



Curriculum Guide for

# ADVANCE CARE PLANNING





## OVERVIEW

- Majority of CKD patients and ESRD patients do not complete advance directives.
- Majority of patients who withdraw from dialysis do not have an advance directive and do not have the ability to speak for themselves at that time.
- Persons who have advance care discussions have a decrease in hospitalizations and ICU stays and are more likely to die at home or in hospice.
- Persons who have advance care discussions have decrease in pain, depression, and insomnia.

### Tips for Using this Guide

- Patients will have varying degrees of readiness to discuss. There might be times a coach can cover all content in 30 minutes, and there might be times that a coach cannot get half way through the entire curriculum during time allotted. The important thing is that coaches do not push the patient. Go at patient's individual pace.
- Do not read the script. This is only a guide and should be an organic process.
- Family involvement in these meetings should be invited and encouraged.

### Time Required

- Allow for a 1-hour discussion, recognizing that it will be essential to go at the patient's own pace. Some patients will have already completed an advance directive and not require a great deal of time while others may need to have more dialogue and engage with the teaching material. This should be a flexible process, and the coach should follow the patient's lead.

### Motivational Interviewing Tips (Rollnick, Miller, & Butler, 2008):

- Flexibility is key. Go at the patient's pace and modify the script as needed.
- Resist the righting reflex. Resist the urge to persuade or tell the patient what to do. Instead, elicit the patient's own ideas and thoughts and use those to guide conversation.
- Understand the patient's motivations. Pay attention to the language the patient uses to describe why he or she might want an advance directive or healthcare agent.
- Listen to your patient. Use empathetic statements to demonstrate understanding and concern. Listen for "change talk," including statements from the patient such as "I wish" or "I want" or "I like."

- Empower your patient. People are much more likely to stick to a plan that they created, rather than the one a healthcare professional prescribed.

## Motivational Interviewing Strategies

- **Ask** - Invite patients to explore issues by asking open ended questions that lead to information needed to guide session.
- **Listen** - Allow patients time to respond to each question. Allow for silences in order to help stretch the patient's thinking. Provide facilitative responses and reflection statements.
- **Inform** - Give patients new information when they are ready. Ask for permission to provide information. Talk about the experiences of others. Reflect with the patient to solicit understanding.

Motivational Interviewing Strategies are highlighted throughout this manual by the following icon:



The guide will generally follow the following format where appropriate:

1. Begin with *asking skills*.
2. Follow up with *listening skills*.
3. Offer *informing skills* when the patient is ready.

## WELCOME AND STATEMENT OF PURPOSE (5 MIN)

Introductory statements should include:

- Your name, position, and role in the healthcare team
- Overview of purpose of meeting
- Statements that reflect patient-centered approach, valuing patient's individual views
- Confidentiality statement
- Questions

An example statement:

“Here at *[insert site name]* we care very much about each of our individual patients. We want to improve communication between you and the healthcare team. We want to help people with more chronic illnesses tell their healthcare team about what is important to them in their care and what their hopes are for future treatment. Today I am hoping to learn more about your thoughts and concerns about your healthcare in the future. Everything you share with me is confidential. I believe that this meeting will help you have a voice in your care for years to come. Thank you for being here today. I can tell that you value your health. Before we get started, do you have any questions?”

## STEP 1: VALUES ASSESSMENT

### Session Objectives:

- Elicit patient's individual preferences about aggressive treatment in various scenarios
- Explore patient's experiences with chronic health issues
- Explore patient's concerns about how those experiences impact him/her

### MI SKILLS

**Ask:** "Sometimes when people are diagnosed with CKD, it brings up many questions and concerns about their medical care in the future. Have you ever known anyone who has had a serious illness?" [open-ended question]

**Listen:** Allow for patient to tell story without interruption. Offer reflective statements.

**Ask:** Elicit patient's own ideas and thoughts by asking exploratory questions and allow patient plenty of time to think and answer. Probing questions include:

- What was your experience like?
- What went well?
- What was difficult?
- How does this compare to your diagnosis?
- Thinking about you and your own kidney disease how would you like things to be?
- What concerns or worries do you have about your own healthcare as a result of this experience?

**Listen:** Some examples you might hear:

- My friend had to rely heavily on friends and family.
- My friend was in a great deal of pain.
- Why do we have to talk about this?
- This is out of my control; it is in God's hands.
- Discussing this makes me feel like you think I am going to die.

**Use reflection, summary, or empathy statements:**

- “Let me see if I have this right” and summarize patients concerns. [reflection and summary]
- “You care a great deal about your own health and you have learned a great deal from your friend’s experience.” [empathy]
- “You wonder if discussing this will really help you.” [empathy]
- “It sounds like you have already begun thinking about what you would like your healthcare to be like in the event that your health worsens.” [reflection and empathy]

**Inform**, if appropriate. Ask for permission to provide information and use examples of others.

- Spirituality is an important part of your healthcare decision. I have heard other people say it is helpful to talk to a spiritual leader.
- No one can predict our future. I want to make sure that every patient I encounter, regardless of age or illness, considers his or her healthcare wishes.
- This is a conversation that we should regularly have. Most people change their minds about their healthcare throughout their lifetime. Our discussion does not have to be permanent.

**Listen:** Allow patient time to reflect.

If a patient is unable to think of a personal circumstance, ask if he/she remembers the Terry Schiavo case and use that discussion as a launching point.

Transition Statement: If it is okay with you, can we talk about writing these concerns down?

Provider Notes:

Patient’s experiences with loved ones with chronic health problems:

- 1.
- 2.

Patient’s healthcare preferences:

- 1.
- 2.

Patient’s concerns about healthcare:

- 1.
- 2.

Possible Resources:

- American Bar Association - Tool 2

## STEP 2: COMPLETING ADVANCE DIRECTIVES

### Session Objectives:

- Assess patient's knowledge of advance directives
- Offer education about advance directives, if needed
- Assess whether patient has advance directive or is ready to complete
- Assist patient in verbalizing understanding of advance directive

Rationale: While most patients have an idea about what they would like in a health crisis, patients rarely complete the necessary documents to ensure they will receive the care they wish. Healthcare is so complex that it is not a yes/no decision, but one that includes complex tasks.

### MI SKILLS

**Ask:** "What do you know about advance directives?"

**Listen:** Allow patient time to process by offering silence, if appropriate. Listen for statements such as "I want" and "I wish" and "I need." For patients who are expressing readiness to change, use listening skills and ask if the patient has already created an advance directive. For patients who are not ready, reinforce their autonomy and respond to patient's emotion with empathetic statements.

**Inform** with permission, using examples:

- An advance directive is a tool for people to use so that they have a voice when medication or medical emergency prevents speaking.
  - This is a formal document that anyone over age 18 can complete. Once signed and notarized, the document becomes legal.
  - Advance directives can be changed any time.
  - Healthcare providers should be asking about advance care directives as soon as a person is old enough to make medical decisions and throughout a person's entire life. All persons should evaluate their advance care directives at the following points:
    - Before each annual exam
    - After any major life change (birth, marriage, divorce, remarriage)
    - After any major medical change, such as diagnosis of CKD or hospitalization
    - After losing the ability to live independently



**Ask** the patient, “Do you have an advance directive?”

- If Yes: “Congratulations! You are one step ahead. We realize that most people change their minds throughout their life. What do you think of revisiting your advance directive now to make sure that I understand your wishes and can document any changes?” [Ask, Listen]
- If No: “It sounds like you might have been wondering about whether this can help you.” [Ask] Pause and allow patient time to reflect. [Listen] “I am interested in making sure you have your wishes met [empathetic statement]. INSERT ANY PERTINENT INFORMATION YOU HAVE LEARNED ABOUT THE PATIENT HERE, SUCH AS MOTIVATORS. What do you think about discussing what would go in your personal advance directive?”

Provider Notes:

Describe patient understanding of advance directive:

- 1.
- 2.

What additional information does the patient need about advance directive?

- 1.
- 2.

Has patient completed advance directive?

- 1.
- 2.

Possible Resources:

- [Caringinfo.org](http://Caringinfo.org)

## STEP 3: REVIEWING THE ADVANCE DIRECTIVE

### Session Objectives:

- Assess what advance directives contain, or what patient would like it to contain, including the following:
  - CPR
  - Tube feedings
  - Artificial respiration
  - Antibiotics
  - Surgery
  - Dialysis
  - Blood transfusions
- Explore patient's concerns about advance directives
  - Specific issues related to CKD
- Reiterate that advance care plans can be changed any time

### MI SKILLS

**Ask:** "Now that we have discussed what an advance directive is, I'm wondering what elements of the advance directive you find most important to cover." [eliciting patient's thoughts and beliefs]

Some specific probing questions to include:

- If you were on dialysis and your health declined and the healthcare team did not believe that life-sustaining treatment, including dialysis, would help you, would you want to continue dialysis or stop?

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- If you were not on dialysis and you had advanced dementia and were unable to recognize your family and friends, would you want to start dialysis if your kidneys failed?

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- If you were in pain and there was medicine that could help, would you want the medicine if it made you so sleepy you could not talk?

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- If you could plan it today, what would the last week of your life look like? What environment would you want to be in? Who would you be with? What would you eat?

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- What would you need for comfort if you became very ill?

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**Listen:** Listen for change language. Allow patient time to process and respond.

*If the patient has an advance directive*, inquire about specifics and how they might change. Example statements may be “Sometimes people tell me that they change their mind about their healthcare choices. I am wondering if you remember what your advance directive contains. Is there anything in it you might want to modify?” Listen for change language. Offer empathetic statements.

*If the patient does **NOT** have an advance directive*, inquire about what specifics he/she might want to include. “Based on what you have said, it sounds like you have some thoughts about the care you would like to receive.” You can begin the discussion by stating “I am wondering if we can look at some specific scenarios and discuss under what circumstances you would like to have the following procedures.” [Invitation to inform] Reiterate that these decisions can change any time. Listen for change language. Offer empathetic statements. Remember to “roll with resistance.”

Some specific areas to cover include:

- Cardiopulmonary resuscitation (CPR) to try to restore breathing and blood circulation. (This includes heart massage, drugs, electric shocks and artificial breathing machines.)
- Tube feedings, including giving food and/or water through a tube into a vein or into the stomach.
- Artificial respiration (ventilator or respirator), which is a machine that breathes for a person through a tube in the throat.
- Antibiotics to fight infection.
- Dialysis for kidney failure.
- Surgery such as heart bypass, gall bladder, etc.
- Blood transfusions or blood products (patient may also decide whether he/she would only want blood from family members or friends).

Transition statement: *“Now that we have covered the specifics, I am wondering if we can discuss healthcare agents.”*

Provide State Advance Directive Form

Possible Resources:

- American Bar Association Tool 2
- Caringinfo.org
- Mayo Clinic

## STEP 4: CHOOSING THE HEALTHCARE AGENT

### Session Objectives:

- Assess patient’s knowledge of healthcare agent
- Offer education on healthcare agents
- Assess whether patient has healthcare agent
- Provide information on how to establish healthcare agent
- Answer any questions or concerns about healthcare agents
- Assist patient in verbalizing understanding of healthcare agent

Rationale: Often patients have ideas about what they would like to have done if their illness progresses, but have not selected a healthcare agent.

**Inform** by discussing others’ experiences. “Sometimes patients complete these advance directives, but they don’t select someone to make healthcare decisions in the event they cannot.

### MI SKILLS

**Ask:** “Could you tell me a little bit about your experience with healthcare agents?”  
[eliciting patient’s thoughts/beliefs]

### Inform:

- You can have control over your wishes by establishing a healthcare agent who can make those decisions for you in the event that you cannot.
- The healthcare agent has no authority in your healthcare unless you are unable to make decisions for yourself.
- A healthcare agent has no power over any other part of your life (finances, will, etc.) except for health decisions.
- A healthcare agent can be any person you choose with some limited exceptions (e.g., healthcare provider).

*If patient has a healthcare agent*, state: “Great news! You have been thinking ahead [empathetic response]. Would you be willing to share the details with me? [permission to inform] Who is your healthcare agent? Have you filled out a form? Does your kidney care team have that form?”

*If patient does NOT have healthcare agent*, state: “Considering all that we have discussed, I am wondering how you would feel about exploring this as an option.” [permission to inform]

**Listen** to patient’s response. Allow time to process and respond with reflective and empathetic statements.

Some possible concerns you may hear from patients:

- I always thought that my husband had the final decision in my care if I could not speak for myself.
- “I can tell that you have already begun to reflect on who you would like to be your healthcare agent.” [summarize and empathy] “Would you like information on how that process goes?” [Listen and inform]
- “If you do not have a healthcare agent, the courts decide who will make your medical decisions, and usually this is the next of kin.”
- I am worried that my husband would not be able to make difficult decisions for me.
- “It is hard to consider what your options are when your loved one may have trouble following through.” [empathy] Explain that is why these discussions are necessary. “Sometimes people choose a healthcare agent who is not a spouse or immediate family member because they are able to be more objective.”

**Listen and Inform**

- Review state form
- Transition statement: “Finally, let’s consider what it will be like to have these conversations with family, friends, and the medical community.”

Provider notes:

1. Healthcare agent is \_\_\_\_\_
2. Patient does not have healthcare agent but would like to designate \_\_\_\_\_
3. What is patient willing to do to designate healthcare agent?  
\_\_\_\_\_

Possible Resources:

- Caringinfo.org
- American Bar Association

## STEP 5: HAVING THE CONVERSATION

### Session Objectives:

- Assess patient readiness to start this conversation with family, friends, and healthcare team
- Determine a plan for the patient to have discussion with family, friends, and healthcare team
- Discuss potential barriers to having conversations and brainstorm solutions
- Provide education on the role of the social worker and nephrologist in advance care planning

### MI SKILLS

**Ask:** “I am wondering if you can tell me about what kinds of conversations you have had with family or loved ones about advance directives or healthcare agents?” [elicit patient thoughts/beliefs]

**Listen:** If patient has had conversations, offer empathy and summary statements such as “You have already taken initiative in making sure that your healthcare needs are met.” Follow up by asking the eliciting question: “Have any of your decisions changed since you last talked to your family?”

If patient has not had a conversation, offer empathetic statements and roll with resistance. “These conversations can be difficult to initiate.” Listen. Pause and allow the patient to reflect. Elicit beliefs and thoughts by asking: “How do you think you might have this conversation with loved ones? What might be some barriers?”

**Ask** the patient, “What is your plan for sharing this information with your kidney care team?” Some possible statements you might hear:

- I was nervous about talking this through with my family.
  - “These conversations can be difficult to initiate [empathy]. Some people tell me they would prefer to have the conversation now, rather than have family disagree about the course of treatment while they are in the hospital.” [inform]
  - Ask family about someone else’s healthcare experience or ask about cases in the media, such as Terry Schiavo.

### **Inform:**

- Share resources on the Coalition for Supportive Care of Kidney Patients website.
- Review any supportive material that you have available based on unique needs of the patient.
- Explain that the patient should talk to his/her kidney care team. Team members can provide him or her with answers to questions about healthcare treatments.

Provider Notes:

- Patient has discussed advance directives and healthcare agent with:

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- Barriers to discussion include:

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- Patient's plan to address barriers:

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- Patient will share decisions with kidney care team by:

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## STEP 6: ASKING FOR A POLST/MOLST FORM

### Session Objectives:

- Assess patient readiness to have kidney care team prepare a POLST/MOLST form
- Inform patient about purpose of POLST/MOLST and how it complements advance directive forms
- Determine a plan for having the kidney care team prepare a POLST/MOLST form based on patient wishes
- Discuss potential barriers to having a POLST/MOLST form prepared

Rationale: Even when patients have completed an advance directive, it may not be readily available in an emergency. The POLST (Physician Orders for Life-Sustaining Treatment) is a portable medical order form (aka “POLST Form”) that records patient’s treatment wishes. It can be used across settings of care. Having a POLST form makes it more likely that patients will receive the type of care they wish even if they are unable to speak for themselves in an emergency.

(For most patients, this step will occur in a follow-up coaching meeting or call, after patient has completed an advance directive.)

### MI SKILLS

**Ask:** “I am wondering if you have heard about a POLST or MOLST form before.” [elicit patient knowledge/experience]

**Listen:** If patient has some knowledge, offer summary statements such as “You have heard of the POLST, but you aren’t sure why you would need one now.” If patient does not know about POLST, offer information, with permission.

### Inform:

- The POLST (Physician Orders for Life-Sustaining Treatment) is a portable medical order form (aka “POLST Form”) that records a patient’s treatment wishes. It is a medical order written by a physician or nurse practitioner or physician assistant (depends on the state). It is written by the healthcare provider based on discussion of his or her advance care plan with the patient.
- The POLST Form documents the patient’s preferred medical orders and helps give the patient more control over receiving treatments he/she wants and avoiding treatments he/she does not want, in the event the patient cannot speak for his/herself during a medical crisis.
- A POLST Form always remains with the patient, regardless of whether the patient is in the hospital, at home, or in a nursing home. The form should be placed in a visible location



recognized by emergency medical personnel (usually the front of the refrigerator or in a medicine cabinet). In a healthcare facility, a copy of the POLST Form should be in the medical record.

- All competent adults should have advance directives, documenting who they want to speak for them whenever they lack capacity to speak for themselves. POLST forms are usually prepared for people who have a serious illness and might need emergency care. Both advance directives and POLST Forms are advance care plans. They support each other but do different things. Because having CKD increases a person’s risk for other health problems, it is recommended that patients have both advance care plans and POLST forms.
- Since the POLST form is prepared by a healthcare professional, the patient’s role is to ask that the form be prepared and to discuss what choices should be recorded on the form.

Share resources from the National POLST Paradigm, especially the FAQ for patients, located at <http://polst.org/faq>.

Make a plan for asking the kidney care team to prepare a POLST form. Decide with patient whether patient will request the POLST at a visit, or whether the coach will ask the team to initiate a POLST.

Provider Notes:

- Patient is ready to have a POLST prepared: Yes \_\_\_\_\_ No \_\_\_\_\_  
Comment \_\_\_\_\_
- Plan:  
Patient plans to ask kidney care team for POLST at next visit \_\_\_\_\_  
OR  
Coach to initiate request for POLST \_\_\_\_\_

## STEP 7: CONCLUSION/WRAP UP

At this point, it is very important for coaches to schedule a follow-up appointment or phone call within 90 days.

**Reflective Statement:** “We have covered so much difficult information in the last hour. It is time for our session to end, but we will have another opportunity to discuss this again.”



### MI SKILLS

**Ask** if the patient has any additional questions.

**Listen.** Allow the patient time to process and respond. Offer reflective and empathetic statements.

**Inform:** Explain to the patient the purpose of the call is to do the following: “I want to make sure that what you have expressed here today becomes a reality, so I would like to follow up with you by phone to check in.”

- The patient should take time to review and reflect on conversations and resources with trusted family or friends.
- Schedule a follow-up phone call or visit with the patient to review items addressed. For example, a follow-up call or visit might include looking at the advance directive the patient has begun working on, or specific questions about healthcare treatment options.
- Encourage the patient to call or contact you with any questions or concerns during that timeframe.
- Remember that this is an organic process and each patient will go at a different pace.

## Follow up in person or by phone

The purpose of this call or visit is to check in with patients about progress since the first meeting. Often patients need several meetings with a coach to complete the entire advance directive and healthcare agent forms. An example opening statements you can use is:

### MI SKILLS

**Ask:** “We talked several months ago about making healthcare decisions in the event you are unable to make them for yourself. We covered a great deal of information. Sometimes those conversations bring up questions or concerns after the meeting. I am wondering if you had any questions or concerns come up.”

**Listen:** Remember this is a fluid process. Go at the patient’s own pace. Use this meeting time to address what progress has been made and connect the patient to necessary resources and complete necessary paperwork in the office.

**Inform:** Many patients do not have access to the internet. It may be helpful to visit websites and show videos in the office (if the visit is in an office).

Wrap up the visit or call by thanking the patient for participating in the research project. Remind the patient that there will be a follow-up phone call by a research assistant. Explain that his or her participation will be valuable in helping medical providers better communicate about their care. Allow time for questions and provide resources as needed.

## Resources:

Check the Coalition for Supportive Care of Kidney Patients website at <http://kidneysupportivecare.org/For-Professionals/Advance-Care-Planning.aspx> for more information. Other resources include:

- Prepare for Your Care helps people make specific medical decisions. This website has videos from other people making medical decisions: <https://www.prepareforyourcare.org>
- The Mayo Clinic provides information on different treatments you may want to consider: <http://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303>
- Access your state’s advance directive form here: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>
- The American Bar Association has a toolkit that each person can use to help with Advance Care Planning: [http://www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/consumer\\_s\\_toolkit\\_for\\_health\\_care\\_advance\\_planning.html](http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html)

- The National POLST Paradigm has information about POLST forms in each state:  
<http://polst.org>



## **Coalition for Supportive Care of Kidney Patients**

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*This material was prepared by Quality Insights Mid-Atlantic Renal Coalition with funding from The Patrick and Catherine Weldon Donaghue Medical Research Foundation. Publication number: ESRD5-020317b*