



# Living the Life You Want

Options for Treating **Stages 4 & 5** Chronic Kidney Disease



Developed by the Medical Education Institute

# ABOUT THE MEDICAL EDUCATION INSTITUTE, INC.

The non-profit Medical Education Institute (MEI), founded in 1992, serves the mission of helping people with chronic disease learn to manage and improve their health.

MEI programs include **Kidney School** ([www.KidneySchool.org](http://www.KidneySchool.org)), **Home Dialysis Central** ([www.HomeDialysis.org](http://www.HomeDialysis.org)), and **Life Options** ([www.LifeOptions.org](http://www.LifeOptions.org)).

MEI has also developed the *My Life, My Dialysis Choice* treatment decision aid ([www.MyDialysisChoice.org](http://www.MyDialysisChoice.org)) and *Help, I Need Dialysis!*—the “lifestyle bible” on how to have a good future with kidney disease. To donate or to learn more, please visit [www.meiresearch.org](http://www.meiresearch.org).

## Disclaimer

*Living the Life You Want* is a guide for people who have chronic kidney disease or kidney failure. Use of this booklet does not replace the need to talk with your own doctor and healthcare team about your care and your options.

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*"It was 1970 and I was 22. Our doctor didn't know what was wrong, but my mother knew of a specialist. He sent me for an X-ray, and then told me I had cysts in my kidneys and would die before I was 40. (Dialysis was too rare and costly for most at the time, and transplant was just at the point of being tested.) But, he said I should live my life normally—because any of us could go out and be hit by a bus! I held on to that "bus theory" and did just what he said. I'm over 65 now, so as they say, the rest is history!"*

**Kate R.**

*"I had so many emotions when I was told I was in stage 4 CKD. I had always lived a healthy lifestyle, never abused my body, etc. I was angry and scared. I didn't know what kidney disease would mean. I went home and cried for days. Then I started researching my disease, changed my diet, and got on with my life, including working."*

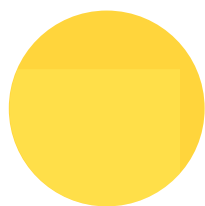
**Terry S.**

*"My GFR has been at the same 22% for 2 years now, but I've had more symptoms in the last 6 months. I get tired more and sometimes a bit "foggy brained." My biggest symptom is swelling, especially on days I forget my blood pressure meds or take them late in the day."*

**Casey G.**

*"I was born with kidney problems. The doctors told my Mom and Dad I would not live to be 5 years old. For some reason I am still here on this earth, so I guess the good Lord has a plan for me yet, whatever it might be. Come June, I will be 64."*

**Matt R.**



## Your Kidneys Are Failing? Don't Panic!

It is *very* normal to be awash in strong feelings when you learn your kidneys are not working well and may fail. Finding out that you have stage 4 or 5 chronic kidney disease (CKD) can be scary. You may not want to think about CKD at all, and hope it will go away on its own. You may blame yourself for things you did or didn't do. You may be angry—at yourself, at your doctor, at God. *CKD is not a punishment.* It may help you to talk with a counselor or pastor.

It is also normal to grieve for the life you thought you would have. Or, you may feel fine, and think that your kidneys must be okay after all, and the doctor was wrong. (Blood and urine tests can show kidney damage long before you may feel any different.)

Here are two things you may not know:

- 1) You may be still able to slow your CKD.**
- 2) You *can* have a good life even if your kidneys fail.**

People whose kidneys fail have friends and pets and hobbies. They travel by jet, car, boat, train, camper—or on a raft down a river. They can keep their jobs and lifestyles and their partners. None of this happens by accident, though. To live well with kidney disease and after kidney failure, you need to:

- **Keep a positive attitude—focus on what is good in your life**
- **Learn all you can—become your own expert**
- **Find people who can support you—in person or online**
- **Take action—be an active partner in your own health**

What you learn here can help you protect the kidney function you have left. You can also learn how to prepare for the road ahead—and choose a treatment that will let you live the life you want.

## Depression Can Be Helped!

Some people faced with CKD become depressed. If this occurs, it can be hard to see the light at the end of the tunnel. When you feel as if what you do won't matter, it can be hard to follow a treatment plan to take care of your health.

Depression is two or more weeks of feeling sad or empty. It can cause you to sleep or eat more or less than usual. Depression can make you feel moody, restless—or worthless. If you are depressed, you may not enjoy things that you like to do.

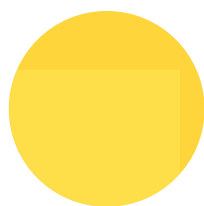
You may find it hard to think clearly. You may even feel like harming yourself or ending your life.

There are a number of ways to help ease depression so you can feel hopeful again:

- **Talk with your healthcare team**—medicines and counseling can help.
- **Exercise** can help mild to moderate depression and give you more energy.

- **Spend time outdoors in nature**, or grow an indoor plant.
- **Care for a pet**—it can make a big difference in how you feel.
- **Volunteer**—Helping others helps you to focus outside of yourself.

Please get help if you feel depressed. Depression does not go away on its own—but it *can* go away, and you can feel better.



## About Your Kidneys

**H**aving a chronic disease can make it feel as if your life has spun out of control. But, knowledge really *is* power. The things we worry about when we don't know what to expect can be far worse than what may really happen. Learning about your kidneys is a way to feel more in control of your life and health again. In this section, we will cover:

- **What kidneys do**
- **Stages of CKD and symptoms**
- **Medicines you may take**
- **Steps you can take to protect your kidney function**
- **Common blood and urine tests, and what they mean**

### What Kidneys Do

The main job of kidneys is to help keep your body chemistry in balance all the time. To do this, kidneys:

- **MAKE URINE** to get rid of wastes and extra water. Wastes come from some foods, breaking down medicines, and even just moving your muscles.
- **BALANCE MINERALS.** Your muscles, blood vessels, nerves, and bones need precise amounts of minerals in your blood all the time. Kidneys sense the levels of minerals in your blood. They hold onto what you need and send the rest to your bladder, as urine.

■ **CONTROL YOUR BLOOD PRESSURE.** Kidneys keep water and salt(s) in balance in your blood. And, they make an enzyme (*renin*) that helps your blood vessels tense up to raise your blood pressure if it drops too low. High blood pressure can harm kidneys and cause CKD. Or, CKD can cause high blood pressure. Like the chicken and the egg, it can be hard to tell which came first.

■ **HELP YOU MAKE RED BLOOD CELLS.** Each cell in your body needs oxygen to live, and red blood cells bring it. If you have too few red blood cells (anemia), your kidneys send out a hormone (*erythropoietin*, or EPO). EPO tells your bone marrow to make more red blood cells. Kidneys that don't work well make less EPO.

■ **KEEP YOUR BONES STRONG.** You need the right level of calcium in your blood all the time to live. Your bones are a "storage bank" for calcium and phosphorus. When you need more blood calcium, the kidneys send out a hormone. Active vitamin D is a hormone that lets your gut absorb calcium from foods. If the hormone signal does not work, your body will pull calcium out of your bones, which can make them weak and more likely to break.

■ **HELP KEEP ACID AND BASE BALANCE IN YOUR BODY.** The pH in your body is close to neutral, but may be a little alkaline, or base (7.38 to 7.42). A pH that is too high or too low can be fatal. Kidneys work with your lungs to keep the right pH level.

## CKD Causes, Stages, and Symptoms

CKD is a slow loss of function over many years (though you may have just felt more tired—or felt the same as always). Each kidney has about a million filters (nephrons) that stop working.

## CAUSES OF CKD

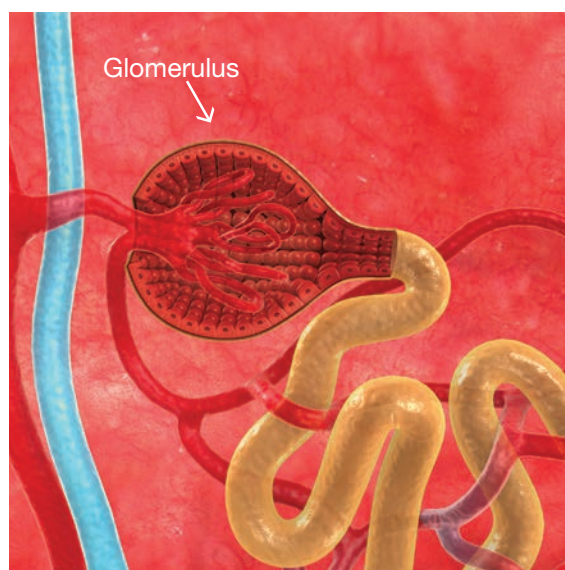
Type 2 diabetes and high blood pressure are the top two causes of CKD. There are other causes, too, like birth defects or diseases that:

- Cause kidney cysts to form, like polycystic kidney disease
- Attack the filters, like focal segmental glomerulonephritis
- Affect the whole body, like lupus, cancer, or HIV/AIDS

## STAGES OF CKD

CKD has five stages, based on how much kidney function you have. Your stage of CKD is based on your estimated glomerular filtration rate (eGFR, or percent kidney function):

- Estimated means a formula is used, with your age, sex, race, and a blood test. The blood test is for creatinine, a waste that healthy kidneys remove.
- Glomerular is the sum of all of the filters (*nephrons*) in the kidneys. A glomerulus is a ball of tiny blood vessels in each nephron that does the filtering.
- Filtration rate means how many milliliters of blood are cleaned each minute.



A Nephron



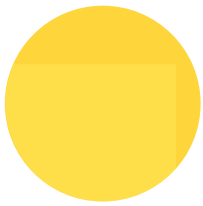
Your eGFR is about the same as your percent kidney function. So, normal kidneys work at about 100%. If your eGFR is 32, you have about 32% function. Here are the stages:<sup>1</sup>

CKD STAGE	GFR	WHAT IT MEANS
1	<b>90+</b>	Kidney function is normal. But, there is something wrong with the structure, or a known disease.
2	<b>60–89</b>	Mild drop in kidney function. There may be something wrong with structure, or a known disease.
3A	<b>45–59</b>	Moderate kidney damage.
3B	<b>30–44</b>	
4	<b>15–29</b>	Severe kidney damage.
5	<b>&lt;15</b>	Very severe kidney damage.



You may have known for years about your CKD. Or, you may not have been aware that your kidneys were in trouble. Early CKD may not have symptoms you would notice. Most people don't learn that they have CKD until stage 3, or later. Even if you did have symptoms, you might not have thought, "It must be my kidneys." Use the chart below to track your symptoms, and bring it to your next doctor visit. Your symptoms can be treated, and you can feel better.

SYMPTOMS OF CKD	RARELY	OFTEN	ALWAYS
I feel tired all the time	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel cold even when others around me are warm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel short of breath after very little effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel faint, dizzy, or weak	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel very itchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My hands or feet are swollen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My face is swollen or puffy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Food tastes like metal and I don't want to eat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel sick to my stomach a lot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can't think clearly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People tell me my breath smells like ammonia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have to get up at night to make urine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My urine is foamy or bubbly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My urine is brown, red, or purple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel pressure when I need to make urine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



# Get the Most from Your Doctor Visits

**D**octors are vital to your healthcare, but they are busy and not always easy to talk to. You can get the most out of your doctor visits if you:

- **WRITE DOWN YOUR QUESTIONS.**

List the most important ones first, in case you can't get to them all. Tell the doctor that you have questions, so he or she knows to save time. If you have a lot of questions, ask for a longer visit when you set up the appointment. Take notes to help remind you of what was said. Some clinics may give you a summary as you leave, which is useful.

- **KEEP YOUR OWN HEALTH**

**NOTEBOOK.** Make a note of any symptoms you have, when they started, and what makes them better or worse. Keep records of your lab test results so you can see how you're doing (some people track their results on a computer). Bring your notes to doctor visits in case the doctor has questions.

- **EXPLAIN WHAT YOU KNOW (BRIEFLY).**

The doctor does not have to start at the beginning if you have been doing your homework and learning about your CKD. You will both get more out of the visit if you can start on the same page.

- **TELL THE DOCTOR WHAT YOU CARE ABOUT MOST.**

Don't assume that he or she knows that you need to keep your job, or you have lost your appetite.

- **ASK IF SOMETHING DOES NOT MAKE SENSE TO YOU.**

Doctors may use medical terms that you don't know. It's okay to say, "would you mind saying that again in plain English?" Ask how terms are spelled so you can look them up later.

- **BRING SOMEONE WITH YOU.**

It can help a lot to have an extra pair of ears. You may stop listening if the doctor says something that scares you, and miss something that you need to know.





## Know Your Medicines

**W**ith CKD, your kidneys may slowly stop doing some of their jobs. The good news is, there are medicines that can pick up where your kidneys leave off.

Any drug can have side effects. Know your body and how you feel any time you start taking a new medicine. Tell your care team if you have any problems. These may go away in time. Or, the doctor may be able to prescribe a drug to help relieve a side effect.

### Anemia Medicines

Anemia is a shortage of red blood cells that is common in CKD. It can make you feel weak, worn out, cold all the time, and mentally fuzzy. In men, anemia can make erectile dysfunction worse. Getting treatment for anemia can mean the difference between being able to

keep a job and go on with your life—or not. A hemoglobin blood test is used to find and treat anemia. There are two main treatments:

- **IRON.** Iron is a key building block for red blood cells. You may take iron as pills, an elixir, or in a vein. Cooking in cast iron pans can help boost your blood iron levels, too. And, some foods, like liver, are high in iron.
- **ESAs.** *Erythrocyte (red blood cell) stimulating agents* are man-made hormones that tell your body to make more red blood cells. ESAs are given by injection. At high doses, ESAs have been linked with heart attacks, strokes, and blood clots. But, not treating anemia has risks for you, too. Talk with your doctor about the right dose of ESA for you.



## Bone Disease Medicines

Healthy kidneys keep calcium and phosphorus (phosphate) in balance to keep your bones healthy. This balance starts to fail as the kidneys lose function. Four parathyroid glands in your neck check the level of calcium in your blood. If your level drops, the glands send out parathyroid hormone (PTH). PTH tells your bones to add calcium into your blood. In time, this loss of calcium can make bones weak and frail. Three treatments can help keep your bones healthy with CKD:

- **PHOSPHATE BINDERS.** When you have too much phosphate in your blood, it can bind with extra calcium to form shards that can harm your blood vessels and tissues. Binders attract excess phosphate in your gut, like a magnet attracts iron. They “bind” the phosphate, which is then removed in your stool.

- **ACTIVE VITAMIN D.** Kidneys make active vitamin D, or calcitriol—a hormone that lets your gut absorb calcium. You may get active vitamin D as pills or injections. The drug will help to keep your bones healthy.
- **CINACALCET.** This pill acts on the parathyroid glands to help shut them off so they don’t make too much PTH. Keeping the right amount of PTH in your blood will help you keep calcium in your bones, where it belongs.

## Cholesterol Medicines

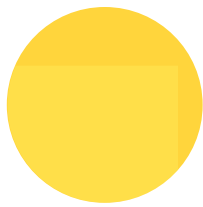
Statins, or drugs to lower high cholesterol, may be prescribed to help protect your heart. If you take these, ask your doctor if you should also take the supplement Coenzyme Q10 (CoQ10). Statins use up CoQ10, which can lead to heart failure in people who take them. Taking CoQ10 with statins can help protect the heart from this type of damage.<sup>2,3</sup>

## Common Blood Pressure Medicines

It is common to have high blood pressure with CKD, even if it was never high before. Your doctor can prescribe many types of blood pressure medicines. Here are some of the most common ones.

TYPE OF MEDICINE	WHAT IT DOES FOR YOU	SOME COMMON GENERIC NAMES
<b>ACE-inhibitors</b>	May help protect kidneys and slow CKD, especially when there is protein in the urine.	Captopril Lisinopril Ramipril
<b>Angiotensin Receptor Blockers (ARBs)</b>	May help protect kidneys and slow CKD, especially when there is protein in the urine.	Irbesartan Losartan Valsartan
<b>Beta blockers</b>	Slows your heart rate and opens your blood vessels to lower your blood pressure.	Atenolol Metoprolol Propranolol
<b>Diuretics</b> ("Water pills")	Helps reduce swelling and eases your breathing. Removes extra water and salt by pushing your kidneys (while they work) to make more urine.	Acetazolamide Chlorthalidone Furosemide Hydrochlorothiazide





# Slowing CKD: There May Still Be Time

**H**aving your kidneys work—even a little—can help you feel better and live longer.<sup>4</sup> If you can slow your CKD, you can delay the need for treatment of kidney failure. The types of changes you might make to help your heart or the rest of your body will help your kidneys, too. Here are some things you can do—or avoid—to protect your kidneys:

- **KEEP YOUR BLOOD SUGAR IN THE TARGET RANGE.**<sup>5</sup>

High blood sugar harms blood vessels, including the nephrons in the kidneys. If you have diabetes, your doctor will give you a target for fasting blood sugar and for 2 hours after you eat. Test your blood sugar often to see how it changes based on what you eat and how active you are. Cut back on added sugars and refined carbs, like bread, cakes, and rice, if you have not done this yet. Take walks or find other ways to be active. Take your diabetes medicine(s) as prescribed.

- **KEEP YOUR BLOOD PRESSURE IN THE TARGET RANGE YOUR DOCTOR GIVES YOU, TOO.**<sup>6</sup>

Even if your blood pressure was low your whole life, it may be high now—and, it may be hard to control. It is normal in CKD to need more than one blood pressure medicine. Check your blood pressure at home. Keep a log of the results so you can tell your care team when it is high or low and what time(s) you take your blood pressure pills. Talk with your doctor if you have side effects; a different medicine might work better for you. Exercise can help lower blood pressure, too.

- **LOSE WEIGHT IF YOU ARE OVERWEIGHT.**

The 10-year CARDIA study of young people (average age of 35) found that the more people weighed, the faster their kidney function fell.<sup>7</sup> This was true even if they did not have diabetes or high blood

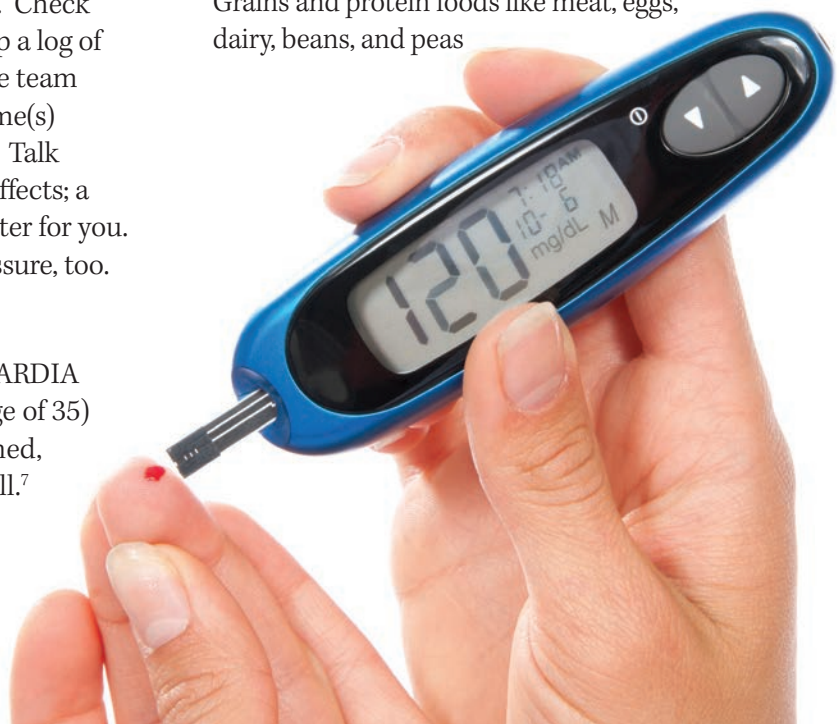
pressure. It's hard to lose weight, but it can be done, and there are many ways that can work. Ask for help from your care team if you need it.

- **DON'T DRINK SODA.** A large study has linked drinking one or more regular sodas a day to kidney damage.<sup>8</sup> A second large study found that two or more diet sodas a day can lead to kidney damage or make it progress faster.<sup>9</sup>

- **IF YOU SMOKE OR USE STREET DRUGS, TRY TO QUIT!** Smoking and most street drugs can harm the kidneys. Of course, if quitting was easy, everyone would do it. There are a number of ways to quit smoking—from going cold turkey to patches, nicotine gum, or e-cigarettes. Even cutting back may help. If you use street drugs, you may need a rehab program. Talk to your care team if you need help to quit a habit that is harming your health.

- **BALANCE YOUR BLOOD pH.**

A healthy blood pH is between 7.38 and 7.42. When the kidneys don't work well, they can fail to keep the acid-base balance in your body. Acid can build up from protein foods you eat. Grains and protein foods like meat, eggs, dairy, beans, and peas



form acid wastes when they break down. Your body needs protein for muscles and self-repair. But, most of us eat a lot more protein than we need. A low acid diet (with lots of veggies) is one way to help kidneys last longer, at least if you are older.<sup>10</sup> Ask your doctor if sodium bicarbonate can help protect your kidneys, too. In tablet form it is very low cost and works.<sup>11</sup>

■ **EAT LESS PROTEIN.** When protein breaks down, it forms blood urea nitrogen (BUN). Removing BUN is hard on the kidneys. When you eat less protein, you make less BUN, which can help your kidneys last a bit longer. Research has found that eating very little protein can help even more, but this is hard to do<sup>12</sup>—and there is a risk of malnutrition.

■ **EAT LESS PHOSPHORUS.** Phosphorus is found in meat, poultry, fish, dairy, nuts, beans, and cola drinks (see page 16). Weak kidneys can't remove as much phosphorus from your blood. When your levels are too high, your bones can become weak.

■ **LIMIT SHELLFISH.** Research has found that a toxin called *domoic acid* in shellfish and some fish that eat algae can harm kidneys—in mice.<sup>13</sup> People are not mice. But, the really troubling finding was that very tiny levels of the toxin could harm kidneys.

Shellfish also have high levels of purines, which can be a problem if you have gout. So, it may be wise to cut back on shellfish if you eat it a lot.

■ **SKIP CANNED FOODS.**

Most food cans in the U.S. are lined with bisphenol A (BPA).<sup>14</sup> BPA has been linked with high blood pressure, diabetes, and obesity. Many canned foods tend to be very high in salt or sugar and highly processed, too. Glass jars or shelf safe cartons don't have BPA.

■ **AVOID CERTAIN PAIN PILLS.**

“Non-steroidal anti-inflammatory drugs” (NSAIDs) like Advil®, Aleve®, and Motrin® can cause kidney damage.<sup>15</sup> Kidneys need a strong blood flow to work. NSAIDs reduce blood flow into and out of the kidneys. In most cases, it takes years of daily use for NSAIDs to cause CKD. But, once CKD is present, NSAIDs can make it get worse faster. Talk to your doctor about treatment options for pain that won't further harm your kidneys. If you take one tablet here and there and your kidneys still work, drink a full glass of water with it.

■ **NEED A CONTRAST DYE X-RAY? ASK FOR KIDNEY PRECAUTIONS.** Dye that is injected into a vein for an MRI or CT scan will pass through your kidneys. A dye called *gadolinium* can cause kidney damage. This

dye can also cause a rare problem called nephrogenic systemic fibrosis (NSF).<sup>16</sup> NSF can make the skin and organs thicken, and can be fatal. There is no treatment for NSF. If a doctor orders an X-ray dye test, ask if there are other ways to learn the same things. Would an ultrasound work, instead? If you must have contrast, be sure to tell the radiologist about your CKD. He or she may be able to dilute the dye or give you an IV with sodium bicarbonate to wash it out of your blood.

■ **ANTIOXIDANTS MAY HELP YOU.**

Every cell in your body needs oxygen. But, too much oxygen in the wrong places can “oxidize” and cause damage, a lot like rust. Antioxidants help protect your cells, and may help your kidneys. Ask your doctor if antioxidants like these might be worth taking:

- Coenzyme Q10
- Turmeric

Fish oil can help slow CKD that is caused by a disease called IgA nephropathy.<sup>17</sup>

**NOTE: Talk to your care team before you take any supplement, vitamin, or over the counter remedy. When your kidneys don't work well, these can build up in your body to levels that could harm you.**



## The Phosphorus Pyramid

Many foods have phosphorus. Aim to eat more of the foods at the base (green). These foods have less phosphorus. Try to eat less of the ones on top (red and orange). These have more phosphorus.

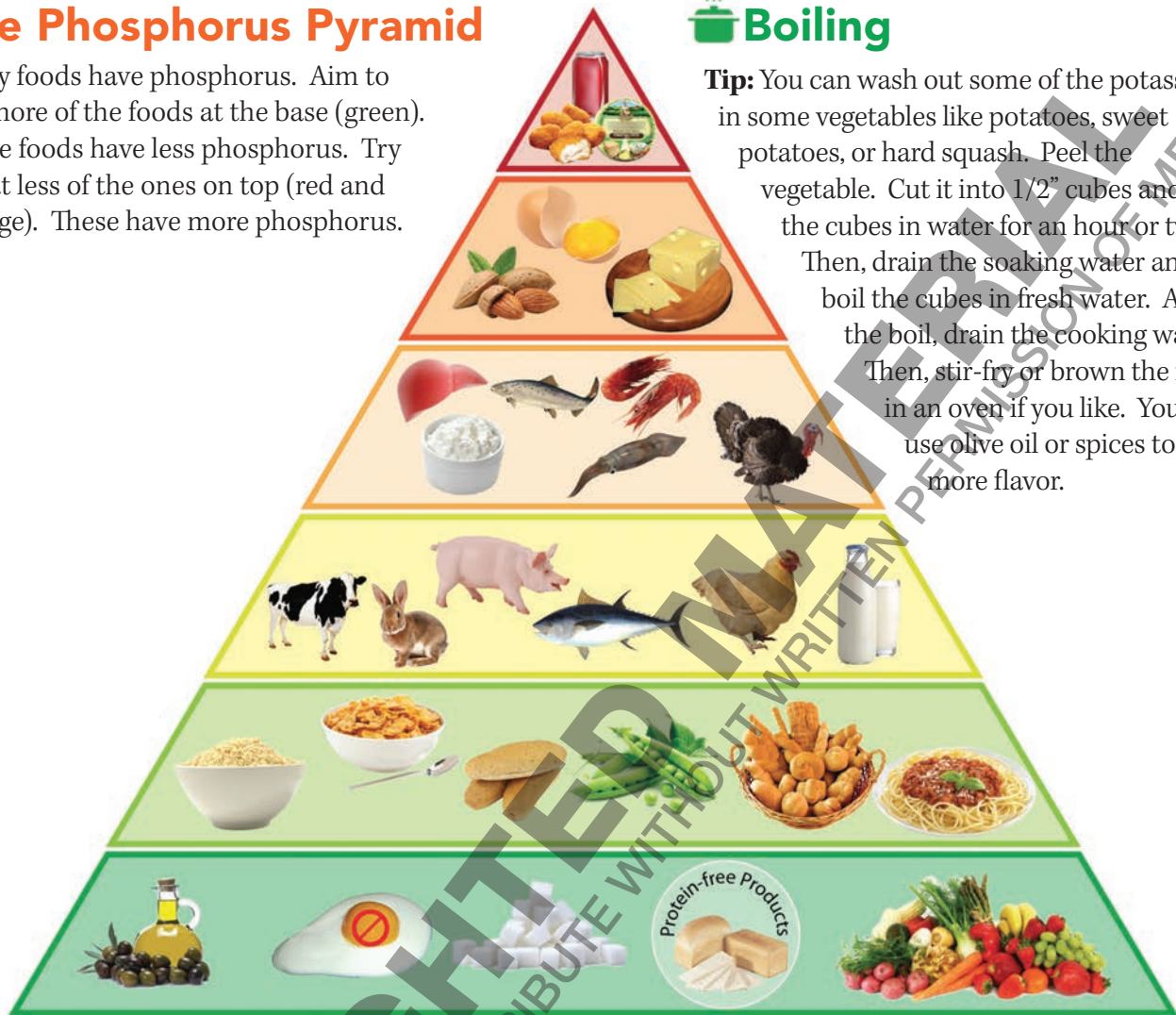


Figure adapted from D'Alessandro et al. BMC Nephrology 2015, 16:9 <http://www.biomedcentral.com/1471-2369/16/9>

## Boiling

**Tip:** You can wash out some of the potassium in some vegetables like potatoes, sweet potatoes, or hard squash. Peel the vegetable. Cut it into 1/2" cubes and soak the cubes in water for an hour or two. Then, drain the soaking water and boil the cubes in fresh water. After the boil, drain the cooking water. Then, stir-fry or brown the food in an oven if you like. You can use olive oil or spices to add more flavor.

**Beverages and foods with added phosphate:** soft drinks (cola), powdered milk, processed cheese or meat (i.e. chicken nuggets), dessert, instant cappuccino

**Nuts, egg yolk, and hard cheeses:** Parmesan, Swiss, cheddar, pecorino

**Meat:** sausages, organ meats (liver, brain). **Poultry:** turkey. **Fish:** shrimp, squid, salmon.  
**Soft cheeses:** cottage, cream, mozzarella

**Meat:** beef, pork, ham with no preservatives, veal. **Poultry:** chicken. **Fish:** trout, tuna fish, cod, sole  
**Milk, yogurt**

**Cereals:** bread, pasta, rice, cous cous, cornmeal, cornflakes. **Legumes:** peas, broad beans, beans, chickpeas, lentils, soy

**Sugar, protein-free products, egg white, fruits and vegetables, butter, olive oil, and vegetable fats** (i.e. margarine, corn oil, peanut oil)



## Beware of Added Phosphorus and Potassium!

Meat has a lot of phosphorus in it. But, some meats have added minerals to preserve them or try to boost their flavor. ***Your body absorbs much more of the added minerals than it does from real foods.*** Fresh meat does not have an ingredient label.

If your meat has a label, it has been processed. Look for the words ***phosphate*** and ***potassium***. They may be part of bigger words, like trisodium phosphate, pyrophosphate, or potassium lactate. These foods can harm you if your kidneys don't work well.



## So, What Should I Eat?

Foods that are good for your heart and the rest of your body are good for your kidneys, too, as long as they still work. Which foods are good for you? Real foods like vegetables, fruits, nuts, seeds, dairy foods, and fresh meats are best. But:

- **You may need to eat less dairy and meat if you are watching acid and protein levels.**
- **You may need to eat less dried fruit, mangos, avocados, bananas, oranges, potatoes, and tomatoes if your doctor gives you a potassium limit.**

Real foods are foods you cook at home, from scratch. Many people are not used to cooking fresh foods these days. If you need help, there are lots of cooking shows on TV or YouTube.com to show you how. (Put “How to cook \_\_\_\_\_” in the YouTube search bar to get quick tips.)

Real foods have few ingredients, and you know what each one is. Get in the habit of reading food labels. Look for foods that have no more than five or six ingredients. Processed foods tend to have a lot of salt (sodium), preservatives, artificial colors, and “trans” fats that raise your risk of heart disease. If a label says “hydrogenated” the food has trans fats. Genetically modified (GMO) grains are used in processed foods, too. These have been shown to cause organ damage in rats.<sup>18</sup> Organic foods do not have GMOs.

Real foods don't come from fast food restaurants. One fast food burger can have a whole day's worth of salt. Most fast foods are highly processed and many are deep-fried.

It can be hard to change how you eat. Baby steps can help. Make one change at a time and see how you feel, then add a second change.

## Get Moving!

CKD is a risk factor for heart disease and stroke. The same diseases that harm the kidneys also tend to damage the heart and blood vessels. The good news is, moving gets your blood pumping, which boosts blood flow to your kidneys—and helps your heart. So, for your body, exercise is a win-win. It may even help slow the rate of CKD.

**THE GOAL IS 30 MINUTES OF ACTIVE MOVING EACH DAY.** And, the 30 minutes don't have to be all at once. You can break your exercise into 10-minute blocks if you like.

Thinking of starting an exercise plan? If it's been a while since you've been active, talk with your doctor first. Start slow, and build up time, distance, or weight slowly. Track your progress so you can see how you're doing. You can even set goals and reward yourself when you reach them.

Exercise does not have to be a boring jog on a machine at a pricey gym. Here are some other options you might think about, and you can come up with more on your own:

- **WALKING IS GREAT EXERCISE,** and if you have a loved one as a partner, you get together time, too. If the weather is nice and you live in a safe place, you can enjoy an outdoor walk. Or, many people walk in malls or at indoor tracks so they don't miss out. A jog-walk (trading off jogging and walking) will give you a more intense workout.
- **TAKE UP A SPORT.** From bowling to tennis to badminton, if there is a team sport you like, you can spend time with others and boost your fitness at the same time.
- **DO SOME WORK.** Paint a fence or a wall. Get out in the garden and pull some weeds or trim the shrubs. Mow the lawn with a push mower. Vacuum a couple of rooms. You'll get something done, feel good about yourself, and be active.
- **DANCE, SKATE, PLAY!** Whether you jump on a trampoline, paddle a canoe, or take your partner out for a spin, moving is moving. Think about what you liked as a kid—it might give you some ideas of things to try.



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## Save Your Veins!

A key task that you need to do now to help yourself is to save your arm veins. You may not want to think about dialysis, but it could be in your future. Your lifeline for one type of treatment (hemodialysis) is a *vascular access*. This is a large vein made by a surgeon that is used to reach your blood to clean it. No lifeline—no treatment.

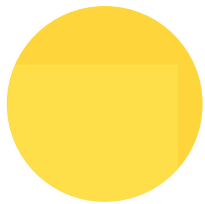
The best kind of access is an *arteriovenous fistula*. To make one, a surgeon links an artery to a vein under the skin of your arm. The next best kind of access is an *arteriovenous graft*. A graft links an

artery and a vein with a man-made vein. You only have about ten sites on your body where a fistula or a graft can be done.

**You can save your veins if you say NO to:**

- **Blood draws from your arm veins (use your hand)**
- **IV lines in your arms (use your hand)**
- **Blood pressure checks on your arms (use your leg—or if you must, use the arm that you DO write with)**

If you can, try to save the veins on both arms. In most cases, a surgeon will try to use the arm you don't write with first. So, at least be sure to save the veins in that arm. Some people wear a "Save the Veins" bracelet or put a sign above the bed if they are in the hospital. Tell the blood drawing staff that you need to save your veins for dialysis.



## Common Blood and Urine Tests

**T**esting your blood and urine can let you and your healthcare team see how your body is working. Tracking your test results over time can show you how your kidneys are doing. Some common tests that are done when you have CKD include:

- **CREATININE** (cree-AT-uh-noon). This waste forms each time you move a muscle. Large, muscular people make more; small, less fit people make less. Healthy kidneys filter creatinine out of the blood. So, rising levels show that there may be a kidney or muscle problem. Normal is 0.7 to 1.3 mg/dL for men and 0.6 to 1.1 mg/dL for women. This test is used to find out eGFR.
- **BUN** (blood urea nitrogen). BUN is a waste that forms when your body breaks down protein from food. Healthy kidneys filter BUN out of the blood. Rising levels show that there may be a kidney problem, or some other health issue. Normal is 6 to 20 mg/dL in both men and women.
- **URINE ALBUMIN** (protein). Protein is too large to fit through the pores of healthy nephrons. Rising levels in the urine can show a kidney problem. A normal level is from 0 to about 8 mg/dL.



■ **ALBUMIN TO CREATININE RATIO (UACR).** Urine protein divided by creatinine gives a good sense of how much protein may leak out of your kidneys in a day. This test is not changed by how much water is in your urine. A normal level is less than 30 mg per gram.

■ **URINE MICROALBUMIN TEST.** Do you have diabetes or high blood sugar? If so, testing for microscopic levels of protein in your urine may help guide your care. Less than 30 mg is normal. A level of 30 to 300 mg may mean early CKD. More than 300 mg may mean a later stage of CKD.

As you can see, there is a big job for you as someone with CKD:

- **You can ask questions of your healthcare team.**
- **You can track your lab test results.**
- **You are the only one who can pay attention to how you feel.**
- **You are the only one who can take your medicines, follow a meal plan, and report your symptoms.**

There is a lot you can do to try to slow your CKD and feel your best. The more you know, the better you can help yourself.

# Choosing a Treatment if Your Kidneys Fail

*“Why do I feel LUCKY to have kidney failure? My mom died from pancreatic cancer after 6 months of terrible suffering. She didn’t get any options to keep living. My only brother died of a massive heart attack on his way to work at age 52. He didn’t get any options to keep living. We have options.”*

Stephen B.

*“Dialysis and transplant are treatments—not cures. They let us extend our lives. Both offer a chance to live as normal and as productive a life as our attitudes allow.”*

Carol Z.

**Y**ou may have found out about your CKD too late to do much about it. Or, the disease that is attacking your kidneys may not respond to your best efforts to slow it down. At some point, you may need to choose a treatment for kidney failure.

It may help you to know that you do have options to live—and you can have a good life. If it turns out that you don’t like a choice that you make, you can change treatments at any time.

In this section, we will cover:

- **Making an active treatment choice**
- **Treatment options and why you might choose them**

## Make an Active Treatment Choice

You *can* live well with kidney failure—but not by accident. Your choice of a treatment can affect every aspect of your life. What and how much you can eat and drink, how well you may sleep, your energy level, job, travel, sex life—even how long you may live—can all change based on what you choose.

So, your treatment is never *just* medical. It’s about what your life will look like from one day to the next.

This means it is vital to ***think about what you want your life to look like.*** Learn your options. Choose based on your values and the things you want to be able to do. That’s the best way to live the life you want.

To help this choice, you may want to use the decision aid found at [www.MyDialysisChoice.org](http://www.MyDialysisChoice.org). You can rate each treatment option based on your chosen values.



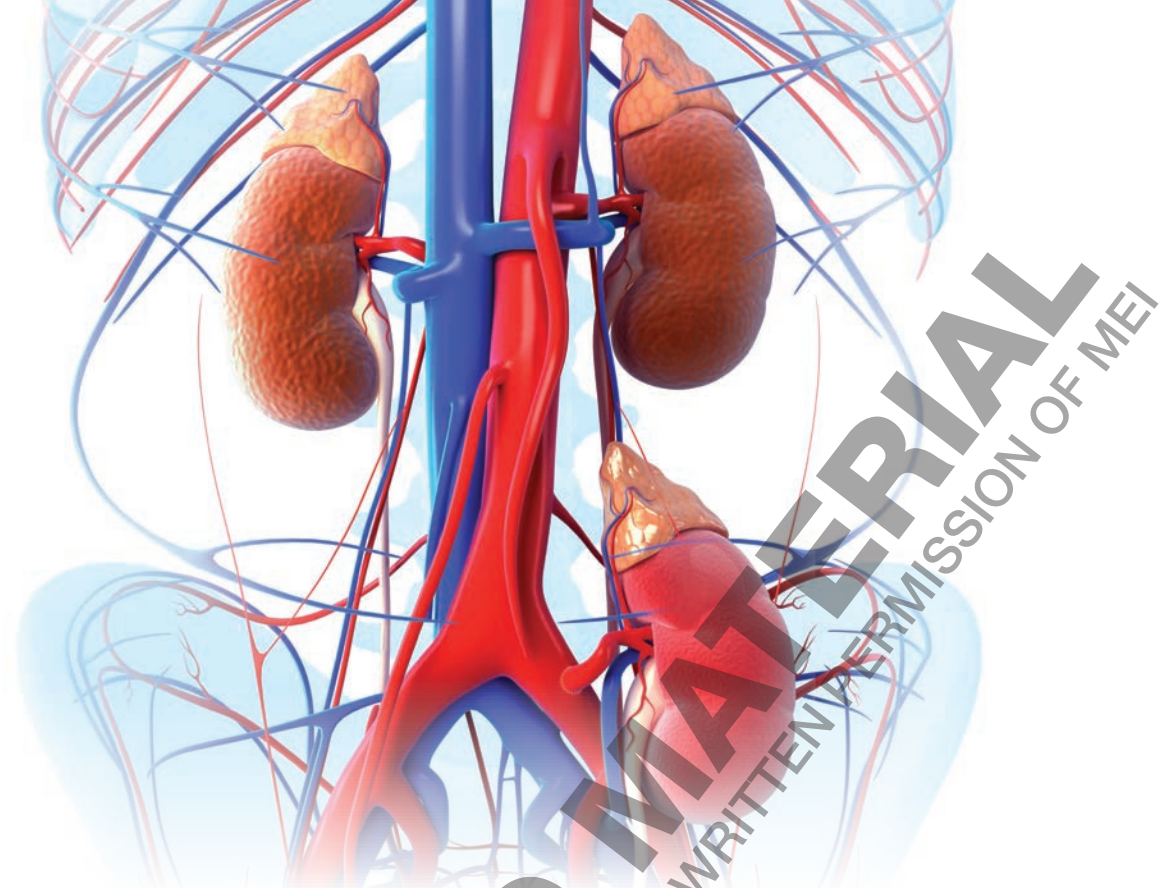
## Paying for Treatment for Kidney Failure

In 1972, Congress passed a law to help people whose kidneys failed pay for treatment. **This law lets you get Medicare—at any age—if your kidneys fail.** You *do* have to be a U.S. citizen. And, you need enough work quarters for Social Security. If you did not work enough, you need to be the spouse or child of someone who did. About 93% of those in the U.S. with kidney failure get help from the Medicare End-Stage Renal Disease (ESRD) program.

Medicare pays 80% of the costs of kidney transplant surgery (yours and a donor's) and dialysis at home or in a clinic. If you do a home treatment, you do NOT have to buy the machine. The clinic will lease it for

you. Most people have a health plan through work or a Medigap plan that will pay for all or most of the other 20%. Or, you may need to get a private policy through the Affordable Care Act. If you qualify, state Medicaid can help pay for treatment. The start date for Medicare depends on your choice of treatment. This can make a big difference for how much you will need to pay out of pocket.

Medicare covers transplant drugs for 3 years. After that, you would need a way to pay for them, unless you are disabled for a reason other than CKD. Some patient groups are trying to get Medicare to pay for these drugs for the life of a transplant.



## Kidney Transplant

*"For me, transplant was the answer and I've been blessed with so very few problems from my two transplants over the past 24 years that I wouldn't even bother listing them."*

John L.

*"I never left the hospital with my first transplant. A second one lasted 23 months. The 3rd never fully worked and I stayed on and off dialysis for a year until it quit. The last one never worked and was taken out because it caused fevers and pain. But, I am still here!"*

Elaine V.

**T**here are three main types of treatment if your kidneys fail, and some have more than one option. You have choices!

For a transplant, a surgeon will put a healthy kidney in your body. The new kidney will go in your belly, tucked into your pelvis. (In most cases, your own kidneys will stay in your body, too.) One new kidney will do most of the work of your two failed ones. You need to pass many medical tests to be approved for a transplant. These tests will see if your body can handle the stress of a long surgery. They will also make sure you are healthy enough to take drugs that will suppress your immune system so you don't reject the new kidney.

A transplant is not a cure—you will still have CKD. But, if a transplant works well, your lifestyle may be a lot like it is now:

- **You may feel well enough and have the energy to work**
- **Travel is easy, since you don't have to set up dialysis everywhere you go**
- **Your schedule will not have to change, except for doctor visits**
- **You can eat and drink without strict limits (a low salt, healthy diet is advised)**
- **You may sleep well at night**
- **Women who have had transplants can have healthy babies**

## Transplant Medicines

Your body can reject a new kidney at any time—even years down the road. While it may feel like the new kidney is now part of you, it is “foreign” to your body. The closer the match of a new kidney to your own blood and tissues, the fewer medicines you may need. Like any medicines, transplant drugs can cause side effects:

- **IN THE SHORT TERM**, some people have stomach upset, diarrhea, mood swings, or strange dreams. They may have weight gain, swollen gums, or a puffy “moon” face. Or, hair may grow where it is not wanted. These problems, if you have them, tend to get much better once your body gets used to the drugs or your doses are reduced after a few weeks.
- **IN THE LONG TERM**, transplant drugs suppress your immune system and raise the risks of cancer and diabetes. The cancer risk is mostly for skin cancer. Staying out of the sun and using sunscreen can help lower this risk. Each transplant center uses a different mix of drugs. Talk to your center about the drugs you would take and their side effects.

Most transplants work well for 5 to 11 years or so—and some last for decades. As the medicines get better, more kidneys may last longer. But, a few new kidney transplants never work at all. Others fail after weeks or months. There are no guarantees. If a transplant fails, you can still do dialysis, either for good or until you get another kidney. Some people have had as many as four transplants.

## Where Kidneys Come From

Kidneys for transplant come from two types of donors:

- **DECEASED DONORS.** Some kidneys come from people whose families donate their organs after brain death. It can be a great comfort when something good comes out of the tragic loss of a loved one. If you have type 1 diabetes you may be able to get a kidney and pancreas transplant (KP). Some centers will do KPs for people with type 2 diabetes who use insulin.<sup>19</sup> When this works, you do not need insulin or dialysis. And, when you need two organs, you may get a transplant faster. If both organs come from the same donor, you may need less medicine than if you had two donors.
- **LIVING DONORS.** A healthy living person can donate a kidney. Most living donors are relatives. But, neighbors, friends, and even strangers can donate. If someone is willing to donate, but is not a blood or tissue match for you, you may be able to trade donors. In a *paired donation*, your donor gives a kidney to someone else who needs one. Then his or her donor gives a kidney to you. All of the transplants are done on the same day so no one backs out. Some “chains” of paired kidney donation have helped dozens of people. Living donor kidneys tend to last longer than deceased donor kidneys.



## Things for you to think about with both kinds of donor:

### DECEASED DONOR

#### HOW TO GET ONE

The United Network for Organ Sharing (UNOS) runs the U.S. program that oversees who gets kidneys from deceased donors. You must go to a transplant center and have many tests done to be on the list. Getting on the list is not automatic. But, when you get on the list, you get credit for the time you wait.

#### HOW LONG IT TAKES

Once on the list, your wait may be just days or weeks, but most people wait years. Just over half of the people on the list for a kidney have waited at least 2 years.<sup>21</sup> The wait time depends on your blood type. You can be listed at more than one transplant center, as long as they are in different states and you can get there quickly if they call you.

#### RISKS

You may not know much about a deceased donor and his or her health history. A donor may have a virus you could catch, or a hidden cancer.

### LIVING DONOR

#### HOW TO GET ONE

You must go to a transplant center and have tests. You will need to tell people you know about your kidneys. When you do, one or more may offer to be tested. Or not. Not wanting to be tested may be due to fear of pain or surgery. Or, they may not be able to lose the month it takes to recover.<sup>20</sup> Someone can love you and not offer you a kidney.

#### HOW LONG IT TAKES

A living kidney transplant can go quite quickly after all of the tests are done. And, you can schedule the transplant at a time that works for you and your donor. If you don't have people who can or will donate, it can take time to find a donor. Some people have found success through Facebook, billboards, and other creative ways.

#### RISKS

Most donors do well. In the short term, all surgery has some risk. In the long-term, there are few studies. A 2013 study of donors from Norway followed for 15 years or more found a 30% higher risk of donor death 10+ years later.<sup>22</sup> (The risk was still quite small.) The study was of donors vs. healthy people—not just the general public. Donors also had 11 times more risk of kidney failure 10+ years later (still a small number).<sup>\*</sup> If you get a living donor kidney and it does not work or fails quickly, this can be heartbreaking for you both.

<sup>\*</sup>Of 1,901 donors, nine had kidney failure 10 to 24 years later. All were family members.





## What to Expect After a Transplant

Right after a transplant, you will be in intensive care. You may stay in the hospital for a week or two. It can take time for a new kidney to “wake up” and work. If the kidney works, you will not need dialysis. You may need biopsy tests to see how the kidney is doing. You will take the new medicines, and the dose may need to be changed based on your test results. You might need *plasmapheresis*. These treatments can clean antibodies out of your blood that could harm the new kidney.

Once you are home, you will need to go to the transplant center often for blood tests to check on your kidney. A healthy lifestyle can help you keep your new kidney working. It is vital not to smoke—those who smoke after a transplant are much more likely to have it fail. Eat a healthy, balanced diet, drink lots of fluids, and stay active. Wash your hands and use hand sanitizer to avoid catching colds and other infections. If you want to have a baby, your doctors may suggest waiting one year.

# Options for Dialysis

*“When my husband found out he was going on dialysis, I was petrified and he was numb. There are so many unknowns when you start out. All the new terms to learn, diet and fluids, what will it feel like. The only thing that seemed to help us was to start learning—read all the pamphlets from the doctor, ask questions, and hear how others dealt with the disease. It really will be OK. It will be different, but it will be OK.”*

Juanita L.

*“My husband just looks at it like a JOB. This made it so much easier to deal with. Positive thinking helps so much!”*

Monique S.

**T**he word “dialysis” may sound scary, but it doesn’t mean “die.” **Dialysis lets you live.** Until the 1960s, if your kidneys failed, you had no options to live. When chronic dialysis started in Seattle, there were too few machines. “Life and Death Committees” made up of citizens and clergy chose who would get the scarce, costly treatment and who would not.<sup>23</sup> Today, most U.S. citizens can get dialysis. And, most even get help from Medicare to pay for it. So, you may want to call it Lifealysis, as one young man who uses the treatment does.<sup>24</sup>

Dialysis can save your life – and change it. Be sure that you can keep doing the things you value most. Visit [www.MyDialysisChoice.org](http://www.MyDialysisChoice.org) and choose your values. You’ll learn how each kind of dialysis might affect you, and can rate each to learn which treatment fits you best!

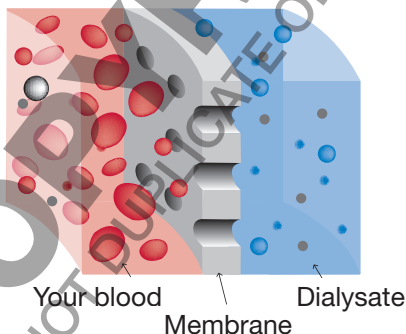




## How Dialysis Works

To do any kind of dialysis, you need three things:

1. **ACCESS TO THE BLOOD.** You need a way to reach the blood so it can be cleaned.
2. **A SEMI-PERMEABLE MEMBRANE.**



A *membrane* is a barrier. In dialysis, it is a thin layer of human or man-made tissue with microscopic pores. The pores let some things pass through the membrane (like water and wastes), but hold others back (like blood cells and protein).

3. **DIALYSATE.** A mix of purified water and minerals helps to pull wastes and water out of the blood. Dialysate may have some glucose (sugar) in it, too.

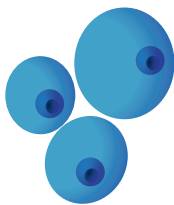
During a treatment, blood is on one side of the membrane—with water and wastes in it. Dialysate is on the other side of the membrane. Dialysis works by using chemical principles found in all of nature:

- **DIFFUSION.** Wastes will *diffuse* (pass through) pores in the membrane, because the level of wastes in the dialysate is less than the level in the blood. Diffusion will go on until the waste levels are the same on both sides.
- **OSMOSIS.** Water will pass through pores in the membrane, too. This will go on until the level of wastes is the same on both sides of the membrane.

**There are three “spaces” in your body that contain water and wastes:**

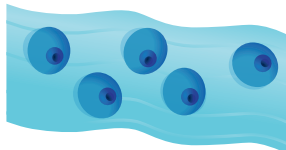
**1. INSIDE YOUR CELLS.**

Each cell is its own bubble, surrounded by a cell membrane. Water and wastes pass in and out through the membranes, which takes time.



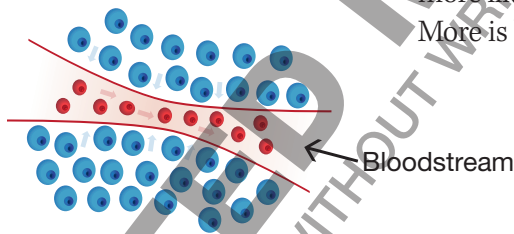
**2. BETWEEN YOUR CELLS.**

All of your cells float in a sort of “soup” made up of water, salts, and nutrients. Water and wastes pass slowly out of the cells and into this “soup.”



**3. IN YOUR BLOODSTREAM.**

Only about 10% of the water and wastes in your body are in your bloodstream at any given moment.



**Dialysis can only directly clean your blood.** This is a key point—because so little of the excess water and wastes in your body are in your blood. During a treatment, first your blood starts to get cleaner. Then, water and wastes start to move from between your cells into your blood. Last of all, water and wastes slowly shift out of your cells and into the spaces between them. Each of these steps takes time. **Wastes that stay in your body can cause long-term harm to your nerves, bones and joints, and tissues.** So, plan to get as much treatment as you can to feel more like you have healthy kidneys. More is better. It’s that simple.

## When Should Dialysis Start?

For many years in the U.S., doctors thought that dialysis should start at stage 5 CKD (an eGFR of 15). Now, a number of large studies have found that it does not help to start that soon.<sup>25, 26, 27</sup> In fact, starting early may even be harmful.<sup>28, 29, 30</sup> Numbers alone are not enough, but an eGFR of 6 to 9 may be the best “window.”<sup>31</sup> If you have symptoms that bother you a lot, you may want to start a bit sooner. Your eGFR can be a useful guide for when to get an access or transplant work up.

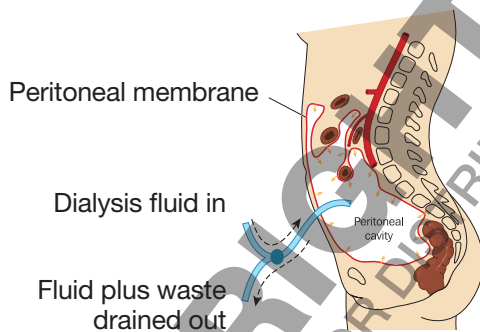


All dialysis is done with the help of a clinic, even if you learn how to do your treatments at home. There are two main types of dialysis:

## Peritoneal dialysis (PD)

The inner lining of your belly is used as a membrane to clean your blood. You fill your belly with sterile fluid using a tube placed by a surgeon. During a “dwell” (wait) time, wastes and water flow into the fluid, which you then drain out. This is called an exchange, and takes 20 minutes or so. There are two ways to do PD:

- **Automated PD (APD)** uses a cycler machine to do exchanges at night while you sleep. You may also need to do one exchange during the day, by hand.
- **Continuous ambulatory (walking around) PD (CAPD)** means that you do all of your exchanges by hand. Most people do one around breakfast, lunch, dinner, and bedtime.



### PD AND YOUR LIFESTYLE

- Most people who do PD use a cycler at night—so their days are free. Some people need a daytime exchange after a while when they have less kidney function left.
- There are no needles with PD, and the exchanges should not hurt. Some people have “drain pain” when they first start to use a cycler. In most cases, this will go away. Some people prefer CAPD.

- If you need to get up during the night, you may be able to get a long drain tube that will let you reach the bathroom or a loved one’s room.
- PD is work-friendly. Your energy level may be constant throughout the day, which can help you keep a job. A manual mid-day PD exchange can be done in a clean room at work.
- You only need to go to the clinic about once a month for blood tests and to meet with your care team.
- Your diet for PD has fewer limits than the diet for standard HD. But, the PD fluid has sugar in it, and you can gain weight if you don’t limit other carbs.
- You can have pets—but they need to stay out of the “clean” room you connect the PD tubing in. It may be best if pets don’t sleep with you at night if you use a cycler.
- Most clinics will not want you to take tub baths or use hot tubs. They also will not want you to swim in ponds, lakes, or public pools, due to the risk of infection. With a special bandage, you may be able to swim in a private pool. With a chest (presteral) PD catheter, you can take tub baths, but many doctors don’t use these.
- Having a PD catheter in your belly (or chest) can change how you feel about your body. Some people have a hard time getting used to this, and it can affect their sex lives.
- PD is travel friendly. You can take a cycler with you for free on an airplane, or put it in the trunk of a car or in an RV. The company that makes the PD fluid will ship it to you for free in most of the U.S. If you want to travel to Alaska, Hawaii, or out of the U.S., you may have to pay to ship the fluid.

## Hemodialysis (HD)

For HD, your blood goes out of your body through an “access” (see the chart on page 33) and through a filter (dialyzer). Then, your blood comes back to you. This happens many times over a few hours, and your blood gets a bit cleaner with each pass. A machine controls flow rates and temperature, and has alarms to keep you safe. There are three schedules for HD:

SCHEDULE	TREATMENTS PER WEEK	HOURS PER TREATMENT	TOTAL HOURS	HOME?	CLINIC?
<b>Standard</b>	3 Mon., Weds. Fri. or Tue., Thu., Sat.	4 (More is better)	12	✓	✓
<b>Short daily</b> (do treatments any time of day)	5–6	2.5–4 (More is better)	12.5–24	✓	A few clinics offer this
<b>Nocturnal</b> (do treatments while you sleep at night)	3 in a clinic or 3–6 at home	8	24–48	✓	✓

**HOME HEMODIALYSIS (HD).** HD can be done in the comfort and privacy of your own home, once a nurse teaches you how. You won't go home until you are *confident* that you can succeed. And, you will have 24-hour nurse backup by phone. For home HD, you may need a partner. Medicare will not pay for one; most HD partners are family members or friends. Even if a partner is required, it is best for you both if you do as much of your own care as you can.



### HOME HD AND YOUR LIFESTYLE.

Home HD can help you feel in more control and give you a more normal life:

- You may feel well enough and have enough energy to work.<sup>32</sup>

- You may be able to take your machine with you for travel, rather than go to a clinic.
- You can do treatments on *your* schedule, and go to the clinic just once a month.
- You can eat and drink with fewer limits—or may have no limits with nocturnal HD.<sup>33</sup>
- Any type of home HD can help you sleep better at night than the other options.<sup>34,35,36</sup>
- Home or nocturnal HD may allow for a more normal sex life.<sup>37</sup>
- Nocturnal HD may make it possible to have a healthy baby.<sup>38</sup>
- Short daily HD or nocturnal HD helps people live longer (about as long as with a transplant from a deceased donor. This is about three times longer than with standard HD or PD).<sup>39,40</sup>

**IN-CENTER HD.** You can also do your treatments in a clinic, where you would spend dialysis time with others whose kidneys have failed. Depending on where you live, you may have one or more choices of nearby clinics to work with. If so, you can

## Medicare starts on day 1 of month 1 when you train for home dialysis

If you do standard HD in a clinic, Medicare will start to cover you on the 1<sup>st</sup> day of your 4<sup>th</sup> full month of treatment. You must pay for your treatments until then. (Your health plan will help pay, if you have one. If you don't, you may be able to get other help.) **But, if you start training for PD, home HD, or in-center self-care before that 4<sup>th</sup> month begins, Medicare**

**will start right away.** In fact, Medicare can be back dated to the 1<sup>st</sup> day of your 1<sup>st</sup> month of training. This can save you thousands of dollars.

To find out when Medicare can start for you, use this handy calculator: [www.homedialysis.org/home-dialysis-basics/calculator](http://www.homedialysis.org/home-dialysis-basics/calculator).



look up each clinic online to see how well it is doing: <http://projects.propublica.org/dialysis/>. Call and set up a tour of the best clinics to see what you think. Look for a clean, friendly place where people get along well with each other. Bring questions with you. See how they treat you when you visit.

### IN-CENTER HD AND YOUR LIFESTYLE.

If you choose in-center treatments, you must make the biggest changes to your lifestyle:

- Treatments may be done during the work day. This can make it hard to work.<sup>40</sup>
- You go to and from the clinic three times a week (Mon.-Weds.-Fri. or Tues.-Thurs.-Sat.) for treatments.
- You can set up treatments somewhere else when you want to travel. (The social worker can help you reserve a time slot.)
- You will have limits on fluid, phosphorus, sodium, and potassium. And, you may still have other diet limits (i.e., for diabetes or heart disease).
- Most people who use this treatment (74%) find that they don't sleep well.<sup>41</sup>
- Many people who use this treatment also find that their sex lives are affected.<sup>42</sup>
- Of those ages 20 to 29 years old using this option in the U.S., 56.2% lived for 10 years. By age 60, 8.3% lived that long.<sup>43</sup>

However...

- In-center nocturnal HD gives you twice as much treatment. It is much more gentle.



## Summing Things Up: PD vs. HD

DETAILS	PERITONEAL DIALYSIS (PD)	HEMODIALYSIS (HD)
<b>Access</b>	You will need a soft, plastic tube called a <i>catheter</i> . A surgeon will place this tube in your belly, next to your belly button. Or, it may go in your chest ( <i>presternal catheter</i> ) and then reach into your belly. This type of catheter can be a big plus if you are heavy or you like to take tub baths.	You will need a link between an artery and a vein under the skin of your arm. A surgeon will make a direct link ( <i>fistula</i> ). This is best. Or, a piece of man-made vein ( <i>graft</i> ) can make the link. If you can, avoid a neck tube ( <i>catheter</i> ) or get rid of it quickly. The end of the tube is in your heart, and there is a high risk of blood infection.
<b>Membrane</b>	The lining of your inner belly ( <i>peritoneum</i> ) is the membrane for PD. Millions of tiny blood vessels in this lining act as filters. Your blood never leaves your body.	The membrane for HD is a set of thousands of hair thin, hollow plastic tubes held in a clear cylinder ( <i>dialyzer</i> ). Your blood flows through the hollow tubes.
<b>Dialysate</b>	For PD, you fill your belly with a bag of sterile dialysate. The dialysate stays (“ <i>dwells</i> ”) for a few hours, and then you drain it out. This is called an <i>exchange</i> .	Dialysate flows around the outsides of the hollow tubes with your blood inside. Once it has been used, the fluid goes down a drain.
<b>Pain</b>	PD should not hurt. Some people have cramps when the fluid drains out. There are ways to help this, such as by leaving a little dialysate in the belly and not draining it all out (called <i>tidal</i> ). Pain is a reason to call the PD nurse.	HD should not hurt. Two needles are placed in the access at each treatment. Numbing cream can reduce needle pain. If the treatments are too fast and/or short, painful muscle cramps, headaches, and vomiting can occur.
<b>Training</b>	PD training may take a week or so. A nurse will teach you how to safely do an exchange, run aycler, and order supplies. S/he will come to your house and help you get a room set up for treatment.	Standard in-center HD does not have training, unless you do self-care. For home HD, training may take 3 to 6 weeks, depending on which machine is used. A nurse will teach you to safely do the treatments, run the machine, and order supplies. S/he will come to your house and help you get a room set up, and will be there for the first home treatment.
<b>Risks</b>	Each exchange must be done with care so you don’t get an infection. Pets need to stay out of the room. With long term PD (more than 5 years) the risk of encapsulating peritoneal sclerosis (EPS) starts to go up. <sup>44</sup> EPS can cause bowel obstruction.	Each treatment must be done with care so you don’t get a blood infection. <sup>45</sup> If a needle pulls out or the tubes come apart, you could lose blood. <sup>46</sup> Treatments that are too short can “stun” your heart and brain, and cause damage. <sup>47</sup>

# What to Expect from Access Surgery

**N**o one wants to have surgery. And, any kind of dialysis access can change how you feel about your body. But, when your kidneys fail, getting an access and keeping it working can let you live the life you want. Thinking of an access as your lifeline can help you feel better about it. Some people hide their accesses, while others show them off with pride as scars of a battle they are winning and use them to teach others about CKD. The choice is up to you.

## Peritoneal Dialysis Catheter

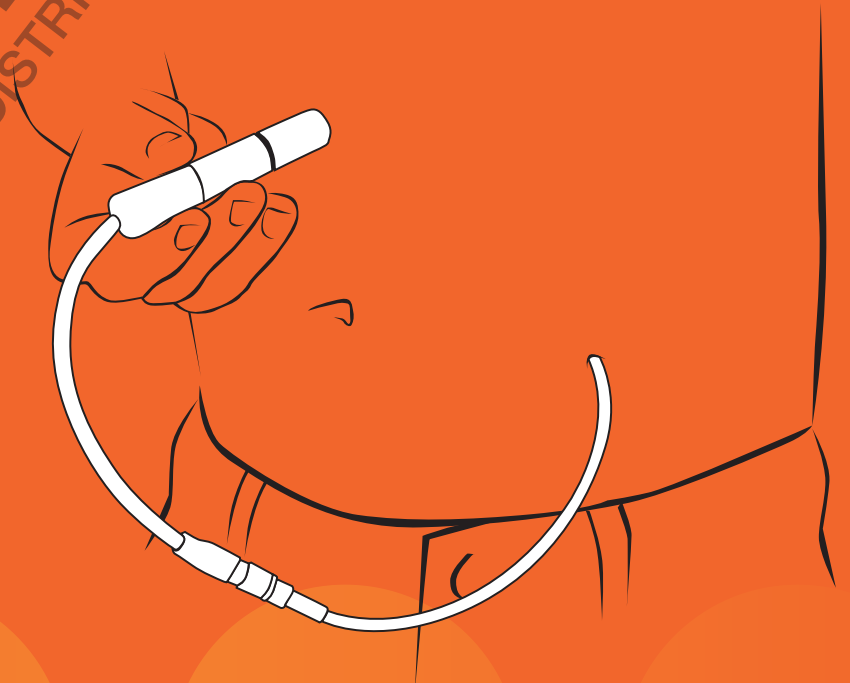
A PD catheter is a tube made of silicone or polyurethane. The tube is about the size of a soda straw, but soft and flexible. A surgeon can place a catheter in half an hour or so, and you'll go home the same day.

After you get your anesthesia, so you won't feel it, the surgeon will:

- Make a small cut in the wall of your belly or chest (presteral) for the tube.
- Move or take out a curtain of tissue in your belly called the *omentum* so it won't get in the way of the catheter.
- Make a pocket under your skin for the cuff that goes around the catheter. Fibrous tissue from your skin will grow around the cuff to hold it in place.

A PD catheter can be used right away, if you need urgent-start PD.<sup>48,49,50</sup> You would need to lie down when fluid is put in your belly, to avoid putting pressure on the new catheter. And, less PD fluid is used at first. This is called *low-volume, recumbent-only* (LVRO) PD,<sup>51</sup> and can be a safer choice than starting HD with a catheter. Or, you may not need to use a PD catheter right away. In this case, the surgeon may leave it under your skin. When it's time to start PD, a small cut will be made and the tube will be pulled out.

Most people don't have a lot of pain after a PD catheter is placed. Some go back to work the next day. Others have a few days where they need to take pain pills, and can't wear regular pants. Your PD training nurse will want to see your catheter, and flush it with fluid. S/he will teach you how to care for it safely and avoid infection. If a PD catheter does not drain, moves to the wrong spot, or hurts, it can be moved or you can get another one.



Here are some questions you can ask the surgeon before you have a PD catheter placed:

- **WHAT KIND OF ANESTHESIA WILL I GET?** Local or general can be used. If you get general anesthesia, you can't eat, drink, or chew gum after midnight the night before. You may spend more time in the recovery room, too.
- **WHICH TYPE OF CATHETER WILL I GET?** Some PD catheters are straight, and some are coiled at the end. A large study found that straight ones work best and last longest.<sup>52</sup>
- **WILL YOU SEW MY CATHETER IN PLACE?** A small study found that when PD catheters were stitched in place, they were less likely to move around.<sup>53</sup>

- **WHERE WILL MY CATHETER COME OUT?** The exit site should not be in a skin fold or any place where your clothes will rub on it.
- **HOW LONG WILL MY CATHETER BE?** It is easier to care for a short catheter (about 4 inches long) than a long one.
- **WILL YOU PUT ON A "TRANSFER SET"?** A transfer set has a valve to open and close the tube. You will need one, and it's best if it is put on in a sterile procedure.
- **HOW SHOULD I CARE FOR MY NEW CATHETER?** Ask for written instructions, so you know what to watch out for and what to do.



## Hemodialysis Vascular Access

To do HD treatments, you need a *vascular* (blood vessel) access. Two needles will be placed in the access for dialysis: one will take your blood from your arm to the dialyzer. The other will bring your blood back to you. It can take more than one try to get an access that works. And, it takes a few weeks to a few months for a new one to heal and be ready for use. So, guidelines for HD say that you should get an access within a year of when you need it. This may mean:

- Your creatinine level is greater than 4.0
- And/or your creatinine clearance level is less than 25 mL/min.<sup>54</sup>

There are three types of access for HD, and **the best one, if you can have it, is a fistula.**



HD Fistula

### ARTERIOVENOUS FISTULA

An HD fistula is a surgical link between an artery and a vein under the skin of your arm. Fast blood flow from your artery makes the vein bigger. Since a vein is close to the surface of your skin, a fistula is easy to reach for HD. A fistula is the best type of HD access, because:

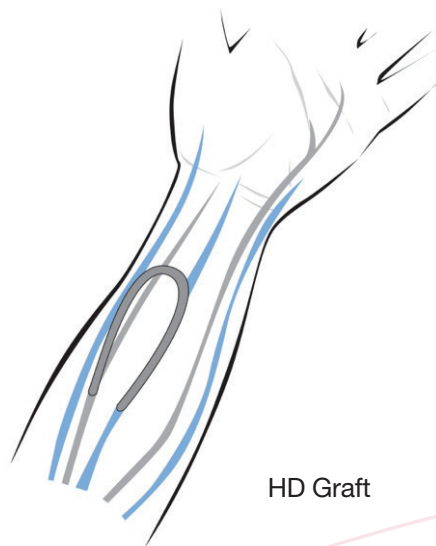
- **It is made only of your own tissue,** which your body is used to.

- **It is under your skin,** so there is less risk of getting a blood infection.
- **It self-heals after each needle,** so it can last for decades if it is taken care of.

### ARTERIOVENOUS GRAFT

An HD graft uses a piece of man-made vein to link an artery and a vein under the skin of your arm. This can be a good choice if you have small or weak veins. A graft is the second best type of HD access you can get, because:

- **It uses man-made tissue** that was not part of your body.
- **It is under your skin.** But, the man-made tissue can be a site for infection.
- **It does not self-heal after each needle,** so it can last for 3–5 years at the most. Then, it must be replaced, or there is a risk that it could rupture.



HD Graft

Fistula or graft surgery may take an hour, or a bit longer. The first attempt is most often done in the wrist of the arm you don't write with. If your veins are too small for this, your forearm is the next option, and then your upper arm. An upper arm fistula may be done in two steps. One step links the artery and the vein together. A second step can then move the new fistula up to the surface of your skin so it can be reached for dialysis.

After you get your anesthesia, so you won't feel it, the surgeon will:

- Make a cut on your arm so s/he can see your blood vessels.
- Sew your artery to your vein.
- Stitch your arm closed.

After surgery, you will have pain pills to take. You won't be able to drive a car until you don't need the pain pills. You will need to keep your arm above your shoulder as much as you can to keep the swelling down. A pillow can help you do this. Cold packs can reduce swelling, too.

Here are some questions you can ask the surgeon before you have a fistula or graft made:

- **HOW MANY FISTULAS DID YOU DO WHILE YOU WERE IN TRAINING?** The success rate for fistulas is 34% higher when a surgeon made at least 25 fistulas during training.<sup>55</sup>
- **WHAT KIND OF ANESTHESIA WILL I GET?** Local or general can be used. If you get general anesthesia, you can't eat, drink, or chew gum after midnight the night before. You may spend more time in the recovery room, too.
- **WILL YOU DO VESSEL MAPPING?** Using an ultrasound to look at your blood vessels may improve your chance of having a fistula that works.<sup>56</sup>
- **HOW SHOULD I CARE FOR MY FISTULA OR GRAFT AFTER SURGERY?** Ask for a written list of what to watch out for and what to do.

## How to Care for Your Access

You will learn how to check on your new fistula or graft each day by:

- 1. LOOKING** – It should not be red or swollen, or have pus or drainage. Look for blisters or tight, shiny skin. Tell your care team if you see any of these problems.
- 2. FEELING** – A healthy access will have a flow of blood you can feel, called a thrill. It's more of a buzz than a pulse. If it stops, or starts to feel like a pulse, tell your care team.
- 3. LISTENING** – If you can get a stethoscope, you can listen for the bruit (brew'-ee)—the sound that the thrill makes. It sounds a bit like hitting a bass drum: A fast, Boom! Boom! Boom! If it stops, or sounds like a tea kettle whistling, tell your care team.

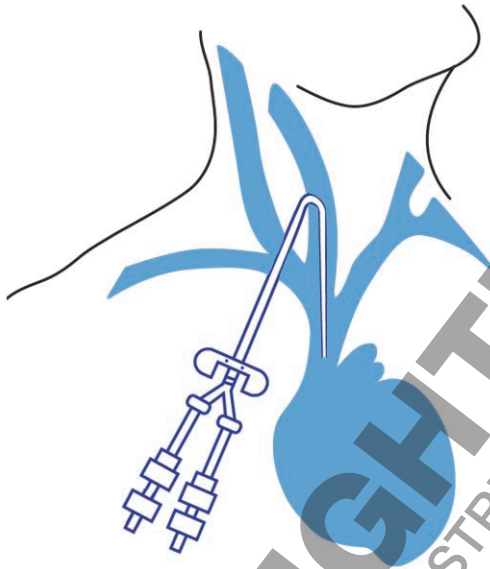
Never squeeze your access—it could clot and stop working:

- Don't wear a tight watch or bracelet over it.
- Don't sleep with your head on your access arm.
- Don't carry something heavy on top of it.

The best thing you can do to have your access last as long as it can is learn to put in your own needles. It may sound scary, but when you focus on getting it right, it hurts less. (You can use numbing cream.) And, you are the only person on earth who can feel both ends of the needle. Your care team can teach you how—and you have the right to learn if you want to.

## Hemodialysis Central Venous Catheter

An HD catheter is a Y-shaped plastic tube. The single end of the Y goes into a central vein in your neck or chest. It is tunneled under your skin, and reaches into your heart. The other two ends come out of your chest. One end takes your blood to the dialyzer and the other brings it back to you. You should get numbing medicine before a catheter is placed. An X-ray should check to be sure it is in the right spot after it is in.



No needles are used for HD with a catheter, so this might *seem* like a good option. Don't be fooled! Because part of the catheter is outside your body and part of it is in your heart, catheters are an open door for germs

to get into your blood. In fact, the risk of blood infection that can cause death is 3 to 4 times higher at the start of HD with a catheter. If a catheter is used long-term, the risk is seven times higher.<sup>57</sup> Some people don't like the way a fistula or graft looks and think they won't have scars with a catheter. Not true. Each catheter does leave a scar on your chest, and these are often where they will show in a shirt neckline.

Why do people use catheters if they are so dangerous?

- **THEY ARE AFRAID OF NEEDLES.**

Numbing creams can reduce pain so the needles don't hurt. And, learning to put the needles in yourself can give you control and reduce fear.

- **THEY DIDN'T MAKE A DIALYSIS CHOICE AND WAITED UNTIL IT WAS AN EMERGENCY.** Choose a treatment. Don't let one be chosen for you. It might not fit your life.

- **THEY DID NOT GET A FISTULA OR GRAFT IN TIME** (or it didn't work). If possible, try to get a working fistula or graft well in advance of when you need it. This could save your life.

Sometimes an HD catheter *must* be used. If so, try to get rid of it as soon as you can.

# Comfort Care – No Dialysis or Transplant

*"I have always regarded the ability to choose the time, the hour, the place and the manner of our death as the greatest privilege that dialysis gives us. And it is unique to us. So I'm grabbing the chance with both hands. I wish I had a third to embrace it even harder. I've had a great life, thoroughly enjoyed it, all 80 years of it. Even the last 10 years on dialysis. Now it's time to call quits, to take the Last Train home, to leave while the going's good."*

**Bob H.**

Dialysis does not always help people live longer. For those who were 80 years old or more *and* were also frail or had other illnesses, dialysis did not extend life.<sup>58</sup> For some, the best way to treat kidney failure may be to let nature take its course. We call this "comfort care." It may also be called "conservative management with no dialysis."

Choosing comfort care may make sense if:

- There is a lot of pain (such as from cancer) that can't be helped.

- More than one severe chronic disease is present at the same time.
- Quality of life is poor, with little hope that it will get better.
- Someone does not know what is going on or fights the treatment (as with dementia).

Comfort care does not mean "doing nothing." It is an active course of treatment, with:

- **PALLIATIVE CARE.** From the word "to cloak," palliative care offers help to cope with a chronic disease and boost quality of life. It does not shorten life or lengthen it. The patient will have clinic visits. In fact, a whole team of healthcare staff will seek ways to relieve pain, symptoms (like shortness of breath or sleep problems), and stress. Physical therapy, massage, medicines, diet, and other techniques may be used.
- **HOSPICE CARE.** Hospice includes all of the above—plus counseling and spiritual aid. Hospice staff will help someone who is dying and his or her loved ones. Services can take place in the home, in a hospital, or in a hospice center. To qualify for hospice, a doctor must write a letter that says someone has six months or less to live. Medicare will pay for hospice care.

## Feeling Hopeless or Afraid is Not a Reason to Choose Comfort Care

It is very normal to be scared when you know that your kidneys are failing. It is also normal to worry about being a burden on your loved ones. You may worry that your life won't be worth living if you have to use a machine to survive. You are not alone if you feel this way.

It's vital to know that **you are still YOU, whether your kidneys work or not.** And, you matter. Don't let depression make choices for you. Talk to someone, get treatment so you feel better, and make a choice when you are not as upset and afraid.



If comfort care is something that you want, talk with your loved ones. Be sure they know how you feel, and why, and what your wishes are. Expect that they will feel sad and may try to change your mind. It may help to have a counselor or chaplain help you talk with them. Most religions view saying no to dialysis as letting natural death occur—not as suicide.

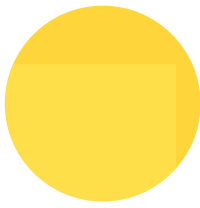
A natural death from kidney failure does not hurt. As toxins build up in your blood, you will start to feel sleepy. Water building up in your blood can make it hard to breathe. You may want to have treatments that remove water but not toxins, to make you comfortable. An *Advance Directive* is a way to say what you do and do not want for your healthcare in case you are not able to speak for yourself. All adults need to have one. A *Healthcare Power of Attorney* form lets you choose someone who can speak for you for healthcare decisions. To get these forms, go to a lawyer, look on the Internet, or ask your doctor's office.

When you know that your time is limited, you can plan to spend time with people you care about. You can get your affairs in order. Be sure that your loved ones know where to find key papers, like deeds, bank accounts, and insurance plans. You may want to gather up photos or write letters, and share what you would like for a memorial service. You can give cherished items away and see the faces of those you give them to. You can say goodbye.

*"I imagine that this is the beginning of the end. That from now on I will grow sleepier and sleepier day by day until I finally lapse into a coma. I still feel as relaxed about it as before... I would recommend it to anybody thinking of trying death for the first time."*

**Bob H.**

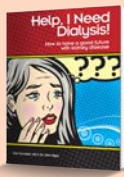




# Conclusion & Resources

In the U.S., millions of people are living with chronic kidney disease. Unlike some other illnesses, CKD *can* be treated, and you *can* live a good life. As you have learned in this booklet, **knowledge is power**. There may be a lot you can do to slow your CKD and protect the function you have left. If not, you have options for treatment that can help you live the life you want.

There are many resources that can help you learn more about CKD. If you use the Internet, put a search term into Google. Look for non-profit and government resources that you can trust. Beware of “cures” and testimonials (they are the easiest things to fake). Always talk with your care team before you try any remedy. Here is a sample of some trusted resources:



### Help, I Need Dialysis: How to Have a Good Future with Kidney Disease!

Easy-to-read book. Fully explains all of the kinds of dialysis and what they can mean for your lifestyle. \$15 plus shipping. [http://LifeOptions.org/help\\_book](http://LifeOptions.org/help_book)



### How to Have a Good Future with Kidney Disease.

Watch this free set of six, 15-minute online classes about kidneys and kidney disease, transplant, paying for treatment, and more. [http://LifeOptions.org/goodfuture\\_patients/](http://LifeOptions.org/goodfuture_patients/)



### My Life, My Dialysis Choice Decision Aid

This free tool lets you choose lifestyle values and matches them to the treatments with the best fit. [www.MyDialysisChoice.org](http://www.MyDialysisChoice.org)

### Kidney School™

Free set of learning modules on 16 topics to help you manage your CKD. [www.KidneySchool.org](http://www.KidneySchool.org)



### Home Dialysis Central

Read patient stories, learn about the home treatment lifestyle, get expert advice, and more! [www.HomeDialysis.org](http://www.HomeDialysis.org)



### Nocturnal Home Haemodialysis

A website for sharing information and for understanding nocturnal home HD. [www.NocturnalDialysis.org](http://www.NocturnalDialysis.org)

### American Association of Kidney Patients

Join for free! AAKP has many booklets and brochures that you can order or download. Visit [www.aakp.org](http://www.aakp.org), or call 1 (800) 749-2257.

### Home Dialyzors United

Join for free! Yearly meeting, buddy program, and more. [www.homedialyzors.org](http://www.homedialyzors.org)

### National Kidney Foundation™

Join for free! NKF has many pamphlets, videos, and other resources. [www.kidney.org](http://www.kidney.org) or call their NKF-CARES line at 1 (855) 653-2273.

### PKD Foundation

Devoted to finding a cure for polycystic kidney disease (PKD). Visit [www.pkdcure.org](http://www.pkdcure.org) or call 1 (800) 753-2873.

### Renal Support Network (RSN)

Join for free! Lots of helpful podcasts, a hotline in English and Spanish, and much more. [www.rsnhope.org](http://www.rsnhope.org)

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