

# COACH GUIDE

## Coaching People with Chronic Kidney Disease in Advance Care Planning



***Planning Today for Tomorrow's Healthcare***

# COACHING PATIENTS

*This guide includes Information, tools and suggested responses to use while coaching patients with chronic kidney disease.*

in  
**Advance Care Planning**

46346710



## OVERVIEW

---

### How MY WAY Coach Guide is organized

This Coach Guide is a companion to the MY WAY Patient Guide - for patients with kidney disease. The Coach Guide gives the MY WAY coach information, tools, and suggested responses to use while coaching patients in advance care planning (ACP). It is based on Motivational Interviewing (MI). MI skills are noted throughout. planning.

### The suggested steps of a MY WAY coaching session:

- 1. Values Assessment:** What makes life worth living
- 2. Advance Directive Initiation:** Readiness to put wishes in writing
- 3. Advance Directive Contents:** The details that matter to patient
- 4. Healthcare Agent Selection:** Person(s) to speak for patient
- 5. Conversation with Family, Friends and Healthcare Team**
- 6. POLST Form Planning**



# ADVANCE CARE PLANNING

---

## MY WAY Key Points

- ✓ **Advance Care Planning (ACP)** is an ongoing process that is much more than helping people fill out legal forms. At its best, it empowers people to control their future care and deepens the relationship between provider and patient.
- ✓ **Advance Directives (AD)** are the forms used to record the content developed during Advance Care Planning discussions. They are a legal tool for helping assure that someone's wishes about their future health care will be honored if they can't speak for themselves at the time.
- ✓ The majority of people with kidney disease have not completed advance directives. Even if they have, they typically have not shared them with their kidney care team unless asked to do so.
- ✓ People who discuss Advance Care Planning have fewer hospitalizations and ICU stays and are more likely to die at home or in hospice care. Some studies also document decreased pain, depression, and insomnia for people who have had Advance Care Planning discussions.
- ✓ Family members often do not know what patients prefer, even when they are the designated decision-makers. If prior Advance Care Planning conversations are shared with family, they experience less anxiety and guilt over decisions they make on their love one's behalf.
- ✓ Emotional experiences are normal when discussing Advance Care Planning, but not a reason to avoid the discussion. Skills for responding to emotions during Advance Care Planning are outlined in the Motivational Interviewing (MI) section of this guide.

## How the MY WAY Guide was tested

- The MY WAY Guide was tested in a randomized control clinical trial comparing coaching sessions with simply providing the MY WAY patient guide to patients. It was tested in three chronic kidney disease clinics with patients who were at least 55 years old and had stage 3-5 kidney disease, but were not yet receiving dialysis.
- The MY WAY trial showed that it is feasible to integrate Advance Care Planning into a busy CKD clinic, but the clinic and clinicians need to create systemic processes to make it a regular part of care. (See the MY WAY Implementation Guide).
- Almost all participants in the MY WAY trial responded positively. 96% of those who participated in coaching said their clinic should give the patient brochure to other patients and 79% said participating helped them seek out more information about advance care planning.
- The coaches in the MY WAY trial reported that patients with CKD who were earlier in the disease process and feeling healthy and well were more interested in having conversations about Advance Care Planning because it was less emotionally threatening. Nevertheless, coaching was helpful to patients at all health levels.

## Tips for using the MY WAY Guide

- Let the patient set the pace. Patients will express varying degrees of readiness for Advance Care Planning discussions. It is more important to proceed at a comfortable pace for each patient than to try to cover all content in a single session.
- Allow an organic discussion to unfold. Use this guide as a suggestion, not as a script. Allow space for listening and reflecting. Feel free to vary the order of the steps as you follow the patient's lead.
- The purpose of Advance Care Planning should not be to achieve “yes” or “no” answers to a list of possible interventions. The purpose is to help people articulate their personal values, life goals, and preferences. Because it is impossible to anticipate every circumstance that might arise, a clear understanding of overall values and wishes can be very helpful in guiding future medical care should the person become unable to make decisions for themselves.
- Whether or not the patient completes an advance care plan in the meeting, ensure the medical record reflects that education was provided and document any of the patient's expressed wishes.
- See the Additional Resources section for links to sites with a variety of advance care planning educational tools and resources. You may find some patients will benefit from and appreciate the option to watch short videos or complete values clarification exercises. Become familiar with these tools so you can point patients to the ones that will help them. You may find some you are especially comfortable with. We encourage you to integrate them into your MY WAY coaching.

## Time Required

Ideally, allow for a 1-hour discussion, and remember proceeding at each patient's pace is essential. Some patients will have already completed an advance directive and not require a great deal of time, while others may need more dialogue and engagement with teaching material. This should be a flexible process, and the coach should follow the patient's lead.

### Advance Care Planning is most successful when:

- All staff members understand the importance of, and where to find, Advance Care Planning documentation in the patient chart.
- The entire care team maintains a high level of communication regarding the Advance Care Planning coaching sessions.
- The nephrologist warmly encourages patients to meet with the Advance Care Planning coach.
- A private, designated space is available to discuss Advance Care Planning.
- Patients have an opportunity to reflect with the coach about past experiences with serious illness and end-of-life care for other family and friends.
- Family members are invited to the meeting and involved in the discussion.
- Clinic has a structured process for referring patients to Advance Care Planning coaches.
- Coaches are friendly, open, and non-judgmental.

## Motivational Interviewing Tips

### (Rollnick, Miller & Butler, 2008)

- Flexibility is key. Go at the patient's pace and modify the script as needed.
- Patient is a partner. Assess their own knowledge and experience before offering information.
- Respond to patient emotion by normalizing and naming the emotion. Resist the urge to "fix it" by minimizing the emotion. Let the patient know you can tolerate strong emotions and that they are safe sharing them with you.
- Resist the righting reflex, or 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 the conversation.

- Understand the patient’s motivations. Pay attention to language the patient uses to describe why they 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,” “I want,” or “I like.”
- Patient motivations to complete an advance care plan include maintaining control over their care, having quality of life throughout life, and reducing family conflict at the end of life.

## Motivational Interviewing Tips

**Ask:** By asking open-ended questions, you invite the patient to explore issues that lead to information needed to guide the session.

**Listen:** Allow patients time to respond to each question. Allow for silent pauses to help stretch patient’s thinking. Provide facilitative responses and reflection statements.

**Inform:** Give patients new information when they are ready. Ask permission to provide information. Talk to others’ experiences. Reflect with the patient to solicit understanding.

## MOTIVATIONAL INTERVIEWING STRATEGIES

Motivational Interviewing (MI) Strategies are highlighted throughout this manual by the following icons

**MI SKILLS**

Where appropriate, the MI SKILLS will act as a general guide, using the following order:



**Ask:** *Begin with asking skills*



**Listen:** *Follow up with listening skills*



**Inform:** *Offer information when patient is ready*

# INTRODUCTION

---

## Introduce yourself and the purpose of the MY WAY Coaching Session

- Your name, position, and role in the healthcare team
- Your relationship with the healthcare provider
- Overview of the meeting's purpose
- Statements that reflect patient-centered approach, valuing patient's individual views
- Confidentiality statement
- Offer to answer any questions the patient may have

### An Example Statement:

*“Here at [INSERT SITE NAME] we care very much about each person who comes here. Sometimes, it seems there is barely time in a visit to do anything more than discuss lab values and medications. But our whole team really wants to know more about YOU as a person. That helps us take better care of you now and in the future. That’s why we have the MY WAY program. It gives us the time to learn more about your wishes and concerns.*

*Today I am hoping to learn more about your thoughts and concerns for your healthcare in the future. Everything you share with me is confidential. I believe 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?”*

## WHAT MAKES LIFE WORTH LIVING?



Patients living with chronic kidney disease have many questions and concerns about their medical care in the future.

# step 1:

## VALUES ASSESSMENT

---

### SESSION OBJECTIVES

- Elicit patient's values and preferences about healthcare treatment in various scenarios.
  - Explore patient's experiences with chronic health issues.
  - Explore how those experiences have shaped their preferences and concerns.
  - Include available caregivers in the conversation.
- 

### MI SKILLS



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



**Listen:** Allow 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 as though you have already begun thinking about your healthcare wishes in the event that your health worsens." [*reflection and empathy*]



**Inform:** If appropriate, ask permission to provide information and use examples of others.

- Spirituality is an important part of your healthcare decision. I have heard other people say they find it helpful to talk with a spiritual leader.
- No one can predict our future. However young or healthy you are now, having a plan is like an insurance policy to have more control over future healthcare.

- This is a conversation that we should have regularly. Over time, many people change their views about their healthcare preferences. Any choices made during our discussion do not have to be permanent. You can change your choices in the future.



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

If a patient is unable to think of a personal circumstance, you can provide a scenario:

*“Since COVID-19, people of all ages have been making plans for their healthcare in case they become very sick. I’m wondering if you have thought about what you may want in situations like that?”*

### Some possible concerns you may hear from patients and model responses:

PATIENT SAYS	MODEL RESPONSES
<p>“Why are you talking to me about this now? My labs are fine!”</p>	<p><b>Listen, reflect and inform:</b> “Many people get nervous when a doctor raises Advance Care Planning because they fear it means they are terminally ill.” [reflect]</p> <p>“Talking about your wishes for future medical treatment is part of our good medical practice for all patients. Here, we think it is better to talk about Advance Care Planning when our patients are not seriously ill, because we believe people can make a clearer decision.” [inform, pause, and allow for patient response]</p>
<p>“My daughter already knows what I want, I don’t need to do it.”</p>	<p><b>Listen and reflect:</b> “You are ahead of the game! You have already done the most important part.” [reflect, pause, and allow for patient response]</p> <p><b>Inform:</b> “One way to help you make sure the physician does what you want, is to fill out an advance care plan and put it on file at the doctor’s office and also at the hospital.”</p>
<p>Patient still says, “My daughter knows.”</p>	<p><b>Ask:</b> “I’m wondering if we can think through a couple different scenarios to make sure you have completed all that you need. Sometimes the decision maker, such as your daughter, is unavailable. What would you want doctors to do in that situation?”</p>

# PROVIDER NOTES

---

## Transition statement

“If it is okay with you, may I write some notes to remember what we have talked about?”

1. Patient experience with loved ones' chronic health problems

---

---

---

2. Patient healthcare preferences

---

---

---

3. Patient concerns about healthcare

---

---

---



## READINESS TO PUT YOUR WISHES IN WRITING



Patients rarely complete the necessary documents to ensure they will receive the kind of care they want.

## step 2:

### ADVANCE DIRECTIVE INITIATION

---

#### SESSION OBJECTIVES

- Assess patient's knowledge of advance directives.
  - Offer education about advance directives, if needed.
  - Assess whether patient has, or is ready to complete, advance directive.
  - Form a plan with patient, based on patient's readiness, to complete an advance directive.
  - Assist patient in verbalizing comprehension 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 want.



**Ask:** “What do you know about advance directives?”



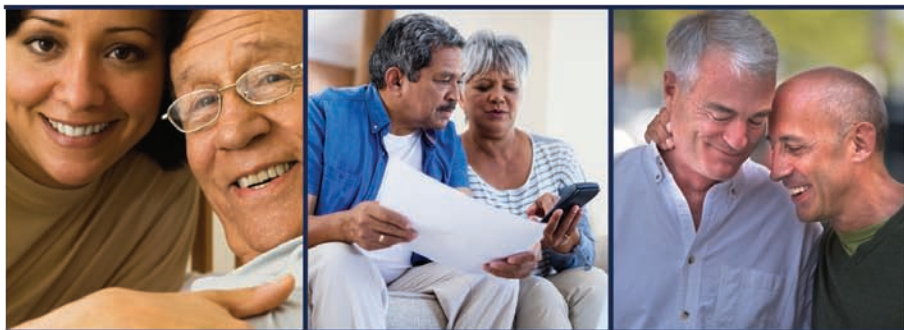
**Listen:** Allow patient time to process by offering silence, if appropriate. Listen for statements, such as, “I want,” “I wish,” “I need.” For patients that are expressing readiness to change, use listening skills and ask if the patient has already created an advance directive. For patients that are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



**Inform:** With permission, use examples to help patient understand advance directives:

- An advance directive is a tool for people to use so they have a voice when medication or medical emergency prevents them from speaking for themselves.
- This is a formal document for anyone over age 18, and it becomes legal, once signed, witnessed and notarized as required in the state. *(Note different requirements by state).*
- Advance directives can be changed any time by the patient.
- Healthcare providers should begin asking about advance care directives as early as age 18, and continue throughout a patient’s life. All persons should evaluate their advanced care directives at the following times:
  - 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 loss of independent living

## When your patient is ready, form a plan to complete an advance directive



## Common misunderstandings about advance directives and suggested responses

PATIENT SAYS	MODEL RESPONSES
<p>“Advance Directives are only for people who are ready to die. I want to live, and I want everything medicine can do for me!”</p>	<p><b>Listen, reflect and inform:</b> “You are clear about what you want. You want everything medicine can do to help you live.” [reflect]</p> <p>“An Advance Directive is not just for people who want to stop treatments. It records what YOU want. We can make sure YOUR advance directive says that you want all efforts to keep you alive.” [inform, pause, and allow for patient response]</p>
<p>“If I sign these forms, then my family is going to get too much control over my money.”</p>	<p><b>Listen and reflect:</b> “You have concerns that an Advance Directive could be misused to get control of your finances. Has something like that happened to you or to someone you know? [reflect, pause, and allow for patient response]</p> <p><b>Inform:</b> “An Advance Directive is ONLY about your healthcare, and it is only used if you can’t speak for yourself.”</p>



**Ask:** “Do you have an advance directive?”

**If yes:** “Congratulations! You are one step ahead. What do you think of revisiting your advance directive now to make sure I understand your wishes?” [ask and listen].

**If no:** “It sounds like you may have been wondering about whether this can help you. [ask, pause, allow patient time to reflect, and listen] I am interested in making sure your wishes are 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

---

## Transition statement

“If it is okay with you, may I write some notes to remember what we have talked about?”

1. Describe patient understanding of advance directive:

---

---

---

2. In which areas does patient need more information?

---

---

---

3. Has patient completed advance directive?

---

---

---



# B

**THE DETAILS  
THAT MATTER TO  
YOUR PATIENT**



Help patient put into words, their views about what makes life worth living and what they want to avoid at the end of life.

## step 3:

### **ADVANCE DIRECTIVE CONTENTS**

---

#### **SESSION OBJECTIVES**

- Assess what advance directive contains, or what patient would like it to contain
  - Building on earlier discussion of values, help patient put into words their views about what makes life worth living and what they want to avoid at end of life
  - Stress that stating general values is helpful because those values can guide decision making in a range of situations
  - Explore patient's views on future treatments related to CKD
  - Explore patient concerns about advance directives
  - Reiterate that patient can easily change their advance care plan at any time
-





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



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

**If the patient has an advance directive,** inquire about specifics and how they might change. Example statements could include: “Sometimes people tell me they change their mind about their healthcare choices. I am wondering if you remember what your advance directive says. Is there anything in it you might want to change?” [*listen for change language and offer empathy*]

**If the patient does not have an advance directive,** inquire about what specifics they 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 have already told me a lot about what is important to you [*name something discussed*]. I am wondering if we can look together at some specific healthcare scenarios and discuss how those would fit into what you want or don’t want.” [*invitation to inform*] Reiterate that the patient can change these decisions at any time. [*listen for change language, offer empathy, and remember to “roll with resistance”*]

### Stating overall values about comfort care/burdensome treatment tradeoff

**Build on patient’s thoughts during values assessment.** “When we started this discussion, you said you would not want to die hooked up to machines. Let’s put that into words in your advance directive.”

or

“As we have been talking, you have said several times that you want every bit of help medicine can offer. Let’s put that into words in your advance directive.”

or

“As we have been talking, you have said that it is hard to decide what to do because it would depend so much on the situation. I’m wondering if we could consider together some scenarios that might help you clarify what you would and would not want.”

If patient is willing, discuss these scenarios:

- “What would bring you comfort if you became very ill?”
- “What are you most worried about if you became very ill?”
- “If you could plan it today, what would the last week of your life look like?”
- Where would you want to be? Who would you be with?  
What would you eat?



**Inform:** After asking permission. “The most helpful instruction you can put into your advance directive is how YOU balance your quality of life with the risks of medical care at the end of life. We’re not talking about what you choose NOW, but what you would want to choose if you were very sick, might die soon, and were not able to speak for yourself.”

“Most people prefer one of these approaches. Let’s talk about which one fits you best.”

Help patient choose, and, if ready, indicate this on their advance directive form.

- My main goal at the end of life is to focus on quality of life and being comfortable. I would NOT want life support treatments if the treatments do not work and there is little hope of getting better or living a life I value.
- I would want to **try out** life support treatments that my doctors think might help. If I am not getting better, I DO NOT want to stay on life support treatments if there is little hope of getting better or living a life I value.
- My main goal at the end of life is to live as long as possible, no matter what. I would want to stay on life support treatments even if there is little hope of getting better or living a life I value.

If patient responds that they are not sure or that it depends on the situation, explore concerns and ask if there is any additional information patient would like.

## Specific Treatments

**Transition statement:** “Now that we have covered your thoughts on the big picture, I am wondering if we can turn to some specific questions. Some people have wishes about specific treatments such as tube feedings, blood transfusion, or breathing machines.”

It is NOT necessary to ask patient to make a yes/no choice on all of the treatments in this list (See chart on page 6 of the My Way Patient Guide). The goal is to capture any strong feelings that the patient already has. “Let’s look at this list together. Are there any that you have strong feelings about wanting or not wanting at the end of life? You don’t have to make a decision about all of them. We just want to make sure that we know what you feel strongly about for yourself. Remember, this is not what you want now, but what you would want in the future if you were very sick and unable to decide for yourself.”

### Specific topics to discuss:

- Cardiopulmonary resuscitation (CPR) to try to restore breathing and blood circulation, including heart massage, drugs, electric shocks, and artificial breathing machines.
- Tubal feedings, which include giving food and/or water through a tube into a vein or the stomach.
- Artificial respiration, which includes a tube in the throat connected to a breathing machine, such as a ventilator or respirator.
- Antibiotics to fight infection.
- Surgery, such as heart bypass, gall bladder, etc.
- Blood transfusions or blood products, and whether the patient would only want blood from family members or friends.
- Dialysis for kidney failure. (See below for further approaches to dialysis.)

# DIALYSIS

## Special considerations about dialysis

Because the patients you are talking with have kidney disease, they face a higher likelihood of needing to make decisions about treatment for kidney failure at the end of life. This is DIFFERENT than deciding about treatments for kidney failure while they are still enjoying good quality of life and able to make their own decisions.

Some patients may have already given this a great deal of thought, while others may be early in their learning about their kidney failure treatment options. The goal in this coaching session is to find out the strong views that patients currently hold to include these in the advance directive. If patients don't yet have a strong view or are early in the process of learning about treatment options, remind them about the education offerings available from your practice or national kidney groups and make a plan to revisit this topic at a later time.



.....

### For patients who are interested in discussing this further, there are two scenarios to consider:

#### There are two scenarios to consider:

1. Whether to START dialysis in the future if you have other severe health problems (such as dementia) and cannot decide about treatments for yourself.
2. Whether to STOP dialysis that has already been started if your health gets much worse.

For those patients who want to learn more, inform patient about options such as time-limited trials, palliative dialysis, active medical management without dialysis, dialysis continuation, and stopping dialysis. See Coach Resources box for more information on these options.

Remember – MY WAY coaching for purpose of advance care planning, is NOT the same as educating patients about choosing a treatment option while they have an expectation of ongoing quality of life. Remind patients that they can change their advance care plan in the future as they learn more about their options.

## PROVIDER NOTES

---

### Transition statement

“If it is okay with you, may I write some notes to remember what we have talked about?”

1. How far did patient get in completing contents of advance directive?:

---

---

---

2. If not finished, what is plan for continuing to work on advance directive?

---

---

---

3. In which areas does patient need more information?

---

---

---





## COACH RESOURCES

### **Active Medical Management Without Dialysis**

Active medical management without dialysis is when the kidney care team treats the symptoms of kidney disease without using dialysis.

#### **This involves:**

- Preventing or managing problems
- Protecting remaining kidney function
- Psychosocial care
- Helping plan for the future

This type of care is also called “conservative kidney care” or “comprehensive conservative care”.

### **Palliative Dialysis**

Palliative dialysis is an option for patients not likely to live longer than a year even with dialysis. This may be a good option for patients who have trouble with the burdens of dialysis but don't wish to stop dialysis. In this model, patients may have more

flexible schedules (such as twice per week, or shorter sessions), more permissive diets, or other adjustments to the standard regimen for purpose of increasing patient's overall well-being and quality of life, even though the usual markers of kidney function may not be optimal.

### **Time-limited Trial of Dialysis**

Time-limited trial of dialysis means trying dialysis out for period of time, such as a month or two, to see how helpful and how burdensome it is. The patient and the care team agree to get back together after the time period to decide whether to continue on with dialysis or not. The trial period gives patients and families a better understanding of the benefits and burdens of dialysis. This may help a patient who is uncertain about their quality of life on dialysis to decide whether or not it is the right treatment choice for them.

# 4

A **TRUSTED PERSON**  
TO **SPEAK** FOR YOU  
IF YOU CAN'T



Establish a healthcare agent that can make medical decisions for you in the event you cannot.

## step 4:

### HEALTHCARE AGENT SELECTION

---

#### 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 comprehension of healthcare agent.
- 

#### Rationale

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



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



**Listen:** Allow patient time to process and respond, before offering the following information.



**Inform:**

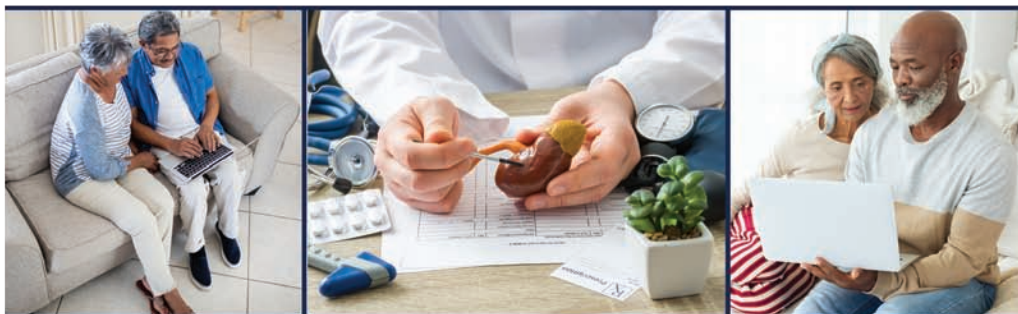
- You can have control over your wishes by establishing a healthcare agent that can make those decisions for you in the event that you cannot.
- The healthcare agent has no authority in your healthcare unless you are unable to make decisions for yourself.
- You can change your healthcare agent any time.
- It is helpful to have at least one back-up healthcare agent.
- Aside from healthcare decisions, a healthcare agent has no power or authority over any other part of your life, such as your finances, will, etc.
- A healthcare agent can be any person you choose, with limited exceptions, such as your healthcare provider.

**If the 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 so that it is recorded in your medical record? This will ensure that everyone treating you knows who you want to make decisions for you in case you are unable? [*permission to inform*] Who is your healthcare agent? Have you filled out a form? Does your kidney care team have that form?”

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



**Listen:** to patient response, allow time to process, and respond with reflective and empathetic statements.



**Some possible concerns you may hear from patients and model responses:**

PATIENT SAYS	MODEL RESPONSES
<p>“I am worried about having this conversation with my family. They are going to insist and say, ‘oh no, we can’t talk about that!’”</p>	<p>“You don’t want to hurt the people that you love.” [<i>listen and respond with reflection</i>]</p> <p>“Tell me about the conversations you have had in the past.” [<i>asking</i>]</p> <p>“I’m wondering if we can think through a few options about how to approach this together.” [<i>ask permission</i>]</p> <p>“What if you said, ‘while I am healthy, I have decided it is important to tell you what I want in the event that I can’t speak for myself. If we can discuss that, I will feel less anxious about my future healthcare.’” [<i>consider role-play</i>]</p> <p>“Research shows that when patients become too sick to speak for themselves, families are very grateful and less stressed when they know what the patient wanted.”</p>
<p>“I always thought that my husband had the final decision in my care if I could not speak for myself.”</p>	<p>“I can tell that you have already begun to reflect on who you would like to be your healthcare agent.” [<i>summarize and respond with empathy</i>]</p> <p>“Would you like information on how that process goes?” [<i>listen and inform</i>] If you do not have a healthcare agent, state law decides who will make your medical decisions, and usually this is the next of kin.” [<i>Provide information on process in your state.</i>]</p>
<p>“I am worried that my husband would not be able to make difficult decisions for me.”</p>	<p>“It is hard to consider what your options are when your loved one may have trouble following through.” [<i>empathy</i>]</p> <p>Explain that is why these discussions are necessary.</p> <p>“Sometimes people choose a healthcare agent that is not a spouse or immediate family member because they are able to be more objective.” [<i>listen and inform</i>]</p>



## PROVIDER NOTES

---

### Transition statement

“Now, let’s consider what it will be like to have these conversations with your family, friends, and medical community.”

1. Healthcare Agent is:

---

2. My backup Healthcare Agent is:

---

3. Patient does not have a Healthcare Agent but would like to designate:

---

4. What is patient willing to do to designate a Healthcare Agent?

---

---

---

---

---



## TALK WITH FRIENDS, FAMILY & HEALTHCARE TEAM



Determine a plan for patient to have discussions with family, friends and healthcare team.

# step 5:

## START THE CONVERSATION

---

### SESSION OBJECTIVES

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



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

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



**Listen:** A possible patient response:

- “I was nervous about talking this through with my family.”

**If the patient *has* had conversations,** offer summary statements, such as, “You have already taken initiative in making sure your healthcare needs are met.” Elicit further thought with follow-up questions, such as, “Have any of your decisions changed since you last talked with your family?”

**If the patient *has not* had conversations,** offer empathetic statements and roll with resistance. “These conversations can be difficult to initiate.” [*offer empathy, 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 family about someone else’s healthcare experience or ask about cases in the media, such as Terry Schiavo. Offer information by stating, “many caregivers tell me they consider it a gift when a patient shares their advance care wishes. They feel a sense of relief.”



**Ask:** “What is your plan for sharing this information with your kidney care team?”



**Listen:** A possible patient response:

- “They have not asked me for my plan.” [*reflect*]

**Respond:** “You would like to talk with your team, but you have not been asked.” [*listen and respond with reflection*] If the patient is not sure how to introduce the plan, provide information, such as, “Your kidney team cares about what your wishes are. Some patients take a copy of their plan to their doctor on their next appointment date.” [*inform, listen, and help prepare for potential barriers*]



**Inform:** A possible patient response:

- Share resources, such as the Coalition for Supportive Care of Kidney Patients website.
- Review any supportive material that you have available, based on unique needs of patient.
- Explain that patient should talk with their kidney care team, and that those team members can answer any questions about healthcare treatments.

# PROVIDER NOTES

---

## Transition statement

Confirm with patient that they have communicated with their Advance care Plan with their Healthcare Agent and Kidney Care Team.

1. Patient has discussed Advance Directives and Healthcare Agent with:

---

2. Barriers to discuss include::

---

---

3. Patient plan to address barriers::

---

---

---

4. Patient will share decisions with Kidney Care Team by:

---

---



# 6

## POLST FORM PLANNING



POLST stands for “Physician Orders for Life-Sustaining Treatment”, and MOLST stands for “Medical Orders for Life-Sustaining Treatment”.

## step 6:

### POLST FORM PLANNING

#### Physician Orders for Life-Sustaining Treatment

---

#### SESSION OBJECTIVES

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

- Assess patient readiness to have kidney care team prepare a POLST: Portable Medical Orders\* form.
  - Inform patient about purpose of POLST and how it complements advance directive forms.
  - Determine a plan for having the kidney care team prepare a POLST form, based on patient wishes.
  - Discuss potential barriers to having a POLST form prepared.
- 

The POLST form has different names in different states: POLST: Physician Orders for Life-Sustaining Treatment, MOLST: Medical Orders for Life-Sustaining Treatment, MOST: Medical Orders for Scope of Treatment. See: <https://polst.org/program-names/>

## Rationale

Even when patients have completed an advance directive, it may not be readily available in an emergency. Also by protocol, EMS can only follow medical orders, not an advance directive. The POLST is a portable medical order form that records patient treatment wishes and can be used across care settings. Preparing a POLST form helps to ensure patients receive the type of care they wish, even if they are unable to speak for themselves in an emergency.

### MI SKILLS



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



**Listen:** Listen and proceed appropriately, based on patient response.

**If patient has heard of the forms,** offer summary statements such as “You have heard of the POLST, but you aren’t sure why you would need one now.”

**If patient has not heard of the forms,** offer information, with permission.



### Inform:

- The **Physician Orders for Life-Sustaining Treatment** form (POLST form) is a portable form that converts patient treatment wishes into medical orders. It is written by a healthcare provider, such as physician, nurse practitioner, or physician assistant, depending upon the state; and it is based on discussion with the patient regarding their treatment wishes for an advance care plan.
- The POLST form documents the patient’s preferred medical orders and helps give the patient more control over receiving treatments they want and avoid treatments they do not want, in the event the patient cannot speak for themselves 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, and should be placed in a visible location recognized by emergency medical personnel (usually on the front of the refrigerator or in a medicine cabinet). In a healthcare facility, a copy of the POLST form should be at the front of patient medical record.
- All competent adults should have advance directives, documenting whom 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, some patients may want the extra layer of protection that a POLST plan provides, in addition to an advance care plan. Other patients may want to postpone a POLST form until their condition has progressed further. POLST forms can be changed over time as the patient’s wishes change.

- 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 section, located at <http://polst.org/faq>.

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



# PROVIDER NOTES

---

## Transition statement

Clarify with patient whether they will request the POLST form or if their Kidney Care Team will request the POLST.

1. Patient is ready to have a POLST prepared: Yes: \_\_\_\_\_ No: \_\_\_\_\_

Comment: \_\_\_\_\_

2. Plan: \_\_\_\_\_

\_\_\_\_\_

Patient plans to ask Kidney care Team for POLST as next visit: \_\_\_\_\_

Or

Coach to initiate request for POLST::

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_





## COACHING PATIENTS

*For many patients, a follow-up phone call within 90 days will be helpful. Some patients may benefit from a second in-person coaching session.*

Schedule a  
**Follow-up  
Phone Call**



## CONCLUSION

---

### Make an appropriate follow-up plan

For many patients, a follow-up phone call within 90 days will be helpful. Some patients may benefit from a second in person coaching session.

### 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:** Does the patient have any additional questions?



**Listen:** Allow the patient time to process and respond, before offering reflective and empathetic statements.

**If patient *has* heard of the forms,** offer summary statements such as “You have heard of the POLST, but you aren’t sure why you would need one now.”

**If patient *has not heard of the forms*, offer information, with permission.**



**Inform:** Explain the purpose of the follow-up call using the following statement: “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.”

- 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, including any progress patient made with advance directive or any questions they may have regarding healthcare treatment options.
- Encourage the patient to call or contact you with any further questions or concerns.
- Remember 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 first meeting. Often patients need several meetings with a coach to complete the entire advance directive and healthcare agent forms. An example opening statement you can use is:

### MI SKILLS



**Ask:** “We talked several months ago about making healthcare decisions in the event you become 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 internet. It may be helpful to visit websites and show videos in the office (*if the visit is in-office*).



## ADDITIONAL RESOURCES

---

### Other recommended resources include:

#### **PREPARE**

<https://prepareforyourcare.org/welcome>

Easy to use website that guides people through the process of making advance care plans. Has many short engaging videos from people discussing their values and medical choices. Has been well tested with patients. Is not kidney disease specific. May be especially helpful for people who are not sure about their values and/or find it easier to engage with videos than read extensive material.

#### **National Hospice and Palliative Care Organization (NHPCO) CaringInfo**

<https://www.nhpc.org/advancedirective/>

An alternate source of free advance directives and instructions for every state.

#### **National POLST**

<https://polst.org/>

Information and videos explaining how POLST works in addition to advance directive and in place of Do Not Resuscitate (DNR) order.

#### **Conversation Project**

<https://theconversationproject.org/>

#### **What Matters to Me workbook:**

<https://theconversationproject.org/wp-content/uploads/2020/09/ConversationProject-WhatMatterstoMe-Workbook-English.pdf>

National effort to engage consumers and health care organizations in advance care planning. The “What Matters to Me” workbook may be useful for people who need help clarifying their values and priorities for healthcare.



The initial version of this material was developed by Quality Insights Renal Network 5 with funding from The Patrick and Catherine Weldon Donaghue Medical Research Foundation. Publication number: ESRD5-043018b. Subsequent revisions incorporating findings from the MY WAY clinical trial have been prepared by the Coalition for Supportive Care of Kidney Patients.

#### **A Guide for People with Chronic Kidney Disease. Coalition for Supportive Care of Kidney Patients**

Suggested Citation: Lupu D., Anderson E., Aldous A. MY WAY: Planning Today for Tomorrow’s Healthcare. February 1, 2021.

<https://go.gwu.edu/mywayguides>





*Download and print:*  
**My Way Patient, Coach & Implementation Guides**  
<https://go.gwu.edu/mywayguides>



*For more information visit:*  
**Coalition for Supportive Care of Kidney Patients**  
<https://kidneysupportivecare.org>