is not intended to be read aloud.*

EXPLORATION

1. Introduction and exploration of understanding advance care planning (ACP); identification of fears or concerns

"Hello. My name is _____. I am an *Advance Care Planning Facilitator*. I help individuals and their families learn how to plan for future healthcare decisions. I will start with a few questions."

"Tell me what brings you here today."

"You may have received information about advance care planning. Tell me what you understand about this type of planning."

"What fears or concerns, if any, do you have about this type of planning?"

For individuals who have completed an advance directive, ask:

"What do you hope this document will do for you in the future?"

"This conversation may help you update your plan."

"Have you chosen a person who would make decisions for you?"

If yes: "What conversations have you had with this person?"

Ask the individual to provide a copy for review.

Provide the following information on ACP or AD as needed. For example:

Advance Care Planning: "Advance care planning is for all adults. It is thinking and talking about future healthcare decisions if you had a sudden event, like a car accident or illness, and could not make your own decisions. A person close to you would need to make choices for you. We call this person a healthcare agent. This conversation will help your agent understand your goals and values. This will help him or her to make decisions for you, if needed."

Advance Directive: "It's important to write down your goals, values, and preferences. There are many ways to do this. We recommend that you use a document called an *advance directive*. This allows you to name a person who can make healthcare decisions for you. This person will *only* make choices if you cannot make them for yourself."

"These are new ideas for many people, so I want to make sure I was clear. Can you tell me what you now understand about advance care planning?"

2. IF AGENT NOT SELECTED—Help individual choose a healthcare agent; if healthcare agent is present, proceed to #3

"One of the most important decisions we encourage people to make is choosing someone you trust to make healthcare decisions for you. This person would only make decisions if you had a sudden event and could not make your own decisions."

"It is important to think carefully about this decision. There are four qualities you should look for. A healthcare agent should be willing to:

- Accept this role;
- Talk to you about your goals, values, and preferences;
- Follow your decisions, even if he or she may not agree with them; our conversation today will help you learn more and will help you prepare him or her to make decisions; and
- Make decisions in difficult moments."

"Do you know anyone who could do this?"

"I'd like to give you some information that you could use to start talking to this person."

Provide written information, such as the Information Card for Healthcare Agents.

"When you talk to *[name],* how will you explain the role of the healthcare agent?"

3. IF AGENT PRESENT—Assess understanding of healthcare agent role

"*[Name of agent]*, thank you for coming in today to learn about the role of the healthcare agent. Tell me what you understand about this role."

Provide written information on the role of the healthcare agent.

"I'd like to review four important qualities of a healthcare agent. A healthcare agent should be willing to:

- Accept this role;
- Talk to *[name of individual]* about his/her goals, values, and preferences;
- Follow *[name of individual's]* decisions, even if you may not agree with them; our conversation today will help you learn more and will prepare you to make decisions; and
- Make decisions in difficult moments."

"What questions do you have about the role of the healthcare agent?"

"*[Name of individual]*, I have a few more questions for you. These questions will help you talk about your goals and values. Our conversation will also prepare *[name of agent]* to make healthcare decisions for you. *[Name of agent]*, please ask questions as needed to best understand your role as a healthcare agent."

4. Explore and listen for experiences that help the individual express goals and values relating to decision making; promote dialogue

"Tell me briefly about any experiences you have had with family or friends who became seriously ill or injured (like in a car accident)."

"What did you learn from that experience?"

"What else did you learn? Anything else?"

If needed, ask: "Are there other experiences?"

"What did you learn from that experience?"

Ask agent, if present: "If you were present for these experiences, do you have anything to add?"

5. Explore 'living well' and listen for themes that help the individual express what is important to live well

"What does 'living well' mean to you? For example, if you were having a good day, what would happen on that day? Who would you talk to? What would you do?"

"What else does living well mean to you? Anything else?"

- **Provide a brief summary of the key themes expressed thus far (e.g., fears, experiences).**

6. Explore cultural or spiritual beliefs

"By talking about your experiences and what it means to live well, you have shared many personal beliefs. I'd like to ask you about any additional beliefs that might help you choose the care you want, or don't want."

"What cultural beliefs do you have, if any?"

Ask follow-up questions, if needed, such as, "How are healthcare decisions made in your culture?" **or** "Who do you want included in such conversations?"

"What spiritual beliefs do you have, if any?" **Provide examples, if needed, such as prayer, meditation, music.**

"How can we support your needs and/or practices?"

GOALS OF CARE

7. Explore individual's goals of care for a severe permanent brain injury

"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. Ask individual, and agent if present:

"What questions do you have about this situation?"

Once the person understands the situation accurately, repeat the situation if needed, and 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: "Can you honor this decision?"

SUMMARY

8. Assist with completion of a written AD (if individual is ready); the presence of the agent is recommended, but not required

"You have made some important decisions today. Are you ready to complete the written advance directive?"

OR for those who have an advance directive: "Are you ready to review and update your AD as needed?"

"Your advance directive may include a decision about cardiopulmonary resuscitation (CPR). Or, you may be asked about this decision at some point in your healthcare. I have a CPR Fact Sheet for you to review, if you would like to learn more. Please talk with your doctor if you have questions or want more information to help you make a decision about CPR at this time in your life."

9. Summary

"Thank you for taking the time to talk about advance care planning."

"I'd like to review our conversation today and talk about next steps."

These are optional categories/follow-up activities. Choose the ones that are appropriate.

IF AGENT PRESENT and/or AD completed—Follow-up plan

- ☐ **Provide assistance completing an AD**
- ☐ **Make recommendations for document, storage, and retrieval.**
- ☐ **Provide copies to agents and other family members, physician/provider, and healthcare organization.**
- ☐ **Identify the need for further discussions with others (such as questions for physician/ provider, other referrals, or other family).**
- ☐ **Discuss when the plan should be reviewed.**

IF AGENT NOT SELECTED—Recommendations for continuing the ACP conversation

- ☐ "You are thinking about asking *[name of person]* to be your healthcare agent. You will talk to that person…"
  - "Invite your agent to come with you to the next appointment for advance care planning."
  - "Invite your agent to attend an advance care planning class with you."
- ☐ "You have the following cultural or spiritual beliefs…"
  - "You may meet with your faith leader to talk about..."
- ☐ "You have the following questions for your doctor…"
- ☐ "You would like to write down your preferences in a document called an advance directive."
  - "You would like assistance in completing an advance directive."

Create other strategies for completing the document.

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