

Advance Directives

for People Living with Kidney Disease



Planning for your medical future can help you stay in control of your health journey, including at the end of life. This guide will review steps that people living with kidney disease can take to make sure that their wishes are followed.

ADVANCE DIRECTIVE VS. HEALTH CARE PROXY: What's the difference?



An **advance directive** is a legal document that states your wishes for your medical care. It is used to make sure your wishes are carried out if you are not able to make or communicate your own choices.



A **health care proxy** is a legal document that allows you to choose another person to make medical decisions for you if you cannot do so yourself. This person is called a **health care agent** and will make sure that your wishes are followed. They will make all medical decisions for you only while you cannot make those choices. Usually, this person is a loved one, a partner, or a close friend. Once you choose someone for this job, make sure to talk to them about your wishes for your medical care in case they need to make a decision for you.

WHAT TOPICS ARE INCLUDED in an advance directive?

There are many types of situations that are discussed in an advance directive. Some important topics include code status, life support options, comfort care, and organ and tissue donation.

CODE STATUS

Your code status states the types of procedures (if any) that you would like your medical team to perform if your heart stops or if you can't breathe on your own. In emergencies, medical teams perform resuscitation procedures right away. Since there is no way to know when an emergency will occur, it is best to make your wishes known ahead of time.

Resuscitation procedures include cardiopulmonary resuscitation (CPR), actions to restart your heart pumping, and/or placing you on a breathing machine known as a mechanical ventilator.

CODE STATUS OPTIONS

These are typically listed in an advance directive so your wishes are clear to others.

Full Code

Full code status means that in an emergency, your medical team will do everything they can to help restart your heart and breathing.

Limited Code

Limited code status means you are okay with some procedures but would like to avoid others.

Do Not Resuscitate (DNR)

DNR status means that you would prefer to die naturally if your heart stops or if you can't breathe on your own. Patients with a DNR code status can still have other treatments such as surgery, chemotherapy, and dialysis.

CPR saves lives in many situations. However, it is important to know the risks if you choose to allow CPR to be performed. Some people with serious health problems may not survive even if they get CPR. CPR is forceful and may cause pain. Often, the brain goes without oxygen for a period of time, which lowers the chance of a full recovery.

TIME LIMITS

If a person cannot breathe or keep their heart pumping on their own, they may need to be placed on life support. It is possible to make a full recovery after being on life support. However, if a person is on long-term life support, their chance of a full recovery goes down over time. Some people set a life support time limit in their advance directive. This means that they would like to remain on life support for a set amount of time (a few days or weeks).

When writing your advance directive, decide your code status. You may also choose to set a time limit for certain treatments. Ask your doctor for help if you are not sure how to make these choices.



LIFE-SUSTAINING TREATMENTS

Life-sustaining treatments (or life support) refers to treatments that may be permanent and are needed to keep a person alive. Stopping treatment would cause a person to die naturally. Life support may involve a feeding tube, a breathing machine (mechanical ventilators), a machine to clean the blood (dialysis), or a tube in a vein to provide fluid, medicine, or blood. Talk to your doctor to learn more about these treatments and help choose what is right for you.

DIALYSIS

It is important for people with chronic kidney disease (CKD) to decide if they would like to go on dialysis if their kidney function worsens. Most people need dialysis when kidney function falls to 5% – 10% of normal function. People with CKD may include their wishes about dialysis care in their advance directive. Most people with CKD who start dialysis must continue treatments for the rest of their life, although there are some cases in which dialysis might be temporary.



For people with kidney failure who want to extend their life, dialysis is usually a good option.

Some people who are older or very sick may be focused on quality of life rather than length of life. In these cases, dialysis may not be the right choice, as dialysis is a large time commitment and involves a fair amount of medical support and potentially complicated treatments.

For people whose life expectancy is short, starting dialysis might cause suffering without many benefits. This means that dialysis is not likely to extend or improve the person's life and might not be the right choice for them.

If a person is more focused on quality of life rather than length of life, they may opt for conservative management of kidney failure. This means they will have other medical treatments but will not start dialysis. This will likely limit the length of their life, but may help protect their quality of life.

When writing your advance directive, include whether you would like to start dialysis, and decide whether chronic (permanent) or acute (short-term) dialysis would be acceptable.



COMFORT CARE

Comfort care or palliative care means your treatments will focus on comfort such as relieving pain, nausea, or other symptoms. This is generally reserved for people who are severely ill and cannot benefit from treatments, people whose life expectancy is short (usually less than six months), or people who want to reduce pain and suffering. If a person chooses comfort care and states in their advance directive that they do not want to have resuscitation procedures, CPR will not be performed if their heart or breathing stops.

ORGAN AND TISSUE DONATION

You can also state if you want to donate your organs and tissues when you pass away. Organ and tissue donors can save up to eight lives and improve over 75 more.



Can an advance directive BE CHANGED?

You can change or cancel your advance directive at any time. You should tell your updated wishes to your family, your doctor, and your health care agent, and create updated documents. Give copies of these documents to your doctor, your health care agent, your family members, your lawyer, and anyone else who may need them. You can keep copies in a safe, but be sure to have copies in an easy-to-access place where others can find them. When you are sick, your family or friends need to easily find your documents, so avoid hiding them or keeping them in a safe deposit box.

HOW DO I COMPLETE an advance directive?

Each state has its own requirements for how to fill out an advance directive. If you spend a lot of time in another state, you should complete the advance directives for that state as well. To download and complete the advance directive for your state, visit <https://www.caringinfo.org/planning/advance-directives/by-state/>.

If you have questions about advance directives or want to learn more, talk to your Healthmap Solutions Care Navigation team member or call Healthmap at 1-800-481-0474.



1-800-481-0474 | patients.healthmapsolutions.com