



Planning Today for Tomorrow's Healthcare:

A Guide for People with Chronic

# KIDNEY DISEASE







*Hi, I am Irene Smith, a 59-year-old CKD patient. I have a plan. Let me tell you my story.*

## OVERVIEW

“When I was diagnosed with chronic kidney disease (CKD) I was grateful that there were lifesaving treatments, but I was also scared because I did not have a plan. I worried that I might be in pain or become a burden to my family. I felt better when I was able to discuss my values and healthcare decisions with my family and healthcare team.”

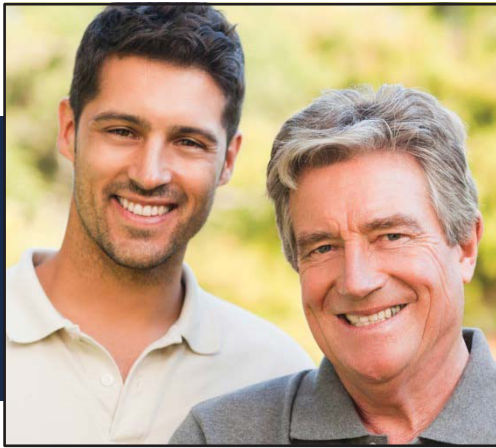
This brochure will provide details on how to have control over your healthcare in the event that you cannot speak for yourself. This process is called advance care planning. Some people know exactly what they would want to happen if they became very ill. For other people, these decisions take time and thought. Go through these sections at your own pace. If you find you are feeling overwhelmed, talk to a friend or family member, or ask your kidney care team to help you make a plan and put it in writing.

### There are five steps to advance care planning:

1. Choose someone to make healthcare decisions for you if you get sick and cannot speak for yourself.
2. Think about what kind of healthcare you would want if you were unlikely to get better. Discuss your wishes with your family and friends.
3. Write your wishes down in a legal form, known as an advance directive (sometimes called a “living will” or a medical power of attorney).
4. Give a copy of your advance directive to your healthcare agent and your kidney care team. Continue talking to your family about your wishes.
5. Work with your kidney care team to complete a medical order form (usually called POLST or MOLST) to record your wishes.



If this brochure is hard to read or understand, talk to a trusted family member or friend or request a conference with a member of your kidney care team to discuss your healthcare goals.



## STEP 1: Who is your healthcare agent?

Choose someone to make healthcare decisions for you if you get sick and cannot speak for yourself.

- A healthcare agent is a family member or friend whom you choose to make healthcare decisions for you if you cannot.
- A 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.
- If you do not have a healthcare agent then your kidney care team will usually ask the next of kin.
- A healthcare agent is only official if you complete an advance directive. Be sure to share the advance directive with family and your kidney care team so they know who to turn to if needed.

## STEP 2: What would you want people to know if you got sick and were not able to speak for yourself?

Think about what kind of healthcare you would want if you were unlikely to get better.

If you got so sick that you could no longer do most of your daily activities, or if you were near the end of your life, what would you prefer be the focus of your care?

- Staying alive at all cost, no matter how much pain or discomfort the medical care involved.
- Making you as comfortable as possible, even if it meant you might not live as long.
- Not sure.

Some specific questions to consider:

- If you were in pain and medicine could help, would you want the medicine if it made you so sleepy you could not talk?
- What would you need for comfort if you became very ill?
- If you were on dialysis and your health declined and your kidney care team did not believe that dialysis would help you, would you want to continue dialysis or stop?
- If you were not on dialysis and were unable to recognize your family and friends, would you want to start dialysis if your kidneys failed?

- Specifically, in what situations would you want the following medical treatments?

- Cardiopulmonary resuscitation (CPR) to try to restore breathing and blood circulation
- Tube feedings, including giving food and/or water through a tube into a vein or into the stomach
- Artificial respiration (ventilator or respirator) – 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

- Each person has a different view based on his or her personal values and current health status. Talk to your kidney care team about the risks and benefits of different treatments for you.

### STEP 3: How do I make my medical wishes known?

Write your wishes down in a form called an advance directive (sometimes called a “living will” or a medical power of attorney).

Your kidney care team can help you write your advance directive.

- An advance directive is a legal document that allows you to have control of your healthcare decisions if you are ever unable to speak for yourself.
- Use the form that is recognized in the state where you live: (<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=328>).
- Share the completed form with your healthcare agent, family members, friends, and kidney care team.
- Advance directives can be changed any time. Simply destroy the old document and create a new one.

Advance directives should be reviewed throughout a person’s entire life, especially:

- Before each annual exam.
- After any major life change (birth, marriage, divorce, remarriage).
- After any major medical change, such as diagnosis of chronic kidney disease or hospitalization.
- After losing the ability to live independently.





#### STEP 4: How do I start the conversation?

Talk to your family and friends about the care you would want. Give a copy of your advance directive to them and your kidney care team.

Avoid family conflict in a hospital by talking about your wishes ahead of time.

- Ask family members to reflect on someone else's experience with chronic illness.
- Talk to your spiritual leader for guidance.
- Ask your kidney care team to help you find a social worker. They will have ideas about how to start conversations. Social workers can give you resources and get documents you need.

#### STEP 5: Complete a medical order form (called POLST or MOLST) with your kidney care team to record your wishes.

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

- It helps individuals with serious illness or frailty to communicate their treatment decisions.
- The POLST form is a portable medical order form that records a patient's treatment wishes so that emergency personnel know what treatments the patient wants in the event of a medical emergency.
- POLST is known by different names in different states; for the list of names, see <http://www.polst.org/programs-in-your-state>.

## ACTION ITEMS

- ✓ Think about what you want your future medical care to be like.
- ✓ Seek input from your kidney care team, spiritual leader, and/or family.
- ✓ Tell your family and friends your wishes.
- ✓ Formally ask someone you trust to be your healthcare agent.
- ✓ Fill out an advance directive naming a healthcare agent.
- ✓ Provide copies of your advance directive to your kidney care team and other doctors.
- ✓ Provide copies of your advance directive to your healthcare agent.
- ✓ Ask your kidney care team to record your wishes as medical orders, often called POLST or MOLST.

## WORKSHEET

1. The person I would like to make healthcare decisions in the event I could not is: \_\_\_\_\_
2. I think that the following side effects would be worth enduring if it meant I could regain my health: \_\_\_\_\_
3. If I was very sick, I would not want to have these treatments:  
\_\_\_\_\_  
\_\_\_\_\_
4. I would like my healthcare team and healthcare agent to know the following things about my spiritual/religious life: \_\_\_\_\_  
\_\_\_\_\_
5. It might be difficult to talk to my family, friends, and kidney care team about my advance directive because: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
6. I plan to make this discussion easier by: \_\_\_\_\_
7. The healthcare team members I need to talk to are: \_\_\_\_\_  
\_\_\_\_\_
8. I will complete an advance directive by this date: \_\_\_\_\_
9. I will provide a copy of my advance directive to my healthcare agent and kidney care team by this date: \_\_\_\_\_



## RESOURCES

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



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