

PATIENT GUIDE

Advance Care Planning for People with Chronic Kidney Disease



Planning Today for Tomorrow's Healthcare

LET ME TELL YOU MY STORY

*Hi, I am Irene Smith,
a 65-year old woman
living with chronic
kidney disease.*

I have a plan.



OVERVIEW

“When I first learned I had chronic kidney disease (CKD) I was grateful that there were lifesaving treatments, but I was also scared because I didn’t 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 wishes and healthcare decisions with my family and healthcare team.”

This brochure will provide details on how to have control over your future 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, family member, spiritual leader, or ask your kidney care team to help you make a plan and put it in writing.



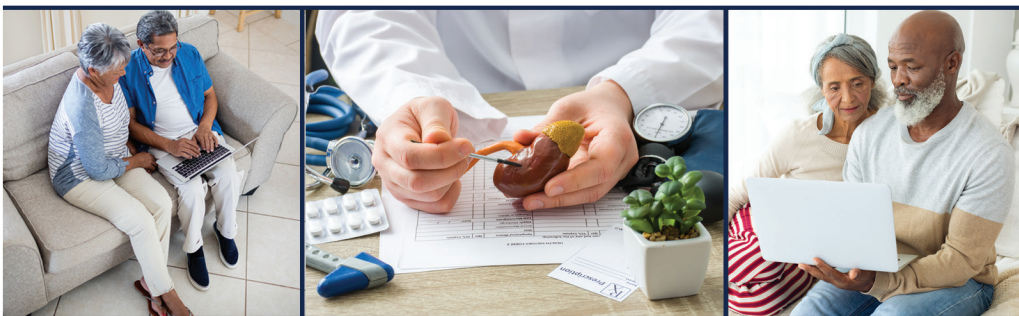
If this brochure is hard to read or understand, talk to a trusted family member or friend or request a conference with a member of your kidney care team to discuss your healthcare wishes.

ADVANCE CARE PLANNING

There are five steps to advance care planning:

1. Choose a healthcare agent 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 (a living will, a medical power of attorney, or durable power of attorney for healthcare).
4. Give a copy of your advance directive to your healthcare agent (a trusted family member or friend you choose to speak for you) and your kidney care team. Continue talking to your family about your wishes.
5. Discuss with your kidney care team when a medical order form (usually called POLST or MOLST) might be right for you.

Discuss your wishes and healthcare decisions with your family and healthcare team



WHO IS YOUR HEALTHCARE AGENT?



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

step 1:

YOUR HEALTHCARE AGENT

- A healthcare agent is a trusted 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 but this person might not be the one you would want.
- A healthcare agent is only official if you complete an advance directive or medical power of attorney form. Be sure to share the advance directive with family and your kidney care team so they know who to turn to if needed.
- Ideally, you will also select a back-up healthcare agent.
- You can change your healthcare agent any time.

WHAT IF YOU GOT SICK AND WERE NOT ABLE TO SPEAK FOR YOURSELF?



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

step 2:

FIRST, LOOK AT THE BIG PICTURE

- How do you balance quality of life with staying alive?
- 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 be your main goal for your medical care?
 - Staying alive as long as possible, even if there is little hope of getting better, and no matter how much pain or discomfort the medical care involves.
 - Being as comfortable as possible, even if it might mean not living as long.
 - Trying out treatments that might help, but not staying on them if there is little hope of getting better or living a life you value.
 - Not sure or it depends.

Now, look at specific treatments you feel strongly about.



You do NOT need to decide now about every treatment on this list.

If there are some treatments you feel strongly about having or not having at the end of life, note that in your plan. Remember, this is not what care you want now, but what you would want in the future if you were very sick and unable to decide for yourself.

Some questions to consider:

- 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?
- If there were options for you to stay at home and keep you comfortable, but not extend your life, would you want to stay at home or go to the hospital?

Do you feel strongly about having or not having certain treatments at the end of life?



The main choices are to

- Try the treatment and stay on it, even if it is very unlikely to restore your health.
- Try the treatment for a time, but stop it if it is not helping you have good quality of life.
- Not start it at all because you want to avoid aggressive medical care and have a more natural death.

Write your thoughts on the worksheet on the next page.

WORKSHEET

Mark the worksheet to show what treatments you do or don't want near the end of life.

Treatments you feel strongly about having or not having near the end of life

TREATMENT OPTIONS	Try this and STAY on it.	Try this but STOP if it won't restore quality of life.	Do not START this. Keep me comfortable.	I'm NOT SURE or don't feel strongly.
Cardiopulmonary resuscitation (CPR) to try to restore breathing and blood circulation, including heart massage, drugs, electric shocks, and artificial breathing machines				
Artificial respiration, which includes a tube in the throat connected to a breathing machine, such as a ventilator or respirator				
Tubal feedings, which include giving food and/or water through a tube into a vein or the stomach				
Antibiotics to fight infection				
Surgery, such as heart bypass, gall bladder, etc.				
Blood transfusions or blood products, and whether patient would only want blood from family members or friends				
Dialysis for kidney failure, which is a machine to clean your blood if your kidneys don't work (See below for more about dialysis)				

Special considerations about dialysis

If you already know what you would want, it is helpful to give your healthcare agent that information. If you don't yet have a strong view or are early in the process of learning about treatment options for kidney disease, it is OK not to give any instructions now.

There are two cases to think about in the future:

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.

Are there specific situations when you think dialysis would not be a good treatment to start or to continue, such as no longer being able to recognize family and friends, being in a lot of pain, or not being able to do the activities you enjoy?



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Because you are someone already living with kidney disease, your healthcare agent may need to decide whether to start or stop treatment for kidney failure at the end of life. This is DIFFERENT than deciding about treatments for kidney failure while you are enjoying good quality of life and able to make your own decisions.

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Supportive care approaches to treating kidney failure

If a kidney transplant is not available, dialysis – either at home or at a dialysis center – is the most common treatment offered when a person’s kidneys no longer work well enough to keep them alive. There are several other approaches that may be right for someone who has many other health problems and may find dialysis too hard to go through. These approaches, called supportive kidney care, are not available at all kidney treatment centers. Ask your kidney care team whether they offer these options and whether they might be right for you if you get sicker.

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
- Supporting your emotional and spiritual well-being
- Supporting your family
- Helping plan for the future

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

Time-limited Trial of Dialysis

Time-limited trial of dialysis means trying dialysis out for a 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.

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 relaxed diets, or other adjustments to the standard regimen for purpose of increasing patient’s overall well-being and quality of life.

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.

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HOW DO YOU MAKE YOUR 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

step 3:

HOW TO USE AN ADVANCE DIRECTIVE

- 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.
- An advance directive is NOT the same thing as a will. An advance directive is only about your health. It is not about your belongings.
- Use the form that is recognized in the state where you live. Forms for every state and in multiple languages are available here: <https://prepareforyourcare.org/prepare/7-intro-home> and here: <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.
- Always give your healthcare providers the most recent copy of your advance directive.

- 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.





HOW DO YOU START THE CONVERSATION?



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

step 4:

TALK ABOUT YOUR WISHES AHEAD OF TIME

- 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.
- **Conversation starters:** "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 better about my future healthcare."
- Consider creating a video of your healthcare wishes for your family members

5 WHEN SHOULD YOU DISCUSS A MEDICAL ORDER FORM WITH YOUR KIDNEY CARE TEAM?



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

step 5:

WHEN WOULD A MEDICAL ORDER FORM BE RIGHT FOR YOU?

- 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.
- It helps individuals with serious illness or frailty to communicate their treatment decisions.
- The POLST form may be especially helpful if you may be at risk for unexpected hospitalization or transfer to a different care setting.
- POLST is known by different names in different states; for the list of names, see <https://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. In addition, you can video record your wishes for loved ones
- ✓ 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 were 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:



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.

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<http://go.gwu.edu/commstrategiesduringpandemic>

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