



Living with Kidney Disease

Taking charge and living well

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Taking charge and living well

If you or a loved one has chronic kidney disease (CKD), you probably have questions about how to manage it along with everything else going on in your life. The information, strategies, and tools in this booklet can help you take control and manage CKD — so you can live a fuller, more enjoyable life.

As you read, keep in mind that this booklet should not replace the instructions you might get from your healthcare providers. Always follow their directions and go to them with questions and concerns.

Sincerely,

Your Kidney Services Team



Chronic Kidney Disease: The Basics



"I couldn't believe it when my doctor said I had CKD — I feel fine. Having a chronic disease is pretty scary, but I can take steps to keep it from getting worse."

~Jennifer, newly diagnosed CKD patient

Chronic kidney disease (CKD) means that your kidneys are not working as well as they should. Although CKD may get worse over time and lead to kidney failure — also called end-stage kidney disease (ESKD) — you can take steps now to keep your kidneys as healthy as possible

What key facts do I need to know?

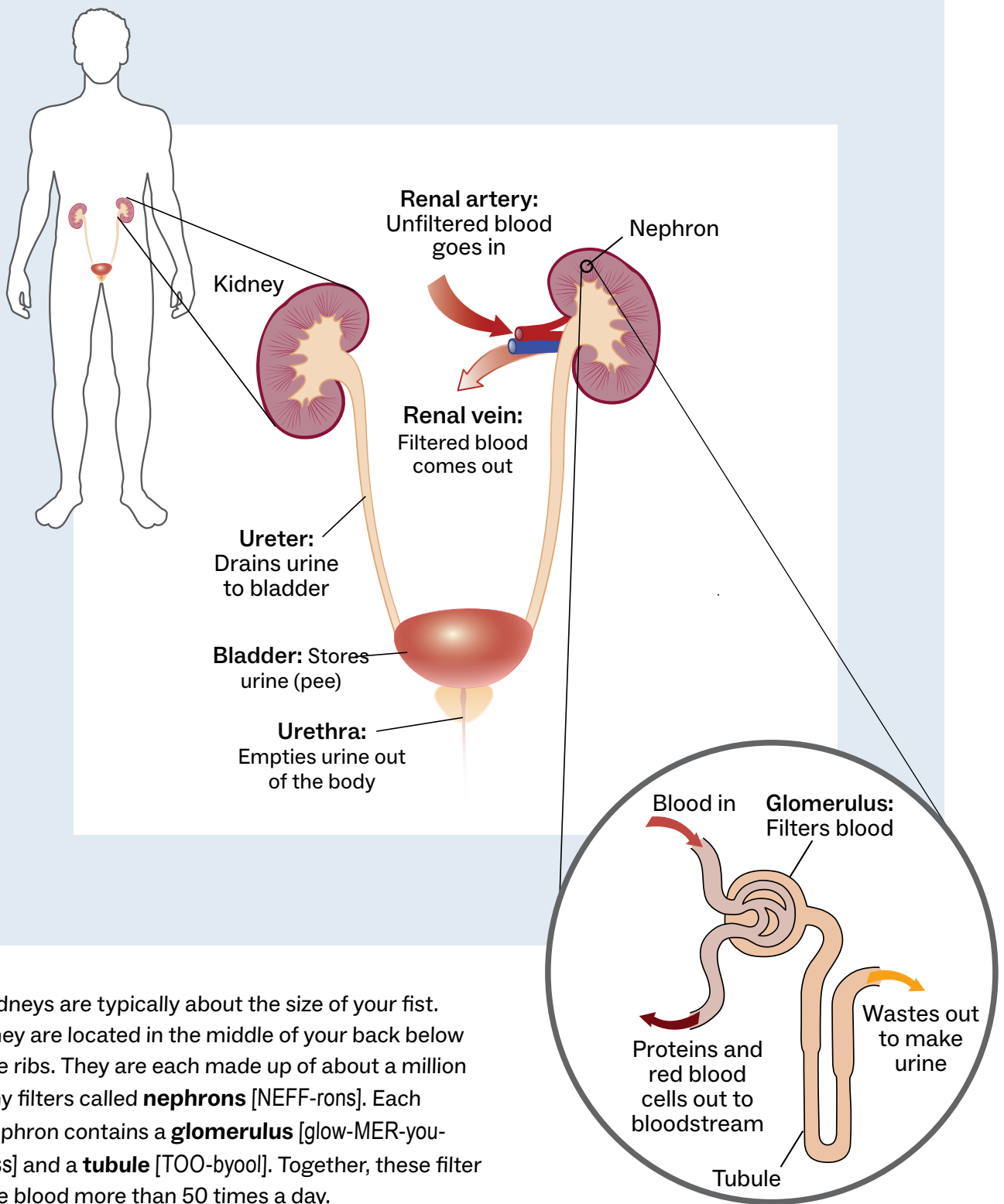
- **You likely feel fine.** You might not have symptoms until your kidney function has significantly declined.
- **You need to get tested.** Blood and urine tests are the only way to know if you have CKD. These tests are recommended at least yearly, and more frequently as kidney function declines.
- **It won't go away.** Without treatment, CKD gets worse over time. It can lead to kidney failure, or ESKD, which can only be treated with dialysis or a kidney transplant.

What do healthy kidneys do?

Knowing what healthy kidneys do makes it easier to understand how they affect your overall health when you have CKD. Healthy kidneys:

- **Filter wastes from your blood**, removing salts, excess water, and other wastes by making urine (see page 5). A buildup of wastes in your body can make you very sick.
- **Adjust levels of sodium, potassium, calcium, and phosphorous in your blood.** These are minerals your body needs to stay balanced.
- **Make hormones** for maintaining healthy blood pressure and bone health as well as producing red blood cells. Without these hormones, you risk bone fractures, have higher blood pressure, and can develop anemia (low number of red blood cells).

Healthy kidneys



Kidneys are typically about the size of your fist. They are located in the middle of your back below the ribs. They are each made up of about a million tiny filters called **nephrons** [NEFF-rons]. Each nephron contains a **glomerulus** [glow-MER-you-luss] and a **tubule** [TOO-byool]. Together, these filter the blood more than 50 times a day.

What causes CKD?

CKD is most often caused by:

- **Diabetes.** High blood glucose (blood sugar) can damage many organs, especially the kidneys. Anyone with diabetes has a higher risk of CKD.
- **Hypertension (high blood pressure).** High blood pressure can damage the delicate blood vessels in the filtering units in your kidneys.
- **Extended use of pain relievers.** Common over-the-counter pain relievers, such as ibuprofen (Advil, Motrin), naproxen (Aleve), and other NSAIDs (non-steroidal anti-inflammatory drugs), can increase your risk of developing CKD.

Other causes include:

- Immune (disease-fighting) system disorders
- Long-term conditions that cause inflammation in the kidneys
- Conditions that run in families
- Problems that prevent the flow of urine
- Many common medications

Make sure your doctor is aware of your kidney disease when prescribing or recommending any medication.

Talk to your doctor about the types of medications that are known to slow the progression of CKD:

- ACE or ARB inhibitors
- SGLT-2 inhibitors
- GLP-1 agonist
- MRAs

How can I slow my kidney disease?

There are several ways to slow your CKD, starting with the education offered by your healthcare team. In addition, you can:

- **Live a healthy lifestyle.** Maintain a healthy weight for you, get at least 30 minutes of physical activity daily, and get plenty of rest. Stop smoking and don't abuse drugs or alcohol.
- **Follow a kidney-friendly diet.** Work with a Registered Dietitian Nutritionist (RDN) to plan a kidney-healthy diet, which may include limiting sodium (salt) and excess sugar. Talk with your RDN about any supplements you are taking to make sure they are safe to continue.
- **Keep regular appointments with your doctor.** This will help make sure your treatment plan is effective and adjusted as needed.
- **Manage any other medical conditions.** Carefully follow your treatment plan for diabetes, high blood pressure, or any other medical condition you may have.
- **Take your medications exactly as directed.** Make sure you always have enough at home and always take them exactly as prescribed. Talk to your doctor before taking any supplements, vitamins, or over-the-counter medications.
- **Avoid NSAIDs.** Medications like ibuprofen or naproxen can make CKD worse.
- **Tell your other healthcare providers about your CKD when having tests or procedures.** Only use your "dominant arm" for blood tests and IVs. This will help your major arteries stay strong in case you need dialysis in the future. If any healthcare providers order an x-ray or other test that uses contrast dye, ask about kidney-safe options. The dye can damage your kidneys.

In Focus: Stages of CKD

CKD can become kidney failure without warning if it goes untreated. Kidneys don't usually fail all at once. Instead, kidney disease often progresses slowly, over a period of years. If it is caught early, medications and lifestyle changes may help slow the progression. Simple urine and blood tests are used to determine if you have CKD. The results of these tests will identify the stage of kidney disease and help guide treatment decisions.

There are 5 stages of CKD:

Stage	eGFR Level	In This Stage...
1	90 or more (+/- protein in urine)	There are few symptoms.
2	60 to 90 (+/- protein in urine)	There are few symptoms. Controlling health risks like diabetes and high blood pressure are important. At a minimum, yearly CKD testing should be performed
3	3A: 46 to 59 3B: 30 to 45	It is recommended that you receive CKD education to learn ways to potentially slow down CKD.
4	15 to 29 (+/- protein in urine)	Anemia, early bone disease, or both may appear. Medications can be used to treat both of these problems. Increased tiredness may be a symptom of anemia. This is the time make a treatment plan. Depending on your treatment decision, you may need to be referred to other specialties. You should attend a "CKD Education Class" if you haven't already. You will have more frequent testing.
5	Less than 15 (+/- protein in urine)	Increased tiredness, decreased appetite, and increased nausea are more common. You may have more problems with fluid retention. Be sure to tell your nephrologist [neh-FROL-uh-jist] if you have these symptoms. You will have more frequent testing.

Health impacts of CKD

Over time, damage to your kidneys can cause problems throughout your body. Some of the more common problems are described below.



Anemia

Anemia [uh-NEE-mee-uh] is a common problem for people with kidney disease. It's a condition in which you have fewer red blood cells. This makes it hard for your body to deliver oxygen throughout your body.

Healthy kidneys make a hormone called **erythropoietin** [ih-rith-roh-POY-eh-tn] (**EPO**) that helps your bone marrow make red blood cells. When you have kidney disease, your kidneys don't make enough EPO. This causes your red blood cell count to decrease and makes you more likely to develop anemia. Symptoms include feeling tired, weak, depressed, or short of breath.

To lower your risk of anemia, you need to:

- Have regular blood tests.
- Ask your doctor about medications that can help.
- See a dietitian who can help with a kidney-healthy eating plan.



Bone disease

With CKD, your kidneys have trouble maintaining proper levels of calcium and phosphorus that keep your bones healthy and strong.

With CKD, your kidneys don't adequately filter out phosphorus from your blood. This extra phosphorus removes the calcium you need from your blood and causes your bones to give up calcium needed to restore the balance. In addition, your kidneys stop activating vitamin D, which tells our bones to absorb calcium. This results in weak and fragile bones.

To reduce your risk of bone disease:

- Limit phosphorus in your diet based on your care team's instructions.
- Quit smoking, and exercise regularly.



Heart disease

People with CKD are at higher risk of developing heart disease — the most common cause of death in all age groups with kidney disease.

Because people with kidney disease typically suffer from diabetes and hypertension, they have a higher risk for cardiovascular disease which includes congestive heart failure, irregular heartbeat, and heart attack.

To lower your risk of heart disease, you need to:

- Carefully manage diabetes and hypertension.
- Follow instructions for medications and diet.
- Lower any other risk factors you may have, such as controlling your cholesterol, stopping smoking, and maintaining a healthy body weight.



High potassium

When in balance, potassium (which has the chemical symbol “K”) helps your muscles work properly and keeps your heart beating evenly.

When you have CKD, your body may have trouble getting rid of excess potassium. In addition, some medications that treat kidney disease can increase your potassium level. The result is muscle weakness, numbness or tingling, and heart problems.

To help detect potassium problems early and avoid serious complications, you should:

- Get regular blood tests to check your potassium levels.
- Meet with a dietitian to learn which foods are high in potassium.
- Limit potassium in your diet based on your care team’s instructions.
- Read food labels carefully, especially salt substitutes which may contain potassium chloride.



Fluid buildup

In late stages of CKD (typically stage 5), your kidneys may not filter out excess fluid from your body.

Healthy kidneys take excess fluid from your blood to make urine. When you have too much fluid, it can interfere with how your heart and lungs function. Fluid buildup can make your heart work harder, make you short of breath, and cause swelling in your feet, ankles, and legs.

To prevent fluid build-up:

- Limit sodium in your diet based on your care team’s instructions.
- Control your blood sugar.
- Meet with a dietitian to develop an eating plan.
- Follow fluid restrictions as recommended by your provider.



High blood pressure and urine proteins

Just as high blood pressure commonly causes kidney disease, kidney disease also can increase your blood pressure.

When your kidneys can’t properly filter the fluids in your body, your blood pressure rises. In addition, high blood pressure makes your body get rid of valuable protein through your urine.

If you have high blood pressure, be sure to:

- Take medications your doctor prescribes to control your blood pressure.
- Limit sodium in your diet based on your care team’s instructions.
- Have a reliable blood pressure monitor at home and check your blood pressure regularly.
- Stay active every day.
- Maintain a healthy weight.
- Stop smoking.

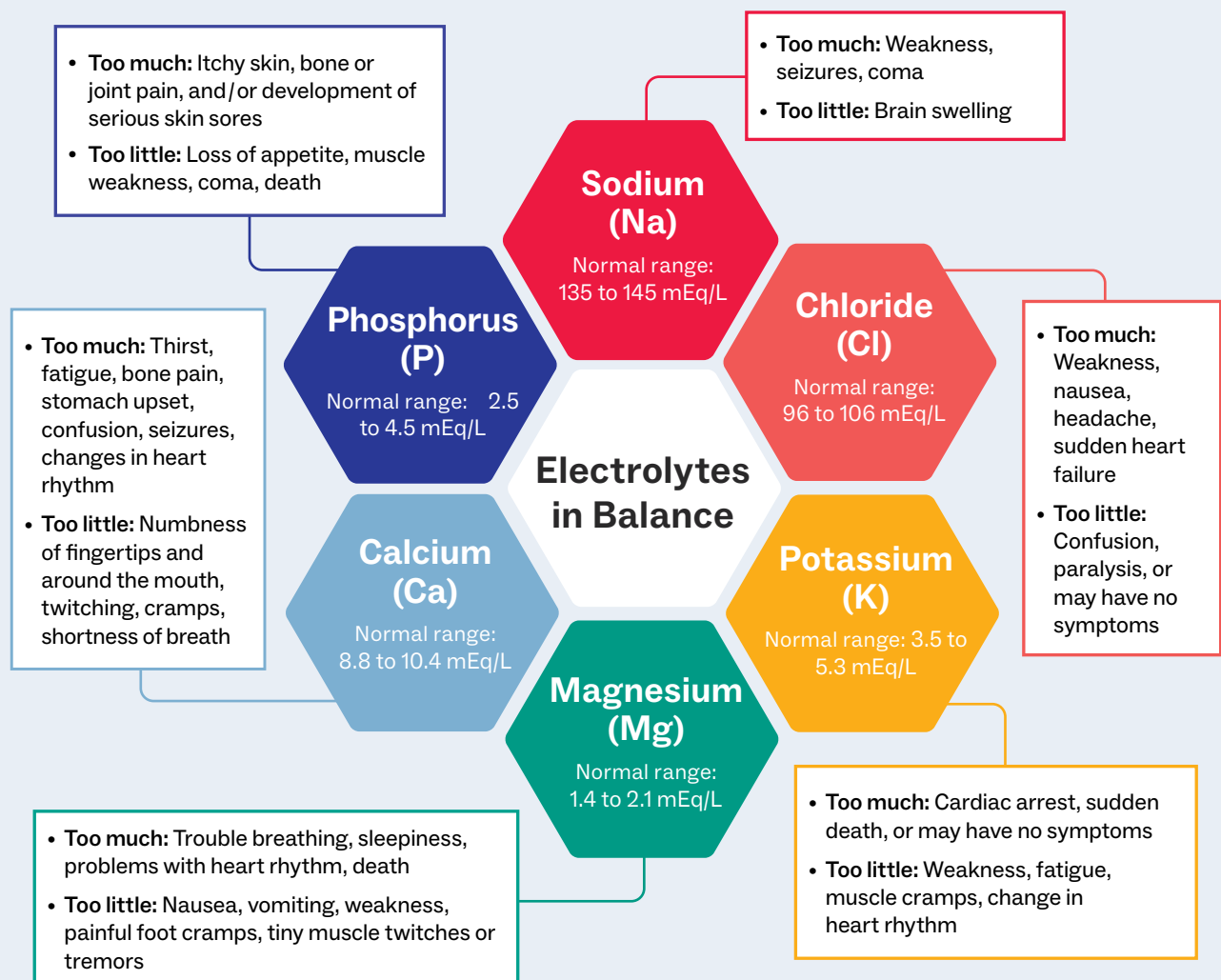
In Focus: Electrolytes

An **electrolyte** [eh-LEK-troh-lite] is a mineral in your bodily fluids (such as urine, blood, and sweat). These minerals must be in balance (not too much or too little) to help your heart to beat, your muscles to contract, your blood to clot, your nerves to send impulses to and from the brain, and much more.

The food you eat and fluids you drink bring electrolytes into your body. You lose them when you sweat and when you urinate (pee). Poor diet, over- or under-exercising, or being sick changes your body's normal electrolyte balance.

In many ways, your kidneys keep these minerals in balance. With CKD, you and your doctor will work to prevent electrolyte problems through regular blood tests and by adjusting your treatment plan as needed.

Here's how each important electrolyte works and the typical symptoms you may have if you have too much or too little.



In Focus: Lab tests

Use the table below to better understand your routine lab tests and results.

Common Lab Tests (monthly or as directed by your doctor)

What you and your doctor need to know	Name of lab test	Type of test		Normal range*
		Blood	Urine	
Are my potassium, calcium, phosphorus, sodium, and potassium levels in balance?	Blood electrolyte levels	X		Potassium: 3.5 to 5.0 mEq/L
				Calcium: 8.4 to 10.4 mEq/L
				Sodium: 137 to 146 mEq/L
				Phosphorus: 2.3 to 4.7 mEq/L
How well are my kidneys working?	Blood urea nitrogen (BUN)	X		8.0 to 20.0 mg/dL
	Serum creatinine	X		0.8 to 1.4 mg/dL
	Glomerular filtration rate (GFR)	X		90+
	Albumin : Creatinine ratio (ACR)		X	Less than 30 mg/g
Do I have anemia (reduced red blood cells)?	Hemoglobin (Hgb)	X		12.0 to 18.0 gm/dL
Is my diabetes under control?	Hemoglobin A1c (A1c)	X		Aim for less than 7.0 %

*Abbreviations

mEq/L: milliequivalents per liter (about a quart)

mg/dL: milligrams per deciliter (10 deciliters in a liter)

gm/dL: grams per deciliter

mg/g: milligrams per gram (1,000 milligrams in a gram)

mL/minute: milliliters per minute (1,000 milliliters in a liter)

Finding help online

Intermountain Healthcare:
[intermountainhealthcare.
org/services/kidney-care](https://intermountainhealthcare.org/services/kidney-care)



National Institutes of Health:
[niddk.nih.gov/health-
information/kidney-disease](https://niddk.nih.gov/health-information/kidney-disease)



National Kidney Foundation:
kidney.org



Your kidney care team

Many people may help you manage your CKD. You might not work with all of the people listed below, and their roles often overlap. Still, it helps to know who they are and what part they may play in your care.

- **YOU are the most important person on your care team!** Take an active role in your care, and always discuss your concerns with your team.
- **Support system.** This may include family, friends, neighbors, clergy, or others.
- **Primary care provider (PCP).** Your PCP is who you usually see for healthcare problems. Your PCP could be a family practice doctor, a general internist, a nurse practitioner, or a physician assistant.
- **Nephrology** [neh-FRAHL-uh-gee] **provider.** Nephrologists [neh-FRAHL-uh-jists] and some Advanced Practice Providers specialize in diseases of the kidneys. When your kidney disease starts to get worse, you will be referred to a specialist to help manage CKD.
- **Kidney care navigator or care manager.** These health professionals are a resource for you and your support system. They provide personalized support, education, and advocacy for patients with CKD and ESKD.
- **Dietitian.** A dietitian can help you create an eating plan based on your diet restrictions (such as low sodium or phosphorus) and what you like to eat. Help from a dietitian may be especially useful if you're on several diet restrictions.
- **Other healthcare providers.** Pharmacists, exercise specialists, and other healthcare providers may also work with you to help you manage your CKD.

YOU are the most important team member

Many people have CKD, however, each person's situation is individual and unique. You need to take an active role in your care. It's important to help your care team know what you need for your situation. **Remember, you have the most to gain by voicing your opinions and questions.**

How can I be involved?

Here are a few ideas:

- **Ask questions.** Getting the answers you need will help you make informed treatment decisions.
- **Be open and honest.** To develop a care plan, your healthcare providers need to know how you are responding to treatment.
- **Trust yourself.** A big part of caring for yourself is learning to pay attention to your body, your emotions, and your behaviors. If something doesn't feel right, don't ignore it. Talk to your healthcare providers. Your treatment plan might need to be adjusted.

Tell us what's on your mind

It's important to discuss your concerns with your care team, even when they involve:

- **Money.** Treatment, medications, supplies, office visits, and lab work can be expensive. Resources may be available to help with financial concerns.
- **Sexual health.** Some patients may experience changes in sexual function or desire. Most people — not just people with kidney disease — have sexual concerns at some point in their lives.
- **Safety.** Share your concerns related to your safety which could include hand hygiene, patient privacy, and a clean environment.
- **Medical terms and concepts.** Don't worry if you don't understand something. Kidney disease is complicated! We are here to help you understand your disease and your care.

Your healthcare providers are trained to help you with a wide range of issues, from the practical to the personal. To help you manage your disease successfully, they need you to speak up and be involved in your care.



"My care team helped me work through all the questions and worries I had when I was diagnosed with CKD."

~Kayla, patient

Using medications with care

For CKD in stages 3 to 5, medications must be used with care as some can cause further damage to your kidneys. Use the information on this page and the next as a guide, but be sure to ask your doctor or pharmacist if it's safe before you take any new medications.*

Medications to avoid	
<div>Pain Medications<ul style="list-style-type: none">• NSAIDs (Non-Steroidal Anti-Inflammatory Drugs)<ul style="list-style-type: none">– Ibuprofen (Motrin or Advil)– Naproxen (Aleve)– Ketoprofen (Orudis)– Indomethacin (Indocin)– Ketorolac (Toradol)– Etodolac• Cox-2 Inhibitors (Celebrex, Mobic, Bextra)• Meperidine (Demerol)• High doses of aspirin, or aspirin-containing products (Excedrin, Alka Seltzer)</div>	<div>Antacids /Supplements<ul style="list-style-type: none">• Magnesium-containing products (Magaldrate, Milk of Magnesium, Magnesium Oxide)• Aluminum-containing products (Amphojel, Alternagel, Aluminum Hydroxide Gel)• Sucralfate</div>
Medications to use with caution (check with your doctor if it is safe for you)	
<div>Narcotics<ul style="list-style-type: none">• Morphine• CodeineDecongestants (limit use to less than 5 days)<ul style="list-style-type: none">• Pseudoephedrine (Sudafed)• Phenylephrine (Sudafed PE)Other<ul style="list-style-type: none">• Denosumab (Prolia, Xgeva)• Bisphosphonates (Fosamax, Actonel, Boniva)• Probenecid• Phenazopyridine (Pyridium)Proton Pump Inhibitors<ul style="list-style-type: none">• Omeprazole (Prilosec)</div>	<div>Anticoagulants /Blood Thinners<ul style="list-style-type: none">• Enoxaparin (Lovenox)• Fondaparinux (Arixtra)• Dabigatran (Pradaxa)• Rivaroxaban (Xarelto)• Edoxaban (Savaysa)Diabetes Medications<ul style="list-style-type: none">• Glyburide (Micronase)• Metformin (Glucophage)</div>

Medications requiring dose adjustments in CKD

- **Antibiotics:** Almost all require dose adjustment
- **Trimethoprim-sulfamethoxazole (Septra or Bactrim):** Use with extreme caution. Avoid unless there is no alternative
- **Acyclovir, Valacyclovir, Valganciclovir**
- **Digoxin**
- **Allopurinol**
- **Antihistamines** (Benadryl, Allegra)
- **Diabetes medications** (Januvia, Onglyza, Nesina)
- **Tramadol**
- **Metoclopramide** (Reglan)
- **H2 blockers** (Pepcid, Zantac)
- **Tamiflu**
- **Duloxetine** (Cymbalta), **Pregabalin** (Lyrica)
- **Gabapentin** (Neurontin)
- **Baclofen:** Avoid if GFR<30

* This list does not include all medications. You should have your medications regularly checked for appropriate dosing and side effects. Make sure all your healthcare providers know that you have chronic kidney disease and that your medications may need to be adjusted. Share this list of important medications with them.

Call your nephrologist’s office if you have any concerns about your medications or before taking any herbal supplements.

Notes

Treatment Options

Advance Care Planning

It is recommended that you have advance care planning documents in place. These documents tell your healthcare team and those closest to you what your healthcare wishes are if you cannot speak for yourself.

It is important to consider what matters most to you, discuss your decisions with those closest to you, and then write it down to ensure your healthcare goals are honored.

To get started, talk with your doctor, nurse, or other trusted healthcare provider.

Scan the QR code below to register for a workshop about advance care planning.



Knowing which treatment options are available is important so you can select the one that will work best for you. Your choice of treatment may change over time. Your care team will support you during those transitions.

Below are the three main treatment options for kidney disease that progresses to kidney failure (ESKD) — kidney transplant, dialysis, and medical management without dialysis. They will each be discussed in greater detail later in this booklet.

What is a kidney transplant?

A kidney transplant is a surgery to place a donated kidney and ureter (the tube that carries urine from your kidney to your bladder) into your abdomen (belly). The transplanted kidney and ureter are connected to your bladder and blood supply. The transplanted kidney takes over the functions of your current kidneys.

What is dialysis?

Dialysis is a way to clean waste and extra fluid from your blood when your kidneys can no longer do so. Dialysis uses special equipment to supplement a failing kidney's natural filtration.

What is medical management without dialysis, or MMWD?

Medical management without dialysis, or MMWD, is a treatment plan you might choose for advanced chronic kidney disease (CKD) if you do not want dialysis or a kidney transplant. The goal of MMWD is to help you live as comfortably as possible while preserving kidney function and managing symptoms. MMWD can also help you prevent or manage complications like anemia and electrolyte imbalances, improve your quality of life, and help you plan for end-of-life care, which includes hospice care.

What is Palliative Care?

Palliative care is not the same as hospice care. Palliative care can start at anytime, including at the time of CKD diagnosis. The goal of palliative care is to improve quality of life, and provide relief from the symptoms and burdens of living with a chronic illness.

Kidney Transplant

If possible, a kidney transplant is the best treatment option available for kidney failure. A kidney transplant is not a cure for kidney failure, it's a treatment, and you will need lifelong follow up care. A transplant may extend your life expectancy compared to dialysis.

What do I need to know about a kidney transplant?

A donated kidney can come from a living donor (such as a friend, relative, or a complete stranger) or someone who has recently died (deceased donor). In either case, doctors make sure that both you and the donor (if living) can safely have this surgery and that your body will function properly.

After kidney transplant, you will have to take anti-rejection medications to ensure the health of the transplanted kidney. These medications keep your body from rejecting your new kidney, but there are potential side effects. You will work with your healthcare team to manage these medications and any side effects.

Kidney transplant is a great option, but it is not a possibility for everyone and may require waiting months or years for a donated kidney. Some people are not healthy enough to have the surgery, or a donor cannot be found in time. As a result, many patients who are pursuing a kidney transplant will require dialysis while they wait for medical tests to be completed and a donated kidney to become available.



Pros

- Ability to return to near normal health after surgery; no dialysis needed
- Better chance of living longer than with dialysis
- Better outcomes overall
- Covered by Medicare, VA, Medicaid, and most health insurance plans

Cons

- Risks of surgery
- Costs
- Side effects of anti-rejection medications
- Follow-up care issues such as:
 - High risk of developing skin cancer (65 times more likely)
 - Frequent appointments and blood testing in the early post-transplant period
 - Possibility of organ rejection
- Long deceased-donor list

Kidney Transplant (continued)

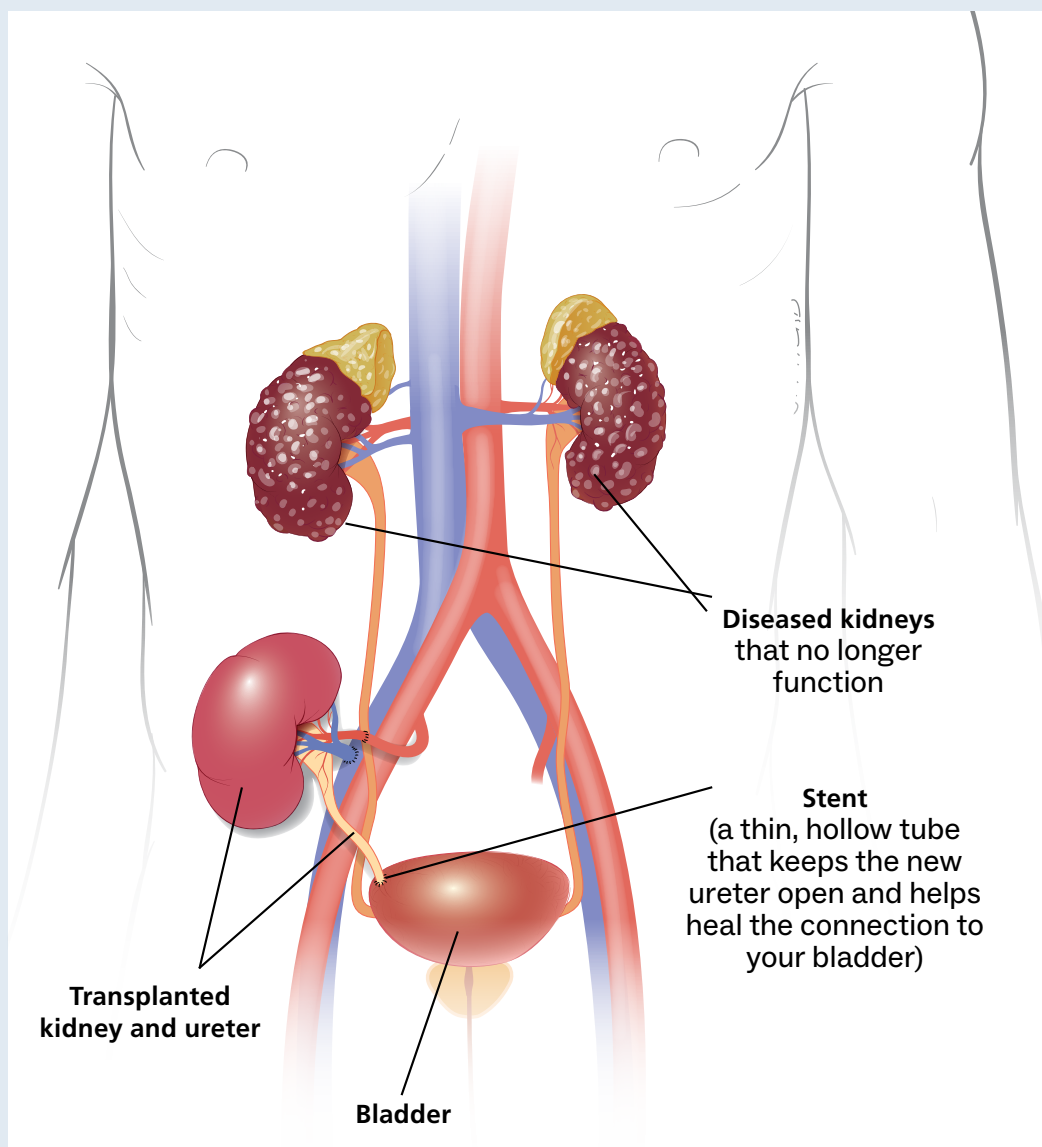
When your blood and urine tests indicate that your CKD has reached stage 4, talk with your doctor about a transplant so that you and your family can prepare.

You might not be able to have a kidney transplant if you have other complex medical issues. A kidney transplant has the best chance of being successful when you are as healthy as possible. A living donor also needs to be healthy enough to have surgery.

- **You might have to wait months or years for a kidney that is a good “match” for your body.** According to the National Kidney Foundation, the average wait for a donated kidney in the U.S. is 3 to 5 years, and sometimes longer. As of 2024, more than 101,000 people were waiting for a kidney. Because of this wait time, you may need dialysis until you can have a transplant.
- **The costs and insurance coverage for a transplant will vary depending on your insurance and the transplant center you choose.** Talk to your insurance carrier regarding your transplant benefits. The transplant care team can help you understand any non-covered expenses.

Carefully consider the pros and cons of kidney transplant listed at left.

Kidney transplant



A kidney transplant is surgery to attach a donated kidney and ureter to your bladder and body's blood supply.

Kidney Transplant (continued)

How do I get a kidney?

A healthy family member, friend, or even a stranger could donate a kidney for you (a living donor) if they qualify medically. If healthy, donors can live a normal life with only 1 kidney.

The benefits of having a living donor include:

- **Less chance of needing dialysis.** With a living donor, the transplant process can often be faster. In contrast, the average wait for a non-living donor kidney is likely 3 to 5 years, making dialysis necessary.
- **A better match.** If your donor is a family member, their kidney may be a better genetic match. This lowers the risk that your body might reject the new kidney.
- **More immediate (and long-term) success.** Kidneys from living donors typically start working right away. Some kidneys from those who have recently died do not work right away, making it necessary to have dialysis until the kidney starts to work.
- **More flexibility.** The transplant can be scheduled when it is convenient for both you and the donor. (With a non-living donor kidney, the kidney must be transplanted within 24 to 48 hours of becoming available.)

If you do not have a living donor that is a good match, you may qualify for an exchange program where your living donor donates their kidney to someone else and you get a kidney from another person's living donor. If a living donor is not available, you will need to get on the deceased donor kidney wait list. Talk to your doctor about your options for getting on the waiting list when your eGFR is less than 20.



“It made such a difference to start talking with my doctor about transplant long before I needed the transplant. I was able to plan for my future and know what to expect.”

— Ella, kidney transplant patient

The **Organ Procurement and Transplantation Network (OPTN)** is the national network overseeing organ donations and managing the waiting list. About 70 out of every 100 kidney transplants involve non-living donor kidney donations. All transplant centers must be members of OPTN and follow their guidelines. You can learn more about OPTN at optn.transplant.hrsa.gov.

For more information about **Intermountain Health's Living Donor Program**, scan the code at right or visit intermountainhealthcare.org/services/transplant-services/become-donor/. You may also contact Intermountain's Transplant Services by calling 801-507-3380.



OPTN



Transplant
Services

Kidney Transplant (continued)

How will having a transplant affect my lifestyle?

Having a kidney transplant is the treatment option that provides the most similar lifestyle to what you experienced before kidney failure. Once you recover from surgery, you will be able to continue to work, attend school, travel, and enjoy most of the same activities and hobbies.

You will, however, need to modify some activities to protect your new kidney and take extra precautions to avoid infections. Follow your transplant team's directions for the level and type of activity that will keep you healthy.



In Focus: Medically qualifying for a kidney transplant

When you are referred to a transplant center, your transplant team will run tests to see if this is a safe and beneficial option for you.

This evaluation will include blood tests, imaging scans, and other tests. Doctors will check you for other serious conditions, including chronic infections, cancer, and heart and blood vessel (cardiovascular) disease. One way to speed up this process is to stay current on vaccines, cancer screenings, and all preventative dental and medical care.

Medical qualification can be impacted by many different factors. For example:

- **Age:** Generally, for those over 70, the decision to transplant requires careful coordination between the transplant center and your doctors.
- **Other illnesses:** Conditions that could make a transplant more difficult include heart and lung disease, diabetes, active cancer, bleeding disorders, birth defects, or active infections like HIV.
- **Additional considerations:** Obesity, tobacco use within 3 months, or alcohol or substance abuse may disqualify you.

Having a history of not following doctors' instructions, not taking medications as directed, or not keeping appointments, as well as having uncontrolled or untreated severe mental health issues, could make it difficult for someone to manage post-transplant care.



Kidney Transplant (continued)

Where can I learn more?



Talking About Transplantation — (transplantliving.org/kidney/)

United Network for Organ Sharing (UNOS).



National Kidney Foundation (kidney.org/atoz/atozTopic_Transplantation)

Dedicated to the awareness, prevention, and treatment of kidney disease, this organization has a wealth of online resources and a regular newsletter.



Medicare Coverage of Kidney Dialysis and Kidney Transplant Services — ([medicare.gov/publications/10128-medicare-coverage-esrd.pdf](https://www.medicare.gov/publications/10128-medicare-coverage-esrd.pdf))

Booklet that explains how Medicare pays for kidney transplant services and provides resources for assistance.



Intermountain Kidney Transplant Services ([intermountainhealthcare.org/ services/transplant-services/services/ kidney-transplant/](https://intermountainhealthcare.org/services/transplant-services/services/kidney-transplant/))

Both Intermountain Medical Center and Children's Hospital are UNOS transplant centers.



Dialysis

Even those who are good candidates for a kidney transplant may need to have dialysis treatments while they wait for a donor. Dialysis will help maintain your health, and there are different options to choose from. In this section, you will learn about peritoneal dialysis (PD) and hemodialysis (HD), as well as information that may help you decide which option is best for you. There is also information on access surgery for HD and PD and routine lab tests necessary for everyone who chooses dialysis.

Types of dialysis

There are 2 main types of dialysis:

1 Peritoneal [per-i-tuh-NEE-uhl] **dialysis (PD)** is when the blood is cleaned inside your body using the lining of your abdomen. This lining is called the **peritoneum** [per-i-tn-EE-uhm].

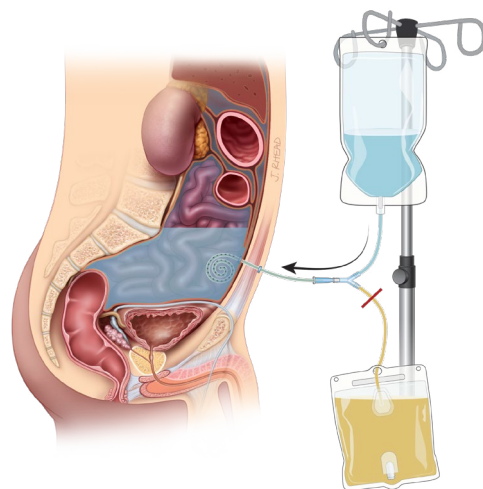
There are 2 ways that PD can be done:

- **Automated PD (APD), sometimes referred to as continuous cycling peritoneal dialysis (CCPD)**, which uses a machine to do your dialysis while you sleep.
- **Continuous ambulatory PD (CAPD)**, which is done manually several times during the day.

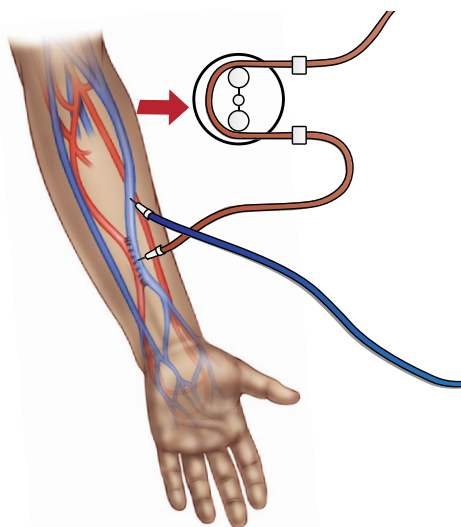
2 Hemodialysis [hee-moh-die-AL-uh-sis] **(HD)**, is when the blood is filtered and cleaned outside of your body using an artificial membrane called a dialyzer [DIE-uh-lie-zer] and a machine. HD requires a surgery to connect an artery to a vein. This allows access to your bloodstream for HD treatments. Hemodialysis is typically performed at home or at a center:

- **Home hemodialysis (HHD)** is done by you or a caregiver in the comfort of your own home.
- **In-center hemodialysis (ICHD)** is done by trained dialysis staff at a set time in a dialysis center.

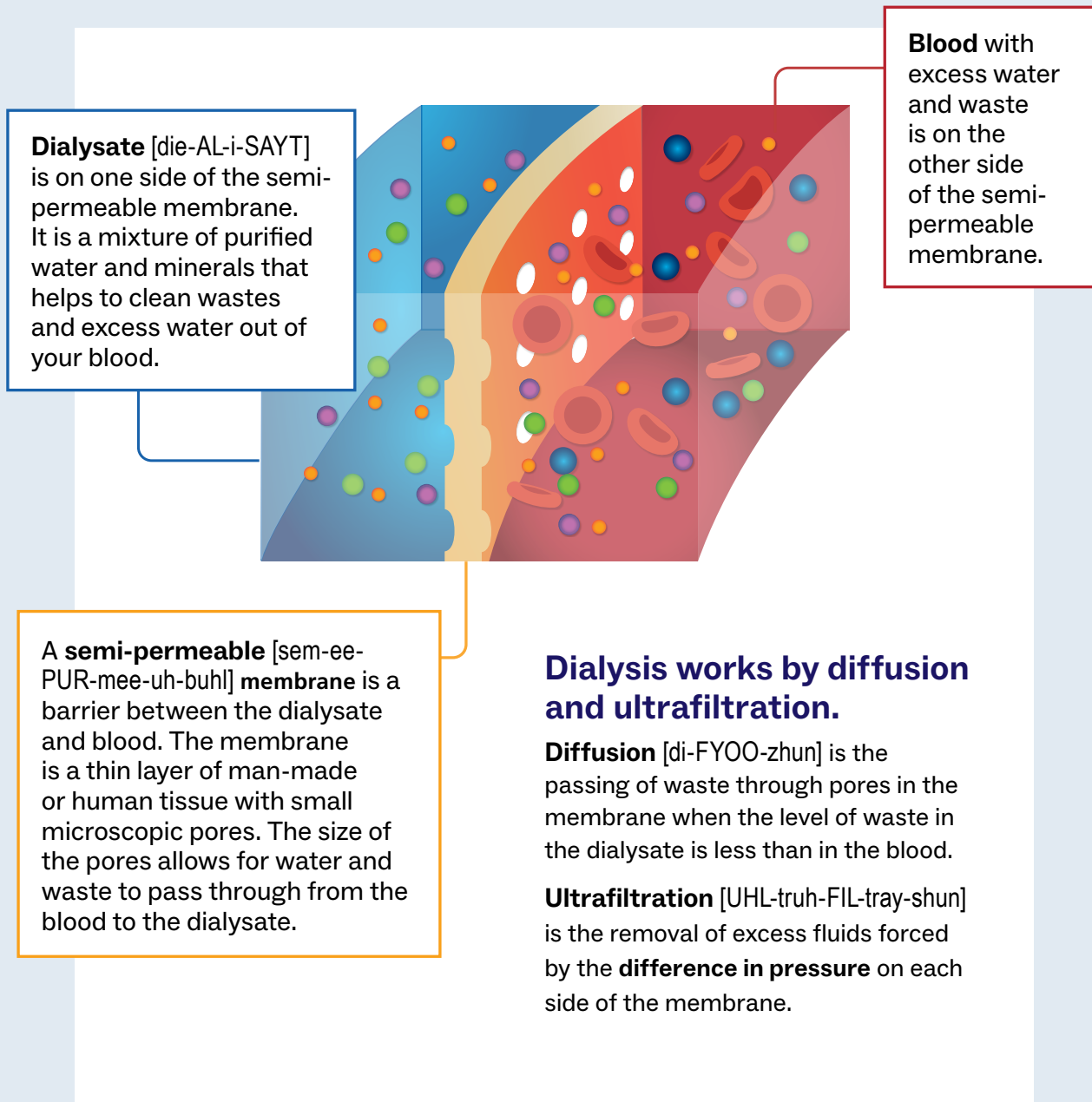
Peritoneal dialysis



Hemodialysis



In Focus: The science behind dialysis



Dialysis and your lifestyle

Talk with your healthcare team about the things that may affect your treatment choice. Together, you can determine what type of dialysis would be best for you.

Situations to consider may include:

- How far you live from a dialysis center
- If you have dependable transportation
- If you have a job or school schedule that allows flexibility
- The freedom to travel

Side effects, complications, or both can occur with either form of dialysis, including:

- Cramps
- Itchy or dry skin
- Shortness of breath
- Chest pain
- Dizziness
- Decreased appetite
- Fatigue (extreme tiredness)
- Numbness in your hands or feet
- Nausea or upset stomach
- Problems with your dialysis access

Your care team will help you manage any side effects you might experience. Most people who choose peritoneal dialysis (PD) or home hemodialysis (HHD) find they have fewer side effects than those who choose in-center hemodialysis (ICHHD) because they are getting more frequent dialysis, which more closely resembles functioning kidneys.



“My healthcare team helped me make a decision about dialysis that was best for my lifestyle.”

~ Robert, dialysis patient

What I need to know about peritoneal dialysis (PD)

Peritoneal dialysis is a slow, gentle, and continuous process that cleans your blood inside your body using the lining of the abdomen (peritoneum). This lining forms a “sac” that contains most of the abdominal organs (the peritoneal cavity).

How does it work?

A catheter (small tube) in your abdomen allows dialysate fluid to flow in and out. A **cycle** is the total amount of time needed for an exchange and dwell to occur. The time when the dialysate fluid is in the peritoneal cavity and blood is being cleaned is called the **dwell time**. The draining and refilling of dialysate is called an **exchange**. Exchanges are done in 1 of 2 ways:

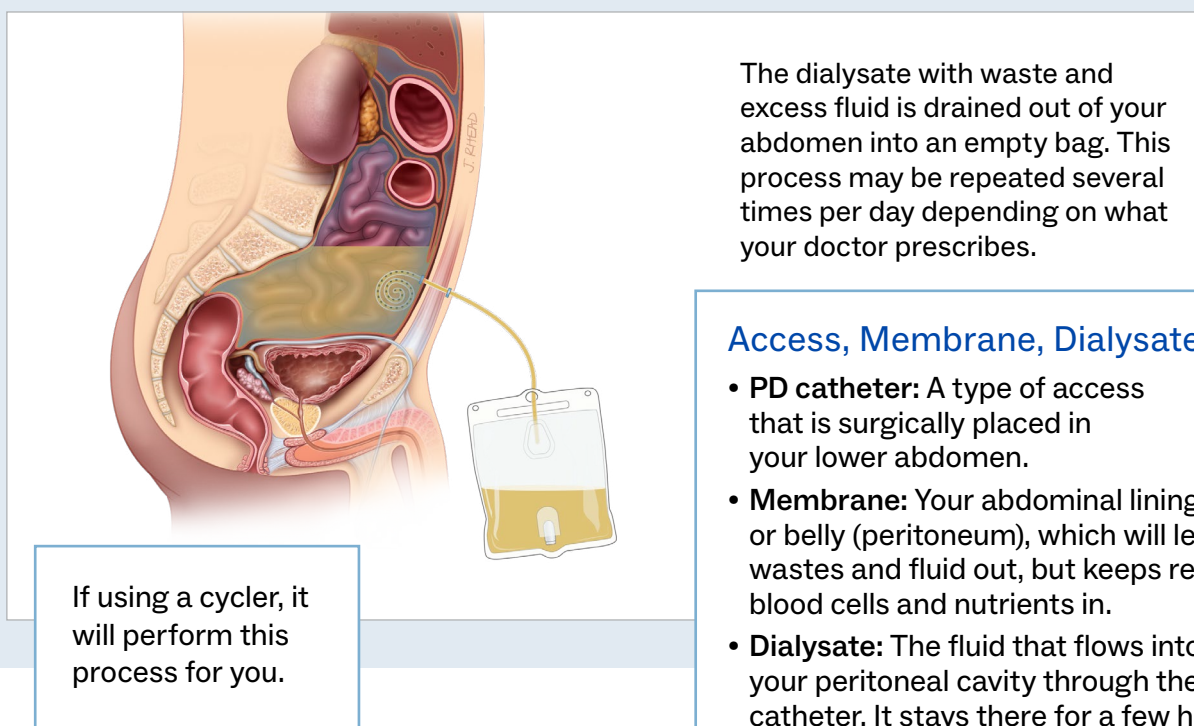
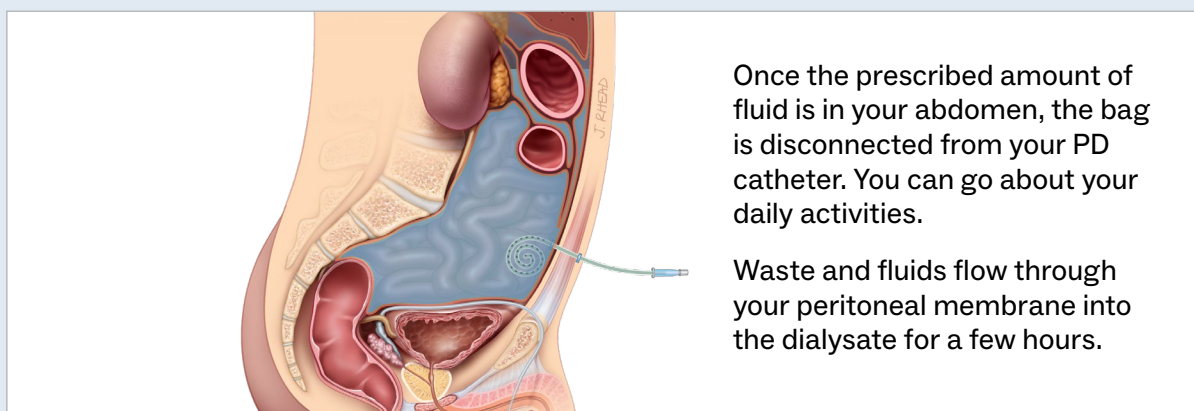
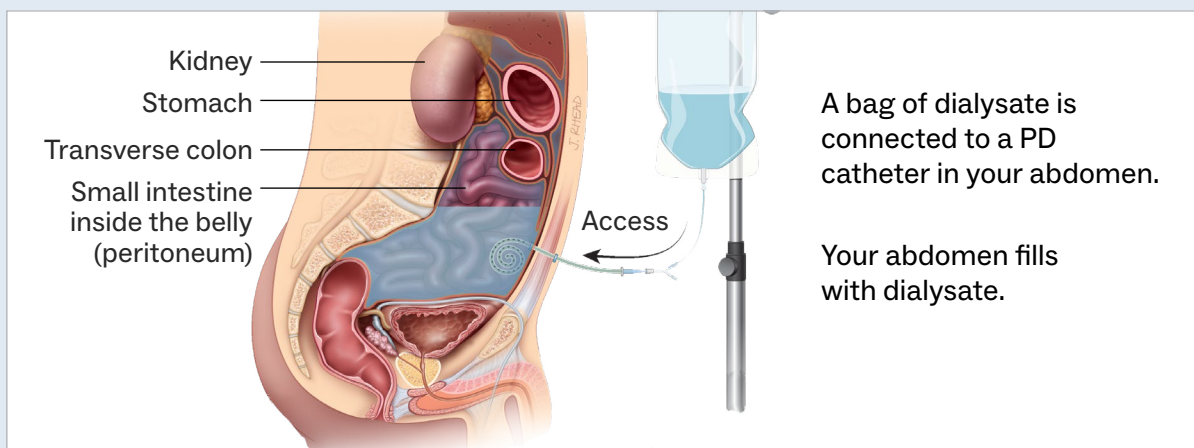
- **Continuous Ambulatory Peritoneal Dialysis (CAPD).** You manually connect your PD catheter to tubing that is connected to a bag of dialysate solution. You control the flow of the fluid into and out of your peritoneal cavity. This is done usually 4 times a day with each exchange taking around 30 minutes to finish. You can be active while the fluid dwells.
- **Automated Peritoneal Dialysis (APD).** A cycler (PD machine) performs a prescribed number of exchanges and dwells, typically while you sleep. This process takes 8 to 10 hours.



With either method, dialysate stays in your peritoneal cavity for several hours, slowly drawing waste products and extra fluid out of your blood and into your peritoneal cavity. The dialysate with the waste and extra fluid is then drained out of your abdomen through the PD catheter. The peritoneal cavity is then refilled with fresh dialysate.

Your lifestyle may be a factor in deciding to try CAPD, APD, or a combination of both. The benefits and side effects are the same with either option.

Continuous Ambulatory Peritoneal Dialysis (CAPD)



Access, Membrane, Dialysate

- **PD catheter:** A type of access that is surgically placed in your lower abdomen.
- **Membrane:** Your abdominal lining or belly (peritoneum), which will let wastes and fluid out, but keeps red blood cells and nutrients in.
- **Dialysate:** The fluid that flows into your peritoneal cavity through the PD catheter. It stays there for a few hours, and is drained from your peritoneal cavity through the PD catheter.

What about access for PD?

Before beginning peritoneal dialysis, you will need to have surgery to place a soft, flexible tube (about the size of a drinking straw) through the wall of your abdomen and into the peritoneal cavity. The surgeon will make a tiny cut, insert a tube with “cuffs” that hold the catheter in place and help prevent infection. The incision is closed and the tube that remains outside of your body is taped to your abdomen.

A PD nurse will monitor your healing and teach you how to care for your catheter during dialysis as well as how to keep it clean to prevent infection. Training and treatments typically start within a week or two after getting your catheter.



How do I care for my PD access?

To prevent infections and stay healthy, you will need to take extra care to keep the access clean. Be sure to:

- Wash your hands with soap and water before handling or using the catheter.
- Clean your catheter and access site using the recommended techniques and soaps.
- Follow all instructions when connecting and disconnecting your PD catheter.
- Apply any antibiotic creams prescribed by your provider.
- Avoid swimming in public pools and freshwater sources.
- Avoid bathing in a tub. Shower instead.
- Keep the catheter protected from being pulled on or snagged.
- Avoid pressure or strain on your abdomen. Practice safe lifting techniques.

How do I get the most from my PD treatments?

- Do not skip treatments.
- Establish a schedule that works for you and stay on it.
- Follow all diet and fluid restrictions your doctor recommends.
- Follow the advice of your doctor and dialysis staff.
- Be an active participant in your care.
- Take care of your access.
- Establish and expect frequent communication from your care team.
- Go to all of your appointments.

Why choose PD?

Peritoneal dialysis is done by you (perhaps with the help of a caregiver) in your own home. People choose PD because it allows more freedom to work, travel, and care for children because there is no requirement to be at a center at a specific time 3 times a week, and supplies are portable.

Other benefits include:

- **Feeling better.** PD is more like having working kidneys since your blood is being cleaned more often.
- **No needles.** PD requires a simple connection to your PD catheter.
- **Flexibility.** You control your treatment schedule and can continue to work, do sports, or travel.
- **Fewer dietary restrictions.** You may be able to eat and drink with fewer restrictions.
- **Fewer medications.** With PD, you may take fewer medications.
- **Residual kidney function.** PD may help preserve any remaining kidney function.

What about side effects?

Peritoneal dialysis may cause side effects, including:

- A feeling of fullness, especially when the peritoneal cavity is filled with dialysate fluid
- Increased blood sugar levels in people with diabetes
- Infection
- Weight gain

If you experience any side effects, talk to your care team. Your care team will work with you to create an individual plan to help manage any side effects.



If you are interested in peritoneal dialysis, ask to meet with the home dialysis team.

What do I need to know about hemodialysis?

Hemodialysis (or HD) is a process that uses a specialized machine and an artificial kidney called a dialyzer to clean your blood outside of your body.

A dialyzer acts as a filter, removing waste products and excess fluid. Only about 8 to 10 ounces (1 to 1½ cups) of blood are being cleaned by the dialyzer at any one time. The blood is continuously circulated, cleaned, and returned to your body during treatment.

There are 2 parts to the system:

- A **dialyzer** [DIE-uh-ly-zer] is made up of small, hollow tubes. Each of these tubes is a semi-permeable membrane with very tiny holes that allow fluid and waste to pass through. Red blood cells and other nutrients are larger and do not pass through the tiny holes in the membrane.
- The **dialysis machine** moves the dialysate fluid through the dialyzer, allowing particles that pass through the semi-permeable membrane from the blood to be collected in the dialysate fluid and drained.

How does it work?

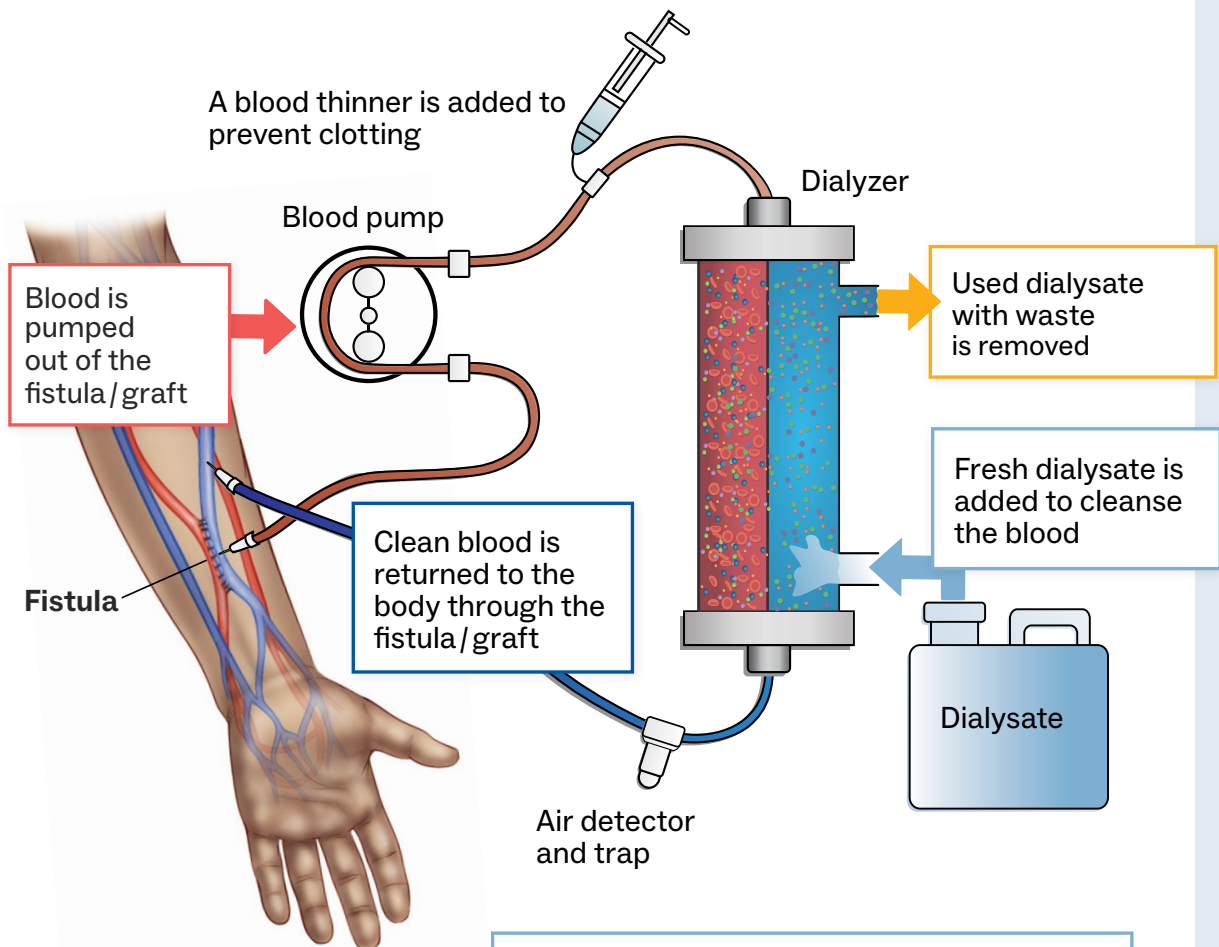
During each hemodialysis treatment, a technician, nurse, or you will access your fistula, graft, or hemodialysis catheter. Two needles are used to access a fistula or graft. Your access is connected to tubing which is used to take your blood to the dialyzer, which is attached to the dialysis machine. The machine has a pump that moves blood from your access through the dialyzer and back to your access after it is cleaned.



“My dialysis care team guided me through what would happen with the process of hemodialysis. Once we started, I felt very informed and secure.”

— *Tamara,*
hemodialysis patient

Hemodialysis (HD)



Access, Membrane, Dialysate

- **Access:** A surgically-placed fistula or graft
- **Membrane / dialyzer:** Small, hollow tubes with microscopic holes that filter waste and excess fluid
- **Dialysate:** Cleans the blood by collecting excess fluid and wastes. It also helps balance electrolyte levels. Once used, this fluid is discarded down a drain.

When and where would I have hemodialysis treatments?

Depending on the type of hemodialysis you choose, this process typically takes around 12 hours* per week if done in a center or around 24 hours* per week if done at home. Dialysis done for a longer period of time results in improved health and fewer side effects.

Treatment times will be adjusted to meet your body's needs. You will have regular blood tests to see how well the treatment is working.

For home hemodialysis (HD), you will need to do treatments 5 days a week, typically for around 3 hours* each time. You and a family member or other caregiver will attend training sessions for 4 to 6 weeks to learn how to use the equipment and manage treatments. During training, you will have your treatments at a dialysis center.

For in-center hemodialysis (ICHD), you will need to have treatments 3 times a week, typically for about 4 hours each time.

If you choose to go to a center for your hemodialysis you will need to:

- Be on time for every appointment
- Attend all scheduled dialysis treatments
- Arrange for transportation to and from dialysis

Nocturnal dialysis (if available in your area) is another option. It can be done at a dialysis center or at home. If at a dialysis center, it requires 3 visits* a week. If at home, it may be done 3 to 6 times a week. Having longer dialysis treatments allow for better cleaning of your blood and is more gentle on your body.

In general, patients who do dialysis more often have a shorter recovery time after treatment. This allows for a better quality of life. Additionally, some are able to reduce their medications and have fewer dietary restrictions.

*Times will vary according to your specific needs. Things that could affect your time commitment include but are not limited to: transportation, machine setup and take down, ordered treatment time, and fluid removal needs.



What do I need to know about a hemodialysis access?

Your access is your lifeline. Without a working access, dialysis cannot take place.

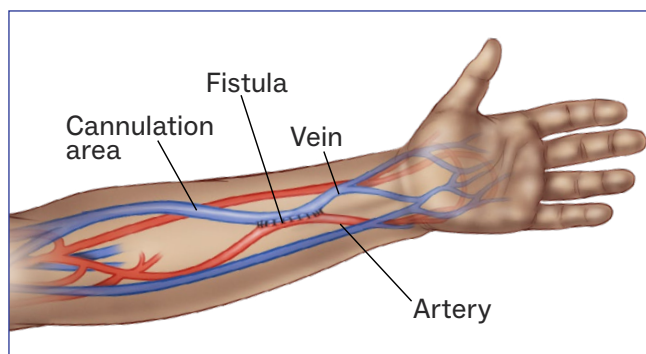
A key part of hemodialysis is having easy access to your blood system. To do this, an artery is connected to a vein. This creates a stronger blood vessel with higher blood flow where 2 needles will be inserted.

What is access surgery?

Hemodialysis access requires surgery several weeks to months before you begin treatment. Access surgery creates a link between a major artery and vein through either a **fistula** or a **graft**. This is an outpatient surgery done at either a hospital or surgical center.

For those who need hemodialysis and cannot wait the weeks needed for a fistula or graft to heal and be ready to use, the only other access option is a hemodialysis **catheter**. A hemodialysis catheter is a narrow tube that is put into a major vein in your neck, chest, or groin. This option is typically used temporarily while a fistula or graft heals or when those options are not possible.

Because the hemodialysis catheter is both in and outside of your body, your risk of an infection, which can be life threatening, is much higher with this type of access.



What is a fistula?

A fistula directly connects a large vein to a nearby artery. The high-pressure flow from the artery into the vein causes the vein to enlarge and become stronger. This “maturing” process will take 8 to 12 weeks before your fistula will be ready to use for hemodialysis. To help your fistula mature, your doctor may suggest squeezing a rubber ball or doing other exercises.

A fistula is often the best access option because:

- It is permanent and safer than the other options.
- There is less risk of infection.
- If taken care of properly, it can last for many years.

What is a graft?

A graft is like a fistula but uses a small tube that connects the artery and vein.

Usually a fistula is considered first, however, for some people a graft is the better option.

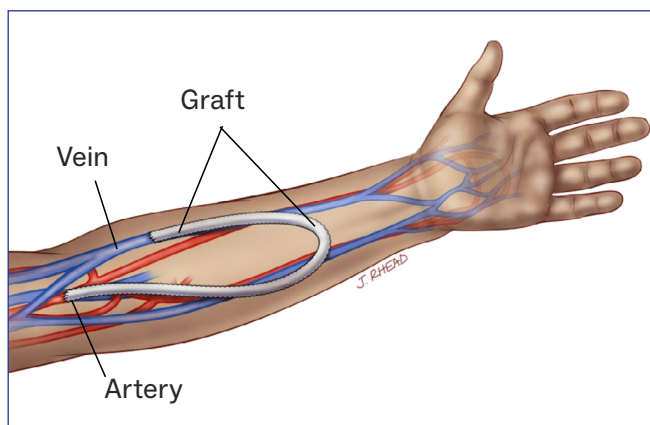
Grafts typically:

- Last for 3 to 5 years before it needs to be replaced
- Have a greater risk of infection and blood clots, compared to a fistula

When you have a graft placed under the skin, you will have bruising, swelling, and discomfort. After about 2 weeks, the swelling will go down, and the access will be ready to use.

How do I know my fistula or graft is working properly?

When your fistula or graft is functioning normally, you should be able to feel a vibration or buzz. This is called a **thrill** and indicates that blood is flowing through the fistula or graft. If you can hear it, you should hear a swishing noise, called a **bruit** [bru-ee].



How do I care for my fistula or graft?

Caring for your fistula or graft is vital to the success of your dialysis treatments. You will need to:

- Keep your access clean at all times.
- Wash your hands with soap and water before touching the access.
- Check for a bruit and thrill everyday.
- Only use the access site for dialysis, and carefully wash the site before each treatment. Your care team will show you how.

When should I call my care team?

Call your care team right away if you experience any of the following:

- Swelling, redness, soreness, or puss around the site.
- A fever of 100.3° F (38.0° C) or higher.
- Bleeding at the site.
- No pulse, or thrill (buzzing), through the fistula or graft.
- A change in feeling in the arm or leg with the access. Signs of a problem include numbness, weakness, tingling, or all of these.

Hemodialysis access care tips

DO

- ☐ Keep your nails trimmed.
- ☐ Avoid exposing the access to extreme cold.
- ☐ Wash your access with antibacterial soap before dialyzing.
- ☐ Leave your post-dialysis dressing on for up to 6 hours.
- ☐ Between treatments, check your access frequently for the thrill (buzz). If you cannot feel it, call the dialysis center or your doctor right away.
- ☐ Watch for signs of infection, including redness, drainage, warmth at the site, or fever.
- ☐ Follow all instructions given by your surgeon, including activity and lifting restrictions.

DON'T

- ☐ Lie on your access.
- ☐ Wear tight clothing, jewelry, or watches.
- ☐ Sleep with your access above your head or under your pillow.
- ☐ Use your access limb to measure blood pressure, draw blood, or get intravenous (IV) solutions.
- ☐ Pick or irritate any scabs or abrasions on your access.
- ☐ Carry purses or shoulder bags with your access arm.

In Focus

Home Hemodialysis

You may have the option of doing home hemodialysis treatments. Home hemodialysis can offer you greater flexibility and control over your treatment. Some of the benefits are:

- Saving time and money with fewer trips to a dialysis clinic.
- Ability to plan dialysis around work or other activities.
- You may feel better due to more frequent dialysis treatments — this means your treatments are shorter and you'll have less waste and fluid buildup in your body.
- Easier travel. Some machines are small enough for domestic travel.
- Fewer dietary restrictions may be possible.

Before considering home hemodialysis, ask yourself these questions:

Can I manage my own treatment? After 4 to 6 weeks of training, you and your caregivers will be responsible for your treatments. This includes setting up and caring for the equipment, placing needles, keeping treatment records, and ordering and storing the supplies. You will also be responsible for disposing of used medical supplies. Your care team will help you learn how to do these things. During dialysis, you will likely need to have someone present the entire time to ensure your safety.

Do I have the right space for home dialysis? A safe environment is required for home dialysis. Our team will visit the intended home dialysis environment to ensure it is safe and meets requirements. You will need a 10-foot by 10-foot space for the dialysis machine and reclining chair as well as easy access to electrical power and plumbing. You will also need space to store your supplies.

Other Treatment Options

Palliative care

Palliative [PAH-lee-uh-tiv] **care** is a medical specialty that focuses on helping people manage the symptoms, burdens, and stress of living with a serious condition such as chronic kidney disease. Palliative care is available to anyone diagnosed with a serious condition. Palliative care is **not** end of life care or hospice care. You may continue to receive curative treatments while receiving palliative care services.

Palliative care can start at any age, or any stage of CKD or ESKD and can continue as long as needed. Palliative care can be a beneficial service during significant and life-changing transitions of care, such as when starting dialysis. Palliative care providers have expert training on how to help patients identify their personal goals for their health and understand their choices for medical treatment. Talk to your care team about how palliative care might benefit you.

Medical management without dialysis (MMWD)

Medical management without dialysis — or MMWD — is used when a person with CKD decides that they do not want to pursue dialysis or have a kidney transplant. The goal of MMWD is to provide medication management and other therapies to manage symptoms related to CKD for as long as possible. MMWD allows patients to continue seeing their nephrologist and other healthcare providers. When the time comes to transition to end-of-life care, a referral to hospice is made.

Hospice care

Hospice care focuses on providing care, comfort, and quality of life to people with a serious illness who are approaching the end of life. They focus on quality of life as opposed to length of life. Hospice care is typically provided in the final weeks or months of life. The goal of hospice care is to manage symptoms and allow a person to make decisions about what they want their end of life to be. When a person chooses hospice, they are no longer actively seeking treatment or a cure for their condition. To be approved for hospice care, a provider must certify that the patient's life expectancy is 6 months or less.



Average outcomes for the different treatment options

- People who have a **kidney transplant** tend to live longer than those who have dialysis. Most people who have a transplant are still living 10 years after surgery.

How long a person lives after transplant depends on many things, including:

- The source of the donated kidney
 - Your age
 - Other conditions you may have, such as diabetes, cardiac conditions, cancer, or high blood pressure
 - How your body reacts to anti-rejection medications
 - How closely you follow your treatment plan
- On average, people on **dialysis** live an additional 5 to 10 years. Life expectancy on dialysis depends on many things, including:
 - The medical conditions you may have
 - How well you follow your treatment plan
 - For those who choose MMWD, life expectancy varies depending on other conditions you may have. Talk to your provider for more information about your specific situation.
 - Those who choose **hospice care** may live from a few days to several months, depending on the amount of kidney function they have left and their general health.



Which treatment approach might be right for me?

	I might CHOOSE this because I:	I might NOT CHOOSE this because I:
Kidney transplant	<input type="checkbox"/> Have been told by my doctor that I AM a good candidate for a transplant <input type="checkbox"/> Have a living donor available <input type="checkbox"/> Don't mind taking anti-rejection medications for the rest of my life <input type="checkbox"/> Am comfortable with having surgery	<input type="checkbox"/> Have been told by my doctor that I AM NOT a good candidate for a transplant <input type="checkbox"/> Don't have a living donor and worry about having to wait too long for a kidney to become available <input type="checkbox"/> Don't want to take anti-rejection medications for life <input type="checkbox"/> Don't want to have surgery
Peritoneal dialysis (PD)	<input type="checkbox"/> Want the freedom to plan my treatments around my schedule, either during the day or at night <input type="checkbox"/> Don't want to have to stop working or traveling <input type="checkbox"/> Like home treatment that I can do by myself <input type="checkbox"/> Feel comfortable managing my treatments <input type="checkbox"/> Don't like needles or the idea of having an access in my arm	<input type="checkbox"/> Would rather not manage treatments myself <input type="checkbox"/> Would not be able to swim, soak in a hot tub, or take a bath, except in certain circumstances <input type="checkbox"/> Don't want to have multiple treatments daily <input type="checkbox"/> Worry that treatments at night will disrupt my sleep or affect intimacy with my partner <input type="checkbox"/> Am concerned about weight gain or insulin problems from absorbing sugar from the solution
Home hemodialysis (HHD)	<input type="checkbox"/> Want to have treatments done in the comfort of my home <input type="checkbox"/> May be able to have shorter, more frequent treatments at a time that is convenient for me <input type="checkbox"/> May have less build-up of toxins and fluid between treatments, which may improve my quality of life <input type="checkbox"/> May need less blood pressure medication <input type="checkbox"/> May have increased ability to travel <input type="checkbox"/> May have fewer dietary restrictions	<input type="checkbox"/> Don't have 4 to 6 weeks to devote to training <input type="checkbox"/> Am unsure how shorter, more frequent treatments would fit into my schedule <input type="checkbox"/> Worry about having enough space to store supplies <input type="checkbox"/> Would rather not insert my own needles and my caregiver is unwilling to insert the needles
In-center hemodialysis (ICHD)	<input type="checkbox"/> Can easily get to a dialysis center 3 times a week and do not have the resources to do home dialysis <input type="checkbox"/> Like healthcare providers doing my treatments and do not have a caregiver committed to helping me at home <input type="checkbox"/> Prefer spending time with other patients during treatments	<input type="checkbox"/> Want more freedom to plan my treatments around my schedule, continue to work, and enjoy travel <input type="checkbox"/> Have no dialysis facilities nearby, or have trouble getting there <input type="checkbox"/> Don't want to deal with needles or have access surgery <input type="checkbox"/> Worry that I will feel sick too much of the time
MMWD	<input type="checkbox"/> Don't want to have dialysis right now <input type="checkbox"/> Want to manage my kidney disease through lifestyle and am comfortable transitioning to hospice when the time comes	<input type="checkbox"/> Want to pursue transplant or dialysis to extend my life
Hospice care	<input type="checkbox"/> Feel that treatment will not extend my life to any great extent given my age and my other medical conditions <input type="checkbox"/> Would rather have my current quality of life than live longer	<input type="checkbox"/> Want to try treatment that will extend my life

Keep in mind that the treatment approach that works best for you now might change in the future.

Paying for Treatment

An important part of managing kidney disease is knowing what treatment will cost. Insurance coverage is different for each patient. Work with your insurance company to understand your specific benefit. Your care team can provide information on:

- How to get or keep your insurance
- Other ways to pay for non-covered (out-of-pocket) expenses
- How Medicare and Medicaid work
- Where to find answers for all your questions

Insurance words to know:

As you work with your providers and insurance companies, these are some words you need to be familiar with:

- **Policy:** A contract issued by an insurance company that spells out what they will pay and what you are responsible for paying.
- **Effective date:** The date when an insurance policy begins to cover you. Some insurance companies, including Medicare, have waiting periods before they begin to pay medical expenses.
- **Premium:** The amount you pay to an insurance company to get and keep insurance.
- **Claim:** A request to have a medical bill paid. Either you or your provider may send claims to your insurance company.
- **Copayment (co-pay):** A preset cost that you pay out of your own pocket for medical services and prescription medications.
- **Deductible:** The amount you pay out of your own pocket for medical services before the insurance company begins to pay. After the deductible is met, you are then responsible for a percentage of your medical costs, known as coinsurance. You will have to pay the full deductible amount again at the beginning of each year, usually on January 1.
- **Coinsurance:** The percentage of the bill you will need to pay. You usually pay a deductible before you start paying coinsurance. With Medicare, your coinsurance payment is typically 20% of the cost while Medicare pays the remaining 80%.
- **Payer:** Your insurance company may be referred to as a payer — they are paying the medical bills. If you have coverage through 2 or more companies, one is referred to as the primary payer, and the other is the secondary payer.
- **Out-of-pocket expenses:** A general term for the money you personally pay for medical expenses, including copays, deductibles, and coinsurance payments. Some insurance plans offer out-of-pocket limits on how much you will pay during a certain period of time (usually a year). Once you reach the limit, the insurance will pay everything that is covered by your policy for the rest of that year.

Medicare

Medicare is a health insurance program provided by the federal government. The program is open to people:

- With a legally-documented U.S. status
- 65 years or older
- Younger than 65 who have a covered disability
- Of any age diagnosed with end stage renal disease (ESRD) requiring dialysis or a transplant

To qualify for Medicare, you must:

- Have worked the required amount of time to receive Social Security (sliding scale based on age)
- Already receive or be eligible for Social Security benefits
- Be the spouse or dependent child of someone who meets either of the previous two bullet points

Lastly, if you qualify for Medicare only because of permanent kidney failure, your treatment must include dialysis or a transplant.

Medicare can be complicated. Be sure to talk to a local Social Security office about your specific situation.

Medicare offers different plans that will cover different portions of your care:

- **Medicare Part A** covers inpatient hospital care. Most people do not pay a premium for Part A. You will pay a deductible and coinsurance.
- **Medicare Part B** covers general medical care, including doctor visits, outpatient dialysis treatments, home dialysis supplies, and lab services. Under Part B, you will pay premiums, a deductible, and coinsurance. If you are eligible for Part A, you are also eligible for Part B.
- **Medicare Part C**, known as a Medicare Advantage plan, is a special form of Medicare that combines Part A and Part B and usually part D. Eligibility, premiums, and your deductible will vary by plan.
- **Medicare Part D** covers prescription medications. Premiums and copays vary. If you are eligible for Medicare, you can buy a Part D plan. It's important to review your Part D coverage every year to make sure the medications you need are still covered.

If you are eligible for Medicare, you can enroll by calling Social Security at **1-800-772-1213** or by visiting your local Social Security office. Find locations online at www.ssa.gov.

Should I keep working?

Talk with your employer and your care team about continuing to work, even if it means a different type of job or reducing your hours. Consider the benefits:

- Research shows that being employed or otherwise feeling productive helps ESRD patients feel better physically and emotionally.
- You can maintain your employer's group insurance plan.



Understanding Medicare Coverage:

- **You can have a group healthcare plan and Medicare.** For the first 30 months of dialysis treatments, Medicare is the secondary payer. This is known as the “coordination period.” Make sure your provider always has your most up to date insurance information, including copies of your insurance cards.
- **Medicare coverage begins at different times for different treatments.** This means you may have a waiting period. During the waiting period, Medicare will not make any payments for services.
 - **If you are on dialysis,** coverage can begin after you complete 3 months of dialysis treatments. However, coverage can start in the first month if you begin home dialysis training.
 - **If you are getting a kidney transplant,** coverage can begin the first month you are admitted to a Medicare-certified hospital for the transplant or care relating to the transplant. Both Intermountain Medical Center and Primary Children’s Hospital are Medicare-certified transplant facilities.
 - **Waiting periods can start even if you don’t sign up for Medicare.** If you use Medicare at a later time and you’ve already been on dialysis for 4 months or more, there won’t be a waiting period. In some cases, the services you had before you even applied may be paid for. Payment of backdated premiums may be required in this situation.
- **Medicare coverage ends at different times for different treatments.** If you qualify for Medicare only because of kidney failure, your Medicare coverage ends:
 - 12 months after you stop dialysis treatments
 - 36 months after having a kidney transplantMedicare coverage can resume again if your treatment changes. Work with your social worker to complete the necessary Medicare application.
- **Ask your doctor or service provider if they accept Medicare assignment.** Medicare sets limits to how much it will pay for a service, called an assignment. For covered services, your doctor agrees to accept the assignment amount as payment in full. This helps you save money on out-of-pocket expenses.
- **Medicare covers Medical Nutrition Therapy (MNT).** Medical nutrition therapy can help people with chronic kidney disease slow its progression and treat complications through a proper diet. The program offers one-on-one meetings with a registered dietitian nutritionist (RDN) who works with you to develop a personalized eating plan. Your diet plan will help you set healthy limits on sodium, protein, potassium, phosphorus, and calcium. MNT is available to people with kidney disease, diabetes, or a recent kidney transplant. You will need a referral from your doctor, but the service is free if the provider accepts Medicare assignment.

Where to find more information

These websites may provide you with helpful information regarding kidney health, kidney disease, and kidney failure.

Website name	URL	What this site offers
American Association of Kidney Patients	<u>aakp.org</u>	This independent organization sponsors education and advocacy and develops patient communities. AAKP hosts a national meeting, provides a webinar-based education program, and maintains an interactive website covering a variety of education topics related to kidney disease.
Centers for Medicare and Medicaid Services	<u>medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf</u>	Medicare offers a free, downloadable booklet, Medicare Coverage of Kidney Dialysis & Kidney Transplant Services, for patients which explains how Medicare pays for a kidney transplant and dialysis services and provides resources for assistance.
Home Dialysis Central	<u>homedialysis.org</u>	This website provides resources for those who are doing home dialysis. The site offers forums for connecting with others doing home dialysis, stories, information on equipment, and much more.
Kidney School	<u>kidneyschool.org</u>	This program (developed by the nonprofit, Medical Education Institute, Inc.,) provides learning modules in English and Spanish and an audio book covering a variety of topics related to kidney disease. Medical Education Institute, Inc. also publishes a helpful book for dialysis patients: <i>Help! I Need Dialysis</i> .
National Kidney Foundation	<u>kidney.org</u>	This organization has a wealth of online resources and a regular newsletter. It is dedicated to the awareness, prevention, and treatment of kidney disease.
Renal Support Network	<u>rsnhope.org</u>	This non-profit, patient-run support organization offers advocacy and education programs. The website allows users to access the KidneyTalk podcast, a newsletter, a peer support phone line, recipes, resources, and more.
United Network for Organ Sharing (UNOS)	<u>unos.org</u>	UNOS is the private, non-profit organization managing the U.S. organ transplant system. It offers a free booklet, <i>Talking about Transplantation</i> , which is available to download at this location.

Glossary

A

Abdominal cavity (also called peritoneal cavity): The fluid-filled space in your body that contains your stomach, small and large intestines, kidneys, and other major organs.

Access: How you exchange blood or fluid to perform dialysis; either via a specially prepared blood vessel (usually in your arm) through which your blood flows to the hemodialysis machine or a small opening in your belly where a catheter (small tube) is permanently connected.

ACR (albumin-creatinine ratio): A measurement of how well your kidneys are functioning (see also urine albumin and creatinine).

Advanced practice provider (APP): A licensed medical professional (typically a physician assistant or advanced practice nurse) who is part of a healthcare team along with physicians and other providers.

Albuminuria (or proteinuria): A term used to indicate an abnormal amount of protein in your urine (see also urine albumin).

Anemia: A condition that occurs when your body fails to produce enough red blood cells, usually causing you to feel very tired.

Automated Peritoneal Dialysis (APD), sometimes referred to as CCPD: A type of peritoneal dialysis that can be done while you sleep using a machine called a “cycler.”

B

Blood pressure: The force of blood pushing against the inner walls of the blood vessels. When blood pressure is consistently higher than normal, it can damage the kidneys and other organs.

BMI (body mass index): A measure of body size. The result can indicate underweight, normal weight, overweight, and obesity.

BUN (blood urea nitrogen): A waste product (filtered out of the blood by healthy kidneys) that forms when your body breaks down protein in the food you eat. If levels increase, it might mean that your kidneys aren't working properly.

C

Care partner: A family member, loved one, or other support person who will help you with treatments at home.

Catheter: A soft plastic tube that is surgically placed in your body for dialysis. With peritoneal dialysis, the catheter is placed in your abdominal cavity. In hemodialysis, the catheter is placed in a large vein, usually in your neck or chest (see also peritoneal dialysis and hemodialysis).

Cholesterol: A fat-like substance in the blood that can increase your risk for heart and blood vessel disease.

Continuous ambulatory peritoneal dialysis (CAPD): A type of peritoneal dialysis that you do manually throughout the day (see also peritoneal dialysis).

Creatinine: A waste product that forms when you move muscles and is filtered out of the body by healthy kidneys. If you have too much creatinine in your blood, you might have either a kidney or muscle problem.

Cycler: Used in peritoneal dialysis (APD type), this is a small machine that does exchanges for you while you sleep (see also automated peritoneal dialysis).

D

Deceased donor: Someone who has recently died and was an organ donor.

Depression: A treatable, chronic medical condition with symptoms that include the following: Sadness, withdrawal, trouble sleeping and concentrating, being irritable, feeling gloomy or like a burden to others, crying, losing interest in things you previously enjoyed, wanting to give up.

Diabetes: A condition that can cause kidney disease and is related to your body's inability to either make enough insulin (type 1) or use it properly (type 2) to control how much sugar is in your blood.

Dialysate: The cleansing solution used in hemodialysis and peritoneal dialysis (see also hemodialysis and peritoneal dialysis).

Dialysis: A treatment that functions like your kidneys by filtering waste products and extra fluid from your blood when your kidneys are no longer working.

Dialysis center: A place where patients go to receive scheduled dialysis treatments.

Dialysis machine: A special machine that uses an artificial kidney to filter waste products and extra fluid from your blood.

Dialysis technician: A member of your healthcare team specially trained to provide dialysis care under the supervision of a nurse.

Dialyzer: The artificial membrane which is used to remove extra fluid from your blood.

Diet plan: The plan that you and your dietitian will develop to make sure you're eating and drinking the right things in the right amounts each day to be as healthy as possible.

Dietitian: A member of your healthcare team who will help you plan what to eat and drink to help you feel your best.

Dwell time: The period of time the dialysate (fluid) is inside your belly before being drained out (see also dialysate).

E

eGFR (estimated glomerular filtration rate): A test that measures the level of kidney function you have (for example, an eGFR of 50 would mean that your kidneys are functioning only half as well as normal).

ESRD (end-stage renal disease), also called end-stage kidney disease (ESKD): It occurs when CKD reaches an advanced state. In ESRD, kidneys are not longer able to work as they should.

Exchange: The process of draining the solution containing waste products and refilling the peritoneal cavity with fresh dialysate.

F

Fistula: A permanent access for hemodialysis created by surgically connecting a vein and an artery in your arm

Fluid: Any liquid you drink or food you eat that would become liquid at room temperature (such as ice cream, gelatin) as well as some foods that have a high water content (such as watermelon).

G

Glomerulus: The area within the kidneys where waste products are filtered out of the blood to make urine.

Graft: A type of dialysis access created by inserting a soft, plastic tube under your skin and joining it to an artery and vein.

H

HbA1c: A blood test performed for individuals with diabetes that reflects how well blood glucose levels are controlled.

Heart attack: A medical emergency where part of the heart muscle is damaged when oxygen is blocked from reaching it, causing severe chest pain, sweating, nausea, and shortness of breath.

Heart disease: A disorder where there is damage to the heart and the blood vessels that supply the heart muscle. This is caused by heart defects, damage from restricted blood supply, abnormal heart rhythms, blockage due to buildup of fatty deposits, or other causes.

Heart failure: A disorder where the heart cannot pump well enough to move blood and fluids through your body.

Heart-healthy diet: A diet that focuses on foods low in fat, cholesterol, and sodium.

Hemodialysis: A type of dialysis for kidney disease in which your blood is cleaned of waste products and extra fluid using a dialysis machine (see also dialysis machine).

High blood pressure (or hypertension): A condition where the force of blood pushing against the inner walls of blood vessels is above the normally expected range and can cause damage to the kidneys, or cause stroke and other serious medical complications.

Home hemodialysis (HHD): A type of hemodialysis that can be done 3 hours a day, 5 to 7 days a week at home (with advanced training for the patient and the care partner) using a home dialysis machine.

Hormones: Chemicals produced by different glands and organs, including the kidneys, to trigger certain responses in other parts of your body. Kidneys make hormones that control blood pressure, signal your bone marrow to make new red blood cells, and help the body absorb calcium from food instead of taking the calcium from your bones (causing bone disease).

Hospice: Care for patients with less than 6 months to live that offers counseling and support to patients and families.

I

Immunosuppressants: Medications that help keep the body's immune system from rejecting the transplanted organ.

K

Kidney care navigator: A registered nurse who provides education and support, and helps coordinate your care in conjunction with other care team members.

Kidney disease: The loss of your kidney function, which can result from diseases you are born with, injury to the kidneys, or conditions such as high blood pressure or diabetes (see also high blood pressure and diabetes).

Kidney failure: When your kidneys no longer work well enough and a kidney transplant or dialysis treatment is required to keep you alive (see also kidney transplant and dialysis).

Kidney transplant: A surgery where a donated kidney (from either a living donor or a deceased donor) is placed into your abdomen to function in place of your failed kidneys

L

Lipids: Fatty substances found in the bloodstream, such as cholesterol and triglycerides, which can damage organs and cause heart disease when out of balance.

Living donor: A living person who donates one of their kidneys to someone needing a kidney transplant (see also kidney transplant).

M

Medical management without dialysis (MMWD): Care which manages the symptoms of kidney failure without the use of dialysis or transplant

Medical nutrition therapy (MNT): A type of one-on-one nutrition counseling with a qualified dietitian covered by Medicare for qualified patients with kidney disease.

Medicaid: A joint federal-state, need-based health insurance program with state-dictated eligibility requirements and covered services.

Medicare: A federal health insurance program for Social Security recipients that includes hospitalization (Part A) and medical care (Part B) and optional programs for additional coverage available in some areas: Medicare Advantage or Part C, which provides managed care and fee-for-service options, and prescription medication coverage or Part D.

Mineral and bone disorder: A disorder where calcium and phosphorus are out of balance due to kidney disease, resulting in bones losing calcium and weakening while calcium and phosphorus deposits end up in the heart, blood vessels and skin, which increases your risk of heart attack, stroke, or other complications (see also heart attack and stroke).

N

Nephrologist: A doctor specially trained in treating kidneys.

Nocturnal (nighttime) hemodialysis: Longer, slower hemodialysis treatments done while you sleep either at home or at a dialysis center (see also hemodialysis and dialysis center).

NSAIDs (non-steroidal anti-inflammatory drugs): A type of medication used to treat minor pain and inflammation that reduces blood flow to the kidney and can be very harmful.

Nutrients: The substances in food that provide nourishment essential for growth and maintenance of life.

O

Obesity: Having too much total body fat, typically indicated as a body mass index (BMI) of 30 or higher (see also BMI).

P

Palliative care: A medical specialty focused on helping patients manage the burdens and challenges associated with a serious illness, including symptom management and serious illness decision making and planning.

Peritoneal cavity (also called abdominal cavity): The space between the wall of your belly and the organs within your belly.

Peritoneal dialysis: A type of dialysis treatment in which dialysate flows through a catheter into your abdominal cavity, where it collects waste products and extra fluids from the body, and then is drained out through the catheter (see also dialysis, dialysate, catheter, and abdominal cavity).

Peritoneum: The lining of the abdominal cavity (your belly).

Phosphorus: A mineral that is important in bone health and the normal function of nerves and muscles.

Potassium: A mineral that helps nerves to function and muscles to contract. It is found in most foods at varying levels.

Protein: A critical nutrient that helps build muscle, repair tissue, and fight infection (see also urine albumin).

Proteinuria: Having protein in the urine.

R

Red blood cells: Cells in your blood that carry oxygen to all parts of your body.

S

Social worker: A member of your healthcare team specially trained to help you navigate the non-medical challenges of your illness such as the stress of serious illness, finding financial resources, etc.

Sodium: A mineral that helps your body maintain fluid balance; found in table salt and many packaged foods (see also fluid).

Sterile: Free of germs.

Stroke: A medical emergency where a blood vessel is blocked or there is bleeding in the brain that causes brain damage; signs typically include weakness, numbness, blurred vision, confusion, and slurred speech.

Supplements: Vitamins, minerals, herbs, and any other nutrients added to your diet and taken as pills or liquids rather than coming from the food you eat.

T

Transplant center: An outpatient clinic that manages organ transplantation.

Transplant coordinator: The person (usually a registered nurse) responsible for arranging many elements of the transplantation process.

Transplant physician: The healthcare provider (often a nephrologist) who will lead much of your transplant care.

Transplant surgeon: A physician who performs transplant surgery.

U

Urine: A liquid containing waste products filtered from the blood by the kidneys; stored in the bladder until it leaves the body during urination (peeing).

Urine albumin (protein): A protein in the blood that a healthy kidney typically keeps from leaving the bloodstream and being expelled in the urine; albumin in your urine typically means that your kidneys are not working properly.

Urine microalbumin test: A urine test that measures microscopic levels of protein in your urine (less than 30 mg is considered normal).

V

Varicella-zoster virus: The virus that causes chickenpox and shingles.

Vascular surgeon: A healthcare provider who performs the surgery to place a fistula or graft under your skin for access (see also hemodialysis and fistula).

Vitamins: Key nutrients found in a healthy diet that are vital for the body to function properly.



