

Making My Wishes Known

Looking ahead can be overwhelming and scary, but it helps to take control of your care by telling your care team and your family about your wishes and the type of care you want as your disease progresses. This will also make it easier for them to make decisions for you if you become too sick to make them yourself.

All of these decisions are called “**advance care planning**,” which is simply planning for your care before you need it. When making plans, it is helpful to have an understanding of the progression of your illness, anticipated outcomes, and treatment options, which include not doing dialysis. Talk with your doctor to make sure you understand and decide on the right care for you. Your care team is ready to work with you to put some of these decisions in writing as an Advance Directive (living will or power of attorney for healthcare decisions) so you can have peace of mind about your future. You can always change any of your decisions later; they are not set in stone.

Advance Directives

Living Wills

A living will tells your doctor or healthcare provider in writing what type of medical care you want or do not want if you should become unable to make these decisions for yourself.

With a living will, you may be able to:

- Accept all treatments recommended by the health care provider;
- Accept some treatments and refuse others; or
- Refuse all recommended treatments. These treatments may include:
 - Cardiopulmonary resuscitation (CPR) to attempt to revive a heart that has stopped beating
 - Tube feedings, including giving food, water or both through a tube into a vein or the stomach
 - Artificial respiration, which is a machine (ventilator or respirator) that breathes for a person through a tube in the throat
 - Antibiotics to fight infection

- Dialysis for kidney failure, either hemodialysis or peritoneal
- Surgery such as heart bypass, gall bladder removal, etc.
- Blood transfusions or blood products

You can choose to receive pain medicine for comfort even if you refuse other treatments.

You may also want to include any situations in which you would want dialysis to be stopped.

These situations could include, if you:

- Do not know or understand what is happening around you
- Have to totally depend on others in your daily living activities



Power of Attorney (POA) for Healthcare Decisions

A power of attorney for healthcare decisions is a document that appoints someone else to make decisions regarding your medical care. Another name for this document is called “durable power of attorney for health care.” You choose a person to make your healthcare decisions for you if/when you become too sick to make them yourself.

- The person you have chosen is called your agent or proxy and acts with your best interest in mind.
- You should choose a person you can trust and who knows your values, beliefs, and wishes.
- Your agent should be able to share your wishes with your doctors and other health care providers.

Why Should I do Advance Planning and have Advance Directives?

Many people with kidney disease say they feel better knowing that they talked with their family, doctor(s), or social worker about their wishes for the future. They say that they:

- Have peace of mind knowing their wishes will be respected
- Feel a sense of control over their future
- Know they have made sure that they will be taken care of with dignity, through pain relief and other chosen treatment
- Feel they will be less of a burden to their family, who will not have to make difficult decisions on their behalf

Other Important Points

- It is your right to have an advance directive but you are not required by law to have one.
- You do not need to see a lawyer to make an advance directive.
- Be sure to tell your family, friends, doctor, or care team about your advance directive. Give your clinic, primary care doctor, and hospital a copy for your medical record.

- If you change your advance directive, you need to tell everyone you have given copies to and give them the new one. If you cancel it, you need to get back all of the copies.
- If you are religious, you may wish to speak with your family and your religious advisor to understand your religion’s views in regard to advance directives.
- An advance directive goes into effect only if and when you are not able to communicate and make your own healthcare decisions.
- Having an advance directive does not affect the quality of your care.
- Having an advance directive does not affect life or health insurance.

Ask Your Care Team:

- Who can I talk with about advance care planning?
- Where can I get a POA form?
- Who should I trust to be my POA?

For more information or to file a grievance, please contact:

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