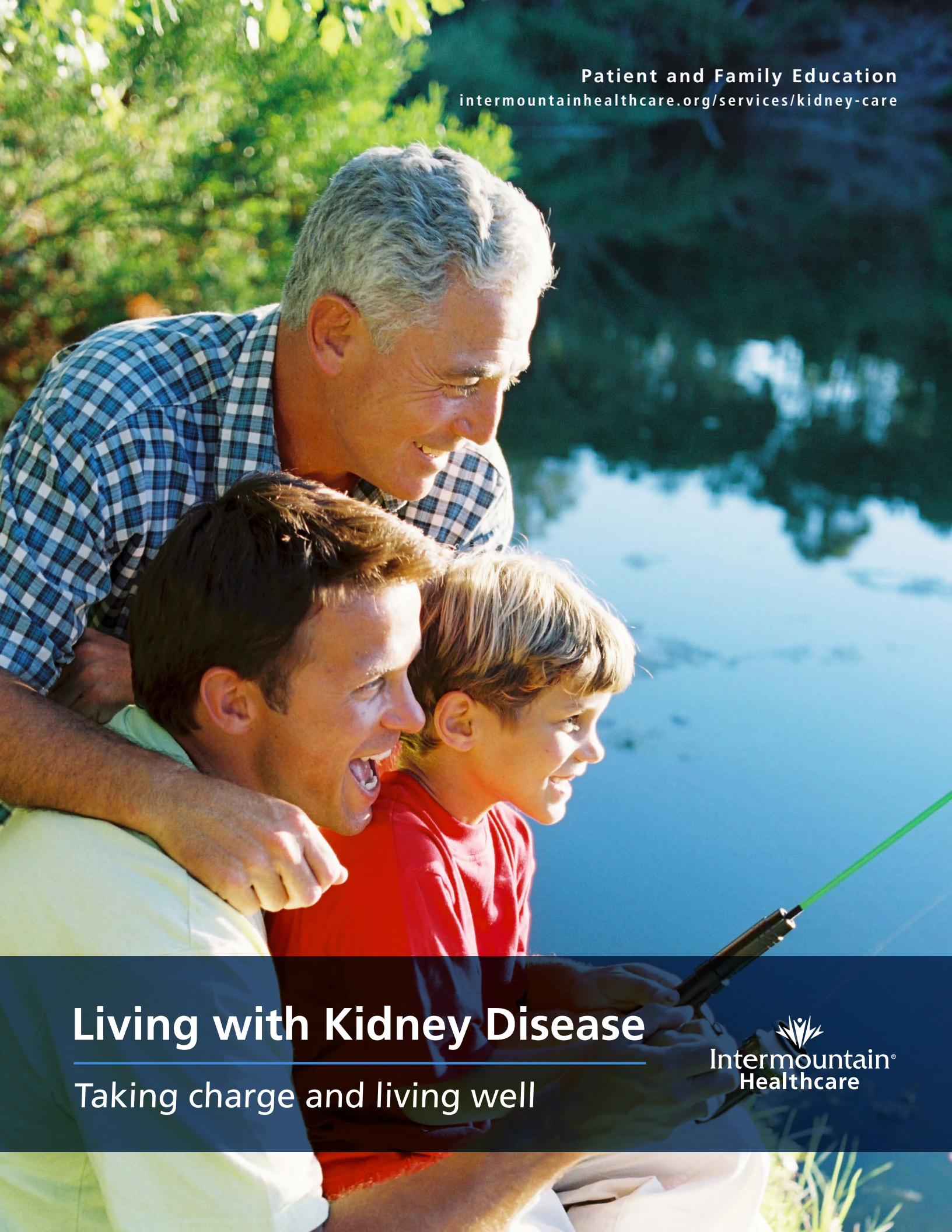


A photograph of a family of three—grandfather, father, and child—fishing by a lake. The grandfather, with grey hair and a blue and white checkered shirt, is leaning over the father and child, smiling. The father, with dark hair and a light green shirt, is also smiling and looking at the child. The child, with light brown hair and a red shirt, is holding a fishing rod with a green line. They are all looking towards the right side of the frame, where the lake and trees are visible. The background is a bright, sunny day with green foliage and a blue sky.

Patient and Family Education
intermountainhealthcare.org/services/kidney-care

Living with Kidney Disease

Taking charge and living well


Intermountain[®]
Healthcare

If you or a loved one has chronic kidney disease, you may feel overwhelmed and discouraged. You probably have questions about the future, and about whether things can get better.

There are many ways to manage chronic kidney disease. This booklet can help. It has information, strategies, and tools that will help you take control and manage the condition — so you can live a fuller, more enjoyable life.

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



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Chronic Kidney Disease: The basics

Chronic kidney disease (CKD) means that your kidneys are not working as well as they should over time, which causes other health problems. Although CKD may get worse over time and lead to kidney failure — also called end-stage renal disease (ESRD) — 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 kidneys are about to fail.
- **You need to get tested.** Blood and urine tests are the only way to know if you have CKD. Get these tests every year or when your doctor recommends.
- **It won't go away.** Without treatment, CKD gets worse over time. It can lead to kidney failure, or ESRD, which can only be treated with dialysis or a transplant.
- **You're in charge.** There are steps you can take right now to keep your kidneys healthier longer and stop CKD from getting worse.

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:

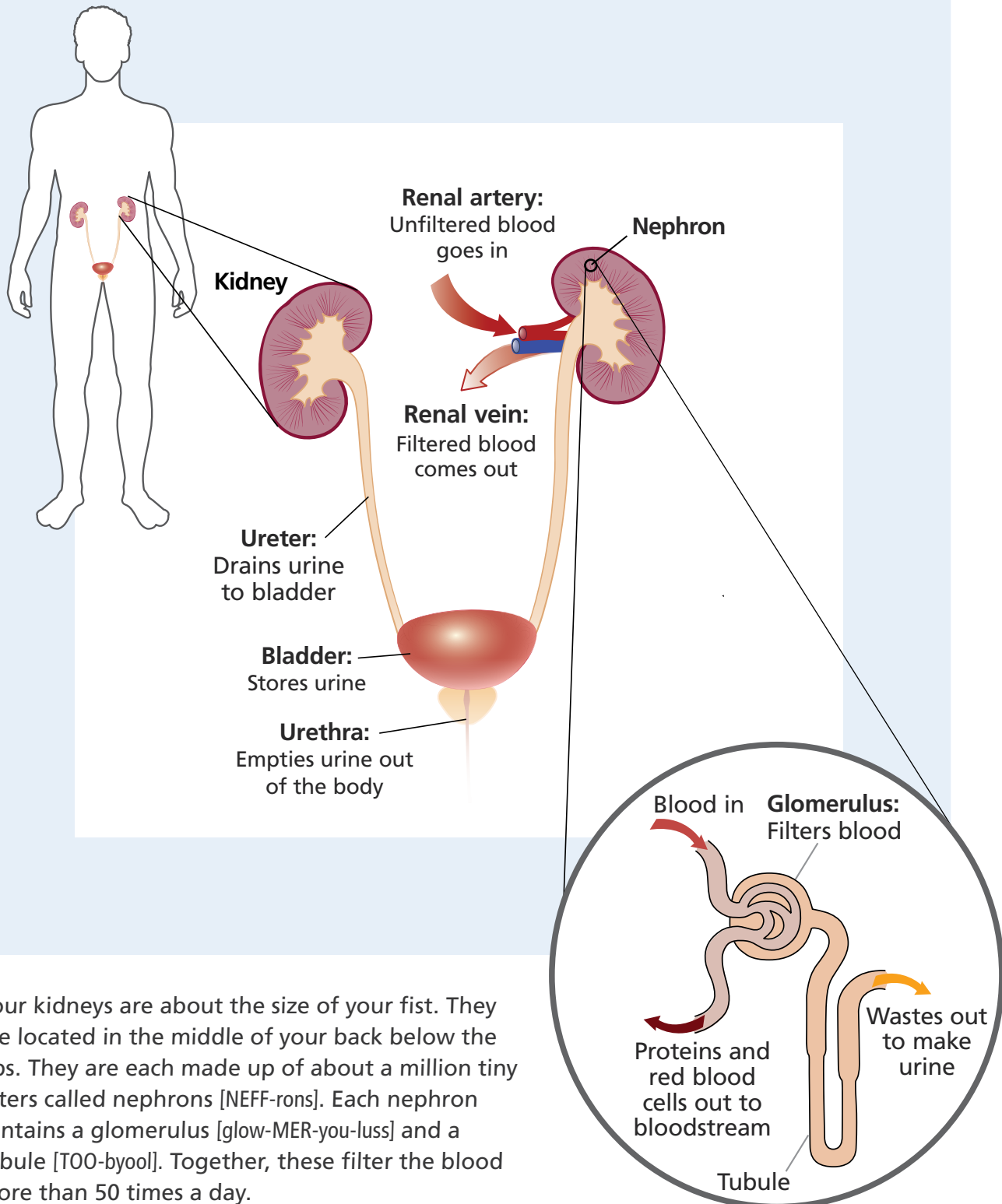
- **Filter wastes from your blood,** removing salts, excess water, and other wastes by making urine (see the picture below). A buildup of wastes in your body can make you very sick.
- **Adjust levels of sodium, potassium, calcium, and phosphorous in your blood.** These are minerals your body needs to 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 get anemia (difficulty getting oxygen throughout your body).



"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

Healthy kidneys



Your kidneys are 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.** Those who take common over-the-counter pain relievers, such as ibuprofen (Advil, Motrin), naproxen (Aleve), and other **NSAIDs** (non-steroidal anti-inflammatory drugs), have a higher risk of developing CKD.

Other causes include immune (disease-fighting) system diseases, long-term conditions that inflame the kidneys, conditions that run in families, and problems that interfere with the flow of urine. Also, many common medications can affect kidney function. **Make sure your doctor is aware of your kidney disease when prescribing or recommending any medication.**

For more healthy lifestyle tips, ask your caregiver for the Intermountain fact sheet, **Better Health with MAWDS.**

How can I prevent the progression of kidney disease?

When diagnosed with kidney disease, you have several options for care. The good news is that there are 7 key ways you can slow the progression of CKD:

- 1 Live a healthy lifestyle.** Maintain a healthy weight, get regular physical activity, and get plenty of rest. Stop smoking and don't use recreational drugs.
- 2 Change your diet.** Make an appointment with a Registered Dietitian Nutritionist (RDN) to help you 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.
- 3 Follow your treatment plan.** Keeping regular follow-up appointments with your doctor is key to managing your CKD and other conditions.
- 4 Manage other medical conditions.** Carefully follow your treatment plan for diabetes and / or high blood pressure. Add at least 30 minutes of physical activity each day to help control them.
- 5 Take medications correctly.** Don't run out of your medications, or take them differently than prescribed. Be sure to talk to your doctor before taking any supplement, vitamin, or over-the-counter medication.
- 6 Avoid NSAIDs.** Medications like ibuprofen or naproxen can make CKD worse.
- 7 Ask for CKD precautions when having tests or procedures.** Only use your "dominant arm" for blood tests and IVs to keep your major arteries strong in case you need dialysis in the future. If any healthcare provider orders an x-ray with contrast dye, ask about kidney-safe options. The dye can damage your kidneys.

In Focus

Stages of chronic kidney disease

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 process. A simple urine and blood test are used to determine if you have CKD. Your nephrologists will use the results of these tests, your age, race, gender, and weight to calculate your Glomerular Filtration Rate (eGFR). The eGFR test is the best test to measure how well your kidneys are cleaning your blood.

There are 5 stages of CKD:

Stage	eGFR Level	Description of Function
1	90 or more (+/- protein in urine)	There are few symptoms in Stage 1 and 2.
2	60 to 90 (+/- protein in urine)	There are few symptoms in Stage 1 and 2.
3	30 to 59 (+/- protein in urine)	Anemia and / or early bone disease may appear. Medications can be used to treat both of these problems down the road. Increased tiredness may be a symptom of anemia. It is recommended that you attend a "CKD Education Class," explaining the types of kidney replacement therapy (types of dialysis, transplant, and conservative care).
4	15 to 30 (+/- protein in urine)	This is the time to be preparing for dialysis and/or transplant. You should attend a "CKD Education Class" if you haven't already. If you should consider dialysis access, an evaluation by a surgeon will be required as it takes a few months for this to be ready to use. Most people will feel more tired.
5	Less than 15 (+/- protein in urine)	Fatigue, decreased appetite and nausea are more common and there may be more problems with fluid retention. Be sure to tell your nephrologist [nuh-FROL-uh-jist] if you have these symptoms.

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 the body has difficulty carrying oxygen throughout it.

Healthy kidneys make a hormone called erythropoietin [ih-rith-roh-POI-i-tin] (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 get anemia. Symptoms include feeling tired, weak, depressed, or short of breath. If not treated, anemia can lead to heart disease.

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 for keeping 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:

- Follow a low-phosphorus diet.
- Ask your doctor about taking a "phosphorus binder," such as Tums, or certain prescription medications.
- Quit smoking, and exercise regularly.



Heart disease

People with CKD are at higher risk of getting 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 are much more at risk for problems such as heart attacks, irregular heartbeat, congestive heart failure, and enlargement of the heart muscle.

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 has more 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 what foods have more potassium.
- Follow a low-potassium diet.
- Read food labels carefully, especially salt substitutes which may contain potassium chloride.



Fluid buildup

With CKD, your kidneys don’t filter out excess fluid from your body, which leads to other health problems.

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 beat faster, make you short of breath, and cause swelling in your feet, ankles, and legs. As CKD worsens, you will need to limit the fluids you take in and avoid salt, which makes your body hold on to fluid.

To limit fluids:

- Follow a low-salt diet.
- Control your blood sugar levels.
- Control thirst with hard candy or gum.
- Meet with a dietitian to learn what foods have more fluid and develop an eating plan.



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 causes more protein to “leak” out of damaged parts of the kidney and can even increase the damage over time.

If you have high blood pressure, be sure to:

- Take medications your doctor prescribes to control your blood pressure.
- Follow a low-sodium diet.
- Stay active every day.
- Maintain a healthy weight.
- Stop smoking and reduce your stress.

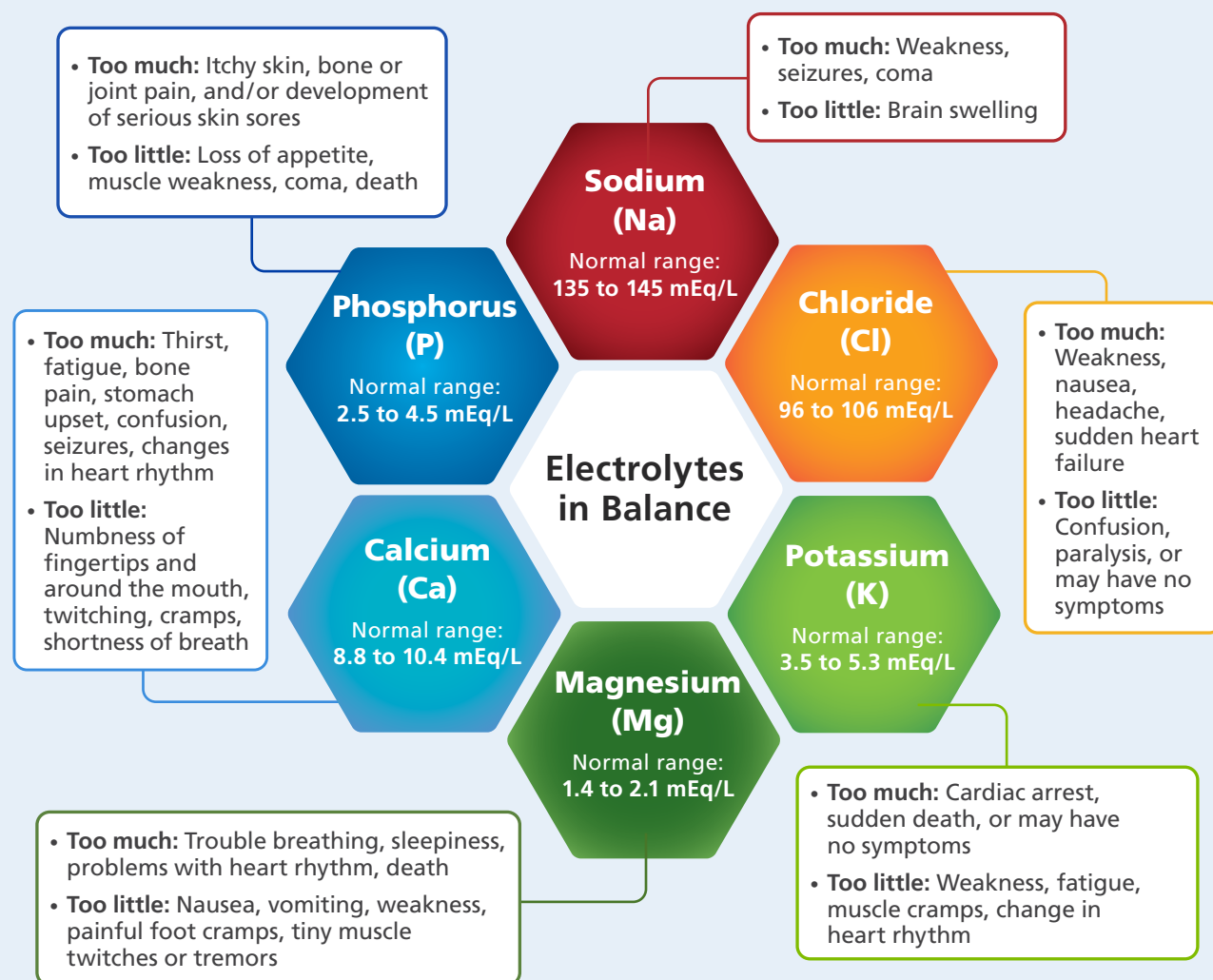
In Focus

Your body's electrolytes

An electrolyte [ih-LEK-truh-lahyt] is a chemical in the fluid in your body (such as urine, blood, and sweat). These chemicals must be in balance (not too much of one or another) 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 during physical activity, sweating, 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 chemicals 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 experience when you have too much or too little of any one of these.



Taking charge

You are in charge of managing your CKD, and your Intermountain Healthcare team is here to help you. Start by talking with your doctor and recording your treatment guidelines and healthcare team's goals in the space below. Then, make notes for your personal goals to slow the progression of CKD. Remember, you are in charge of keeping your kidneys as healthy as possible.

In order to keep track of routine lab work, you will want to meet the goals you and your doctor are looking for (check out the **In Focus** box on [page 12](#)). It covers the most common lab tests your doctor may order to monitor your health when you are on dialysis. Your doctor may need to order other lab tests to manage your personal care needs.

Treatment guidelines

Your current lab results (write down any you know)

eGFR: _____

ACR: _____

Blood Pressure: _____ / _____

HbA1c (if diabetic): _____

Lipids: _____

Sodium: _____

Chloride: _____

Potassium: _____

Magnesium: _____

Calcium: _____

Phosphorus: _____

Other: _____

Your treatment goals

Your treatment goals for preventing your CKD from progressing (write down your goals)

eGFR: _____

ACR: _____

Blood Pressure: _____ / _____

HbA1c (if diabetic): _____

Lipids: _____

Sodium: _____

Chloride: _____

Potassium: _____

Magnesium: _____

Calcium: _____

Phosphorus: _____

Other: _____

In Focus

Lab tests

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

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

What you and your doctor need to know	Name of lab test your doctor orders	Type of test		Compare your test results to these*
		Blood	Urine	
Are my calcium, phosphorus, potassium, and sodium levels in balance?	Blood electrolyte levels	X		Potassium: 3.5 to 5.5 mEq/L
				Calcium: 8.4 to 9.5 mEq/L
				Sodium: 135 to 145 mEq/L
				Phosphorus: 3.5 to 5.5 mEq/L
How well are my kidneys working?	Blood urea nitrogen (BUN)	X		7.0 to 20.0 mg/dL
	Creatinine clearance (CCr)	X	X	Men: 97.0 to 137.0 mL/minute Women: 88.0 to 128.0 mL/minute
	Serum creatinine	X		0.8 to 1.4 mg/dL
Is my condition getting worse?	Glomerular filtration rate (GFR)	X		90+ with little or no protein or albumin in urine
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		Less than 7.0 gm/dL

*** What are the abbreviations in the last column?** Some measurements in the last column tell you and your doctor how much of something is in your blood.

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

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

gm / dL: grams per deciliter

Others tell you how long it takes an amount of something to flow in your body such as mL/minute, which stands for milliliters per minute. (There are 1,000 milliliters in a liter.)

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 provider.** Nephrologists and some Advanced Practice Providers specialize in diseases of the kidneys. When your kidney disease starts to progress, you will be referred to a specialist to help manage CKD.
- **Kidney care navigator/care manager.** Care managers (also called case managers or disease managers) may help coordinate and reinforce your CKD treatment plan.
- **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. Medicare covers 2 visits with a dietitian each year for those in CKD stage 3 or higher.
- **Other healthcare providers.** Pharmacists, exercise specialists, and other healthcare providers may also work with you to help you manage your CKD.
- **Social worker.** The social worker provides a major support service for patients and their families, especially when facing decisions about kidney disease treatment. Your social worker will help you manage emotional issues, connect you with community resources, and help navigate family, workplace, and financial or insurance challenges.



Online resources

- Intermountain Healthcare: [intermountainhealthcare.org/services/kidney-care](https://www.intermountainhealthcare.org/services/kidney-care)
- National Institutes of Health: [niddk.nih.gov/health-information/kidney-disease](https://www.niddk.nih.gov/health-information/kidney-disease)
- National Kidney Center: [nationalkidneycenter.org](https://www.nationalkidneycenter.org)
- National Kidney Foundation: [kidney.org](https://www.kidney.org)

Chronic kidney disease medication information*

Medications that should be avoided in CKD	
Pain Medications • NSAIDs (Non-Steroidal Anti-Inflammatory Drugs) – 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)	Contrast Media • IV Contrast Dye Antacids / Supplements • Magnesium-containing products (Magaldrate, Milk of Magnesium, Magnesium Oxide) • Aluminum-containing products (Amphojel, Alternagel, Aluminum Hydroxide Gel) • Sucralfate Antibiotics (oral and IV) • Aminoglycosides (Gentamicin, Tobramycin) • Nitrofurantoin (Macrobid)
Medications to be used with caution (check with your doctor if it is safe for you)	
Narcotics • Morphine • Codeine Decongestants (limit use to less than 5 days) • Pseudoephedrine (Sudafed) • Phenylephrine (Sudafed PE) Contrast Media • Gadolinium contrast for MRAs Other • Denosumab (Prolia, Xgeva) • Bisphosphonates (Fosamax, Actonel, Boniva) • Probenecid • Phenazopyridine (Pyridium) Proton Pump Inhibitors • Omeprazole (Prilosec)	Anticoagulants / Blood Thinners • Enoxaparin (Lovenox) • Fondaparinux (Arixtra) • Apixaban (Eliquis) • Dabigatran (Pradaxa) • Rivaroxaban (Xarelto) • Edoxaban (Savaysa) Diabetes Medications • Glyburide (Micronase) • Metformin (Glucophage) • Liraglutide (Victoza) • Exenatide (Byetta) • Dulaglutide (Trulicity) • Lixisenatide (Adlyxin) • SGLT2 Inhibitors (Farxiga, Invokana, Jardiance)

Medications requiring dose adjustments in CKD

- **Antibiotics:** Almost all require dose adjustment
- **Trimethoprim-sulfamethoxazole** (Septra or Bactrim): **Use with extreme caution**
- **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)

* 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.

Be prepared to tell your healthcare providers what your eGFR is or if you are on dialysis so they can include you in the decision-making process. **Please call your nephrologist's office if you have any concerns about your medications or before taking any herbal supplements.**

Notes

Treatment Options: Overview

For various reasons, your kidneys have stopped functioning properly, making you feel uncomfortable as well as causing life-threatening medical problems. However, there are effective treatment options available to help you live a full life with kidney disease.

This section presents a brief overview of the 3 treatment options for kidney disease — **kidney transplant, dialysis, and conservative care** — and how each might fit with your lifestyle and preferences. (Additional details about transplant and dialysis are covered in [Section 3](#) and [Section 4](#).)

What's important to you is key.

Whatever decision you make, you will have a care team that will help you every step of the way.

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. The transplanted kidney and ureter are connected to your bladder and blood supply. The transplanted kidney takes over the functions of your current kidneys.

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 special medications for the rest of your life. These are called **anti-rejection medications**.

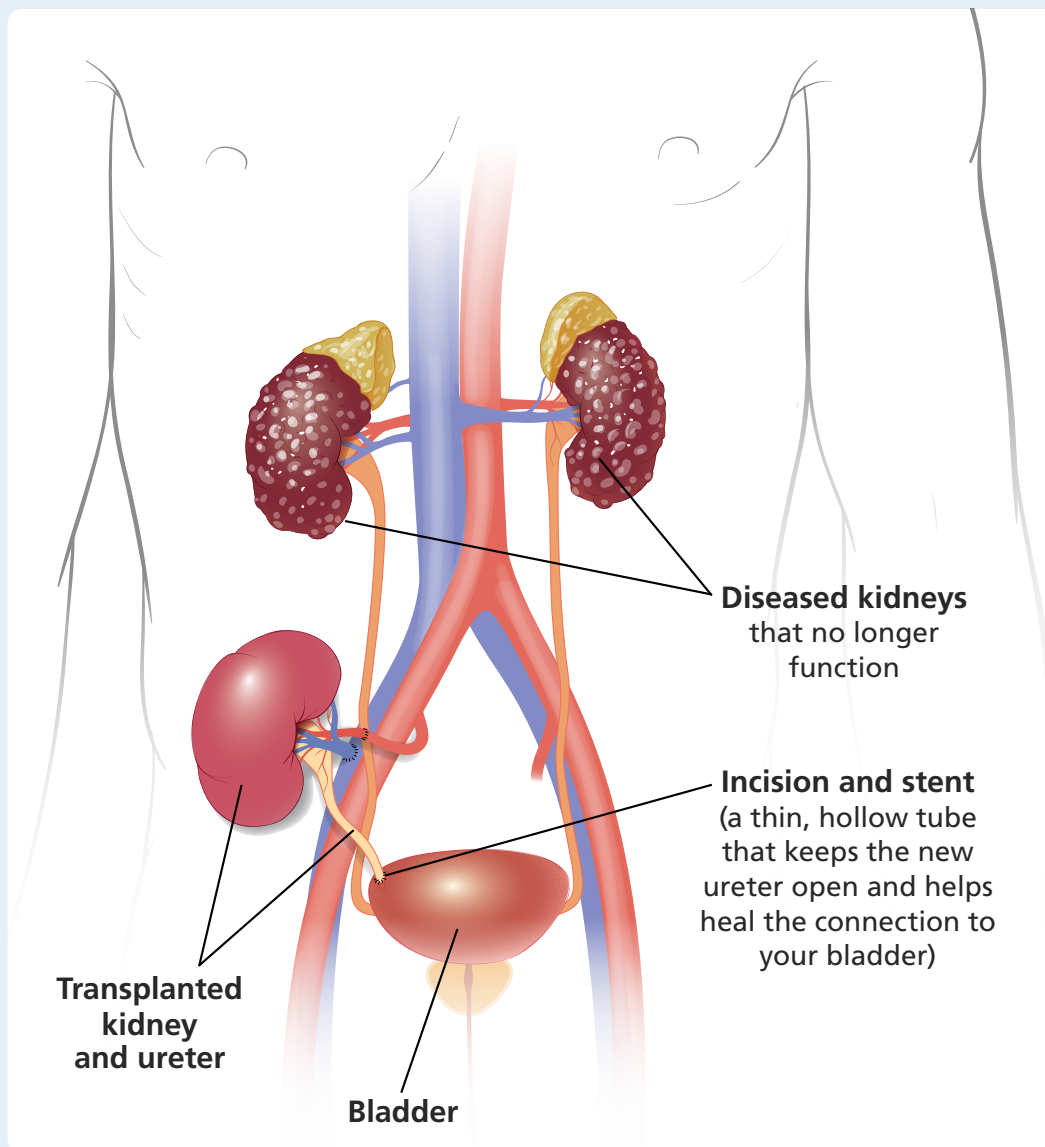
These medications keep your body from rejecting your new kidney, but there are potential effects. You will work with your healthcare team to manage these medications.

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. Even if you plan on a transplant, some people are just 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 some dialysis treatments while they wait for:

- A donated kidney
- Medical tests to be completed
- Transplant surgery to be scheduled

Learn more about kidney transplant in [Section 3](#).

Kidney transplant



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

What is dialysis?

Dialysis is a way to clean waste products from your blood when your kidneys can no longer do so. For dialysis, you and your care team need 3 things:

- 1 A way to get to your blood (called an **access**)
- 2 A filter (called a **membrane**) that does the same job that a healthy kidney would
- 3 A place for wastes to go (**dialysate** [die-AL-i-SAYT] **fluid**) when your kidneys aren't making urine.

If you have kidney disease and do not receive a transplant, you will likely need dialysis for the rest of your life. It is critical that you follow the dialysis treatment plan you choose very carefully. To learn more about the science of dialysis, check out the *In Focus* box on the next page.

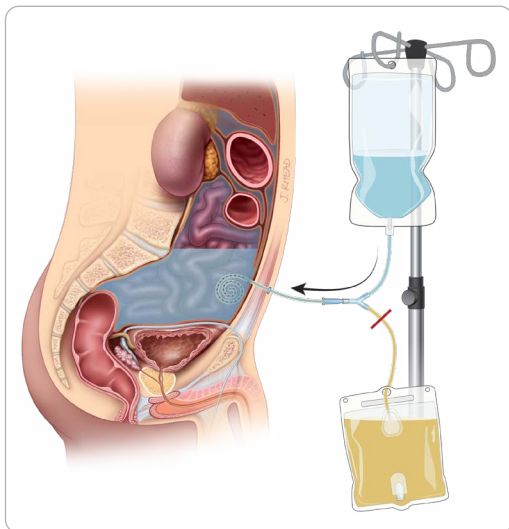
Types of dialysis

There are 2 main types of dialysis:

- 1 **Peritoneal** [per-i-tuh-NEE-uhl] **dialysis (PD)**, where the blood is cleaned inside your body using the lining of your abdomen (belly). This lining is called the **peritoneum** [per-i-tn-EE-uhm]. Learn about how PD works in [Section 4](#).

There are 2 ways that PD can be done:

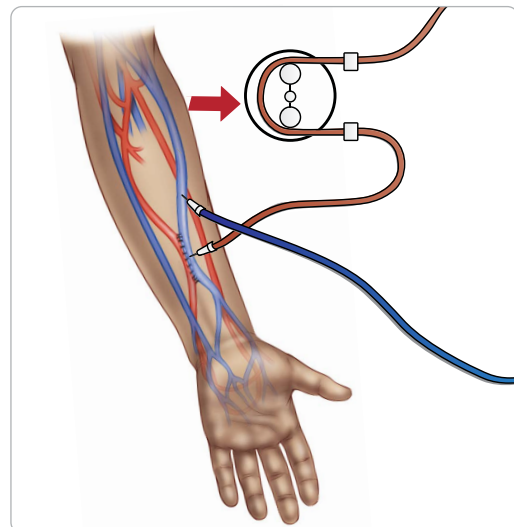
- **Continuous ambulatory PD (CAPD)**, which is done several times during the day
- **Continuous cycler-assisted PD (CCPD)**, which uses a machine to do your dialysis while you sleep



- 2 **Hemodialysis (HD)**, where the blood is filtered and cleaned outside of your body using a machine. HD requires a surgery to connect an artery to a vein in your arm. This allows access to your bloodstream for HD treatments. There are 2 settings where HD can occur:

- **Home hemodialysis** [hee-moh-die-AL-uh-sis] (**HHD**) is performed by you in the comfort of your own home.
- **In-center hemodialysis (ICHD)** is performed at a set time in a dialysis center.

Learn about HD and types of access surgeries in [Section 4](#).



In Focus

The science behind dialysis

Dialysate [die-AL-i-SAYT] is on one side of the semi-permeable membrane. It is a mixture of purified minerals and water that helps to clean wastes and excess water out of your blood.

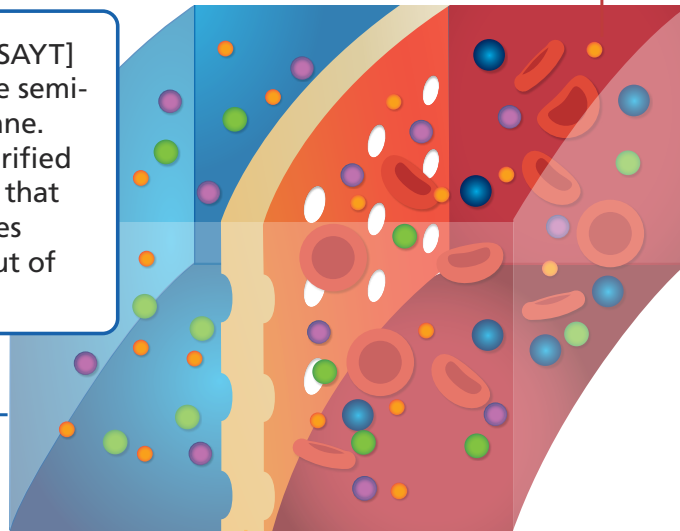
Blood with excess **water** and **waste** is on the other side of the semi-permeable membrane.

A **semi-permeable** [sem-ee-PUR-mee-uh-buhl] **membrane** is a barrier between the dialysate and blood. The membrane is a thin layer of man-made or human tissue with small microscopic pores. The size of the pores allows for water and waste to pass through from the blood to the dialysate.

Dialysis works by diffusion and ultrafiltration

Diffusion [di-FYOO-zhun] is the passing of waste through pores in the membrane when the level of waste in the dialysate is less than in the blood.

Ultrafiltration [UHL-truh-FIL-tray-shun] is the removal of excess fluids forced by the **difference in pressure** on each side of the membrane.



Dialysis and your lifestyle

Talk with your healthcare team about the things that may affect your choice of treatment option. 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 requires flexibility
- Wanting the freedom to travel

There are some side effects and/or complications that can occur with either form of dialysis, including:

- Muscle soreness
- Chest pain
- Cramps
- Itchy or dry skin
- Shortness of breath
- Faintness or dizziness
- Changes in appetite
- Feeling washed out or drained
- Numbness in your hands or feet
- Nausea or upset stomach
- Problems with the access site (with HD) or with the catheter site (with PD)

Your care team will help you manage any side effects you might experience. Most people who choose PD or HHD find they have fewer side effects than those who choose ICHD because they are getting more frequent dialysis, which more closely resembles functioning kidneys.

“Talking with the healthcare team really helped me make the best decision for what type of dialysis was best for me at this time.”

Robert, dialysis patient



Dialysis options — compare when and where you get treatment

Peritoneal dialysis (PD) exchange	A PD exchange consists of the following 3 steps: 1 Fill the abdomen with dialysate fluid. 2 Allow fluid to dwell in the abdomen for a specified amount of time. 3 Drain fluid from the abdomen and repeat. Continuous ambulatory PD (CAPD), which does not use a machine to make exchanges, involves doing them: • Wherever it is convenient for you (instead of at a dialysis center). • Every 4 to 6 hours, 7 days a week. Each exchange takes 20 to 30 minutes to drain the used solution and replace it with a new one. Continuous cycler-assisted PD (CCPD), which uses a machine to make exchanges, involves doing them: • At home (typically), overnight. While you sleep, a machine cycles the solution. • Once in the morning and maybe again in the afternoon.
Home hemodialysis (HHD)	The features of home hemodialysis (HHD) consist of the following: • Requires 3 to 5 weeks of training, including how to operate the machine, access your bloodstream, and how to manage your treatment. • Convenience of treatment done in the comfort of your home. • Treatments occur 4 to 5 times a week for 2½ to 3 hours each time. More frequent treatments may improve quality of life by giving you more energy to do what you enjoy. • Increased ability to travel. • Less build-up of toxins and fluid between treatments. • May help control blood pressure and reduce the need for blood pressure medication. • Must have a clean and safe home, including space to store supplies.
Hemodialysis (HD)	The features of hemodialysis (HD) consist of the following: • Travel to a dialysis center, usually 3 times a week, for 4 hours each time. • Days and times you have treatment depend on availability. Some centers have day, evening, or overnight hours. • Some centers offer overnight hemodialysis shifts where you have your treatment at the center at night while you sleep. This can help you continue to work or care for others at home during the day. • Some centers offer self-care options, where you have more control over your treatment within the center. • You can compare centers at medicare.gov/dialysis, or contact an Intermountain Healthcare social worker or center representative for education and support.

What is conservative care?

Conservative care is for those who may not want to start any treatment or who may choose to stop treatment at some point. Those with many health problems may feel that treatment will not add to their quality of life, and simply make their suffering last longer.

Types of conservative care

There are 2 different types of conservative care:

- 1 Palliative care** starts at diagnosis. A team focuses on improving your quality of life with medications, nutrition counseling, and relief from suffering but no other treatment. If you choose to not treat your kidney disease, your life may come to an end rather quickly — often within weeks or months.
- 2 Hospice care.** If you choose hospice care, a physician, nurse, dietitian, and social worker will manage your care closely to ensure you are comfortable at the end of your life.

"With Harry's lung cancer, we knew transplant wasn't an option, and dialysis would just make the time he had left so difficult. Conservative care gave him more quality time at home with his family."

Mary, patient's wife

If you are considering conservative care, it is very important to discuss it with your loved ones and healthcare providers. For some, conservative care may offer the best quality of life for their remaining days.

For more information about conservative care, review the **Intermountain Homecare & Hospice Services** booklet or visit their website:

intermountainhealthcare.org/services/hospice-palliative-care

What can I expect?

In general:

- Those who can have a **kidney transplant** tend to live longer than those who have dialysis, with most still alive 10 years following the surgery.
- How long a person lives after transplant depends on many things and varies for each person. Some of these things may include:
 - The source of the donated kidney
 - Age, gender, or race
 - If you have other conditions (such as diabetes, cardiac conditions, cancer, or high blood pressure) and how serious they are
 - How anti-rejection medications affect your immune system
 - How closely you follow your treatment plan

Anyone faced with these treatment choices would want to know which treatments might work the best.

How long you will live depends on many things besides your health and the **treatment you choose.**

- Life expectancy on **dialysis** depends on other medical conditions you may have but especially how well you follow your treatment plan. On average, people on dialysis live an additional 5 to 10 years. However, many people live well on dialysis for 20 to 30 years.
- Those who choose **conservative care** may live from a few days to several months, depending on the amount of kidney function they have left and their general health.

What treatment approach might be right for me?

	I might CHOOSE this because I:	I might NOT CHOOSE this because I:
Kidney transplant	☐ Have been told by my doctor that I AM a good candidate for a transplant ☐ Have a living donor available ☐ Don't mind taking anti-rejection medications for the rest of my life ☐ Am comfortable with having surgery ☐ Feel that, between insurance coverage and my own finances, I can afford the costs of surgery and necessary medications	☐ Have been told by my doctor that I AM NOT a good candidate for a transplant ☐ Don't have a living donor and worry about having to wait too long for a kidney to become available ☐ Don't want to take anti-rejection medications for life ☐ Don't want to have surgery ☐ Can't afford to miss that much work ☐ Worry about affording surgery and monthly medication costs that might not be covered by insurance
Peritoneal dialysis	☐ Want the freedom to plan my treatments around my schedule, either during the day or at night ☐ Don't want to have to stop working or traveling ☐ Like home treatment that I can do by myself ☐ Feel comfortable managing my treatments ☐ Don't like needles or the idea of having an access in my arm	☐ Would rather not manage treatments myself ☐ Like to swim or take tub baths (not possible with a permanent catheter) ☐ Don't want to have multiple treatments daily ☐ Worry that treatments at night will disrupt my sleep or affect intimacy with my partner ☐ Am concerned about weight gain or insulin problems from absorbing calories in the solution
Home hemodialysis	☐ Have treatments done in the comfort of my home ☐ Can have shorter treatments of 2½ to 3 hours at a convenient time for me ☐ May have less build-up of toxins and fluid between treatments, which may improve my quality of life ☐ May need less blood pressure medication ☐ Have increased ability to travel ☐ Have fewer dietary restrictions	☐ Don't have 3 to 5 weeks to devote to training ☐ Am unsure how 5 to 6 treatments per week would fit into my schedule ☐ Worry about having enough space to store supplies ☐ Would rather not insert my own needles and my caregiver is unwilling to insert the needles
Hemodialysis	☐ Can easily get to a dialysis center 3 times a week or have the resources to do home dialysis ☐ Like healthcare providers doing my treatments or have a caregiver committed to helping me at home ☐ Prefer spending time with others during treatments (at a center)	☐ Want more freedom to plan my treatments around my schedule, continue to work, and enjoy travel ☐ Have no dialysis facilities nearby, or have trouble getting there ☐ Don't want to deal with needles or have access surgery ☐ Worry that I will feel sick too much of the time
Conservative care	☐ Don't want to have any surgeries or procedures right now ☐ Feel that treatment will not extend my life to any great extent given my age and my other medical conditions ☐ Would rather have my current quality of life than live longer having treatments ☐ Don't want to make any changes to my lifestyle	☐ Don't have other serious medical conditions that could impact my life ☐ Want to try any treatment that will extend my life ☐ Am concerned that my insurance might not pay for palliative care

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

Kidney Transplant

The result of a kidney transplant is that your body responds as it would if you had your own healthy kidneys. It is not a cure for CKD as you will need follow-up care. However, on average, a transplant can double your lifespan as compared to staying on dialysis. Knowing what’s involved to qualify, find a donor, prepare for surgery, and manage your care after transplant will improve your chances of success.

What do I need to know about a kidney transplant?

When your blood and urine tests indicate that your CKD has reached stage 3B (see **Section 1** for information on CKD stages), 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 one of several medical issues (see the *In Focus* box on **page 27**). A kidney transplant is a surgery that can only be successful if your are fairly healthy other than having kidney disease. If you have a living donor (typically someone you know), that person needs to also 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 more than 3 ½ years. As of May 2019, more than 95,000 people were waiting for a kidney. Learn about donor options and timing on **page 26**. Because of this wait time, you may need dialysis until you can have a transplant.

The costs and insurance coverage for a transplant may vary depending on your insurance coverage and the transplant center you choose. Non-covered costs can include candidate testing and evaluation; surgical and other medical costs for a living donor not covered by your insurance; follow-up care and lab tests, anti-rejection medications; food, lodging, and transportation near a transplant center; and loss of income during the process. Talk to your insurance carrier regarding your transplant benefits. The transplant social worker can help you understand any non-covered expenses.

Carefully consider the pros and cons of kidney transplant (see below).

Pros	Cons
• Ability to return to near normal health after surgery; no dialysis needed • Better chance of living longer than with ongoing dialysis • Best outcomes • Surgery covered by Medicare, VA, Medicaid, and most health insurance plans	• Risks that go with having surgery • Costs and side effects of anti-rejection medications you will take for life • Follow-up care issues such as: – High risk of developing skin cancer (65 times more likely) – Frequent in the early post-transplant period – Possibility of organ rejection • Deceased donor waiting list may be long

What is the transplant process?

There are several critical steps to your transplant success. Understanding the following steps will help you determine if a kidney transplant is right for you:

1

ASK

- **Voice a desire.** Ask your nephrologist or dialysis center to provide a referral to a transplant center. Some transplant centers also allow a self-referral.
- **Start the process.** Contact the transplant center and your insurance provider.

2

QUALIFY

- **Medical qualification.** You (and a living donor, if applicable) will have every major system in your body tested.
- **Support qualification.** Team members will verify that you have the needed psychological, social, and financial support resources for a successful transplant.

3

FIND A DONOR

- **If you HAVE a living donor,** this person will need to be evaluated to make sure they qualify medically. For you, these transplants can occur quicker and have better outcomes; however, donors face all the risks of having surgery.
- **If you DON'T HAVE a living donor,** the transplant center will add your name to the national organ transplant waiting list. It can take months or years to find a match.

4

PLAN

- **If you have to wait for a donor,** Ask your physician what to do to prepare for dialysis, and check your transplant status regularly!
- **Maintain** a positive outlook and live healthy while you wait.
- **Think ahead.** Prepare your home for recovery after surgery, and identify caregivers.
- **Be money smart.** Plan for loss of income, employment, insurance, medical bills, and financial help.

5

GO FOR IT

- **Be ready.** If you are on the waiting list, you could get a call any time day or night. Kidneys can only be preserved outside the body for 24 to 48 hours.
- **Be patient.** There will still be a final evaluation to verify a match once the organ arrives.
- **Plan for recovery.** Hospital stays are 4 to 8 days for you and 4 to 5 days for a living donor. You may need to stay close to the transplant center for up to 4 weeks after surgery and come back in 5 to 6 weeks to have the stent removed.

6

RECOVER

- **Take it easy.** Don't rush your recovery. Be patient while healing occurs. Follow recommendations for activity.
- **Follow orders.** Take medications as instructed and have blood drawn as directed.
- **Be prepared for change.** You may experience physical and emotional changes. Talk with your transplant team about these changes.

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 of their 2 kidneys. The benefits of having a living donor include:

- **Less chance of needing dialysis.** With a **living donor**, you can start the transplant process right away. In contrast, the average wait for a **non-living donor** kidney is 3 ½ years, making dialysis necessary.
- **A better match.** If the 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 will need to get on a waiting list for a non-living donor kidney, which comes from someone who is expected to die and they or their family have agreed to donate their healthy organs. **Talk to your doctor about getting on the waiting list when you reach CKD stage 5** (see [Section 1](#) for information on CKD stages). **This might allow you to perhaps avoid dialysis altogether.**

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 Healthcare's living donor program, visit intermountainhealthcare.org/services/transplant-services/become-donor/. You may also contact Intermountain's Transplant Services by calling 801-507-3380.



Transplant
Services

"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

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. A living donor may need to have many of the same tests.

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 related to your general health.

For example:

- **Age:** Transplants are possible at any age; however, the risk of transplant may outweigh its benefit over being on dialysis with advancing age. 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.
- **Wellness and other issues:** Challenges that could make a transplant riskier include obesity (BMI over 35), tobacco use within 3 months, or alcohol or substance use.

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



How much medical care will I need after a kidney transplant?

On average, a transplanted kidney lasts about 10 to 12 years. The long-term outlook for a successful kidney transplant depends largely on how well you take care of yourself. You will need to:

- **Keep all appointments with your transplant team** and follow their advice on when to have lab tests and how often to see your doctor.
- **Take all medications your doctor prescribes** to keep your body from rejecting your new kidney. You will need to take these every day without fail.
- **Live healthy.** Eat healthy, don't smoke, get regular physical activity, and lose weight if needed to reduce your risk of developing diabetes, heart disease, stroke, high blood pressure, and other conditions.

There are 3 major health risks to manage following your transplant surgery:

- Rejection
- Infection
- Increased risk of skin cancer

Rejection

Your body's immune (disease-fighting) system knows that your new kidney is not the one you were born with and will normally try to reject it (unless the donor was your identical twin). This rejection response can be managed by taking **immunosuppressants** [im-you-no-sup-PRESS-ents], also called **anti-rejection medications**. These medications lower your body's natural immune response, making it less likely that it will reject the new kidney.

When you have your transplant surgery, you will get a powerful anti-rejection medication. You will need to continue to take maintenance doses of these medications every day from that point on as long as you have your transplanted kidney. **Remembering to take your prescribed anti-rejection medication every day is critical to the health of your new kidney.**

The main side effects of anti-rejection medications are increased risk of infection, certain cancers, and stomach upset. Stomach upset can be managed by taking the medications at different times. (Ask your doctor before you take any medication at a different time than prescribed.) At 6 to 12 months after your surgery, your doctor will likely lower the dose, which reduces the side effects.

There are other medications and some foods that can impact the effectiveness of anti-rejection drugs. Make sure you talk to your transplant doctor before taking any grapefruit juice, St. John's Wort (an herb used sometimes for depression, erythromycin (an antibiotic), anti-TB (tuberculosis) medications, anti-seizure medications, or common blood pressure medications (Cardizem or diltiazem, and Verapamil).

Infection

While taking anti-rejection medications, your immune system will be less effective at fighting infections. You will need to be extra careful to prevent infections. Avoid getting infections by:

- **Using good hand washing technique**, especially after contact with pets and when preparing food.
- **Avoiding close contact with anyone who has a contagious illness** or children who have recently been vaccinated with a "live vaccine" such as oral polio (within 3 weeks), measles, or mumps (learn more about vaccine precautions in the *In Focus* box on [page 29](#)).
- **Letting your doctor know about any travel plans**, especially to foreign countries.

Increased skin cancer risk

Anti-rejection medications can increase the risk of skin and lip cancers for people who have fair skin, live in places where they are more exposed to the sun, or have a history of skin cancer. To protect yourself, avoid direct sunlight and tanning booths, wear sunscreen, and be extra aware of changes in your skin (such as lumps, bumps, sores, ulcers, or areas that changes color). See a skin doctor at least once a year for a skin check.

When should I call my transplant doctor or other care team members?

To best manage possible rejection, call your transplant center immediately if you:

- ☐ Have a drop in the amount of urine (pee) you pass or have blood in your urine
- ☐ Run a fever above 100°F (38°C)
- ☐ Feel tenderness in the area of your new kidney
- ☐ Feel like you have the flu
- ☐ Gain more than 3 pounds in 2 days
- ☐ Have symptoms of a respiratory infection (fever, cough, nasal congestion, runny nose, a sore or scratchy throat) or a cough or cold that will not go away
- ☐ Forget to take any dose of anti-rejection medication or take it later than you should

To best manage infections, call your doctor as soon as possible if you have:

- ☐ A fever above 100°F (38°C)
- ☐ Sores, wounds, or injuries (especially if they fail to heal)
- ☐ Drainage from a surgical scar
- ☐ Symptoms of a bladder or kidney infection (needing to urinate more often, having pain or burning when you urinate, or having urine that is cloudy or reddish in color or smells bad)
- ☐ Symptoms of a respiratory infection (fever, cough, nasal congestion, runny nose, a sore or scratchy throat) or a cough or cold that will not go away

In Focus

Transplant and vaccines

Some live vaccines can be harmful if you have a transplanted kidney. A “live vaccine” is one that uses a weakened form of the virus so that the body’s immune system knows how to fight the infection when it occurs. This weakened form may cause problems when taking anti-rejection medications.

As a result, those with transplants should avoid children who have had the oral polio vaccine (for at least 3 weeks) or who have had measles or mumps vaccines.

Avoid adults who have received the **attenuated** [uh-TEN-you-ate-tid] varicella [var-uh-SEL-uh] vaccine to prevent shingles and anyone who has had the nasal influenza vaccine.

Check with your doctor to see what vaccines you should have before you travel. Use the table below as a general guideline for which vaccines to get and which to avoid. If you plan to travel to another country, check with your doctor to see what vaccines you should have beforehand.

Vaccines to have	Vaccines to avoid
• Hepatitis B before your transplant • Inactivated influenza (flu), annually • Hepatitis A (for travel and other risks) • Human papillomavirus (HPV), for those 9 to 45 years • Pneumovax (single booster at 5 years) • Inactivated polio • Meningococcus (if at high risk) • Tdap (tetanus, diphtheria, and acellular pertussis) • Shingrix (for prevention of shingles)	• Varicella-zoster • Bacillus Calmette-Guérin (BCG) • Smallpox • Nasal influenza (For your protection, no one in your household should get this vaccine.) • Live oral typhoid (Ty21a and other newer vaccines) • Measles (except during an outbreak) • Mumps • Rubella • Oral polio • Live Japanese encephalitis vaccine • Yellow fever

How will having a transplant affect my lifestyle?

Having a kidney transplant is the treatment option that allows you the most similar lifestyle to what you experienced when your own kidneys were healthy. 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. Use the information on the next couple of pages as a general guide and follow your transplant team's directions for the level and type of activity that will keep you healthy.

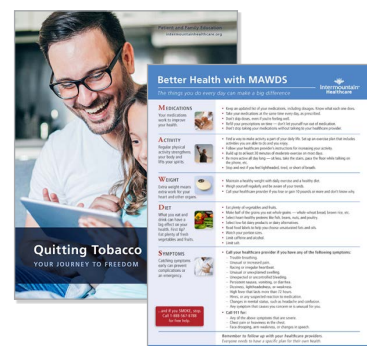
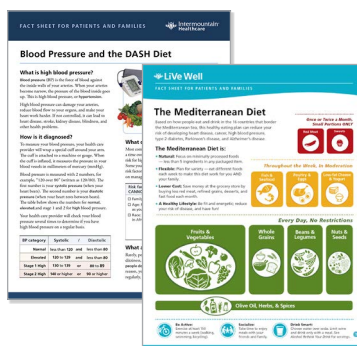
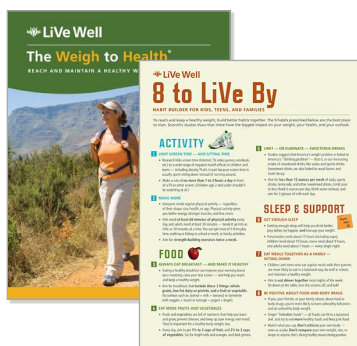
Make healthy choices

One side effect of anti-rejection medications is weight gain and developing diabetes or heart disease as a result. However, you can reduce your risk by:

- **Maintaining a healthy weight.** Follow a healthy diet with the help of your dietitian.
- **Controlling high blood pressure and cholesterol.** Eat a low-salt, heart-healthy diet (such as the DASH diet), take prescribed medications for these conditions, and check your blood pressure every day.
- **Remaining physically active** (as directed by your doctor).
- **Quitting smoking.**
- **Controlling your diabetes.** Follow your care plan for medications, diet, and glucose monitoring.



Intermountain resources for a healthy lifestyle



Safely return to work, school, sports

After you recover from surgery, you can likely return to most of your previous activities. However, your doctor may suggest certain precautions.

Depending on your occupation, you will likely be able to return to work (or school) within 2 months following surgery. If your job previously required heavy lifting or some exposure to germs, you might need to talk with the transplant social worker or others on your transplant team about some career counseling to discuss other job options. Remember, you will need to protect your new kidney from injury and avoid the risk of infection.

Talk to your physician before driving. It will likely be a few weeks after surgery before you can safely drive. The medications you will be taking when you leave the hospital can make you dizzy or have blurred vision, which makes driving dangerous.

Once your doctor gives you the okay, walking, biking, hiking, swimming are all good forms of physical activity for staying healthy and building muscle and bone strength. Work with your transplant team to develop an exercise plan for your needs. **Avoid physical exercise or weightlifting until your doctor says it is okay, and do not participate in contact sports** (for example, football, soccer, or basketball).

Travel smart

You may be asked to limit or avoid travel for a period of time after surgery. Talk with your transplant team about any travel plans you have while recovering and adjusting to life with a kidney transplant. Be sure to discuss your travel plans with your transplant care team.

Return to normal family life

After the transplant, you will likely be able to resume sexual activity. **Talk with your doctor about any concerns you or your partner have related to sexual activity, fertility, or pregnancy.** It is important that women take special precautions to avoid urinary tract infections and follow these guidelines before becoming pregnant:

- Use birth control to avoid pregnancy for at least 1 year after transplant.
- Make sure your kidney function is stable.
- Find an obstetrician who specializes in high-risk pregnancies.
- Talk to your obstetrician about the risks and benefits of breastfeeding while taking anti-rejection medications. Some medications that could be harmful to your baby can be passed through breast milk.

Where can I learn more?

- **Talking About Transplantation** — United Network for Organ Sharing (UNOS) booklet (Read and download at: unos.org/wp-content/uploads/unos/WEPNK.pdf).
- **Medicare Coverage of Kidney Dialysis and Kidney Transplant Services** (medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf) — Booklet that explains how Medicare pays for kidney transplant services and provides resources for assistance.
- **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.
- **American Kidney Foundation** (kidneyfund.org/financial-assistance/) This non-profit organization provides charitable assistance to kidney patients to pay for health insurance premiums and other treatment-related expenses.
- **Intermountain Kidney Transplant Services** — (Access information at: intermountainhealthcare.org/services/transplant-services/services/kidney-transplant/). Both Intermountain Medical Center and Primary 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. The good news is that dialysis will help maintain your health, and there are more options than in the past.

Dialysis is a treatment for kidney disease that filters waste from your blood and keeps important chemicals in your body in balance.

Most patients who choose treatment for kidney disease will have one of two types of dialysis:

- 1 Peritoneal dialysis (PD)**, which can be done at home or other places such as at work or while traveling
- 2 Hemodialysis (HD)**, which can be done at home or in a dialysis center

In this section, you will find options for PD and HD explained in detail. There is also information on access surgery for HD and PD and routine lab tests necessary for everyone who chooses dialysis.

At the end of each dialysis type (PD and HD) discussion, you will find a worksheet that can help you assess which dialysis option might work best for you. Use this worksheet to talk with your family and your doctor about your preferences and values.

Access, Membrane, and Dialysate

For dialysis to work, you need to have these 3 elements:

- 1 Access** to your blood (either through something called a fistula [FISS-tyou-luh] or graft for HD or through a catheter for PD)
- 2 A filter** (called a **membrane**) that does the same job that a healthy kidney would
- 3 A place for wastes to go** (**dialysate** fluid) when your kidneys don't make urine

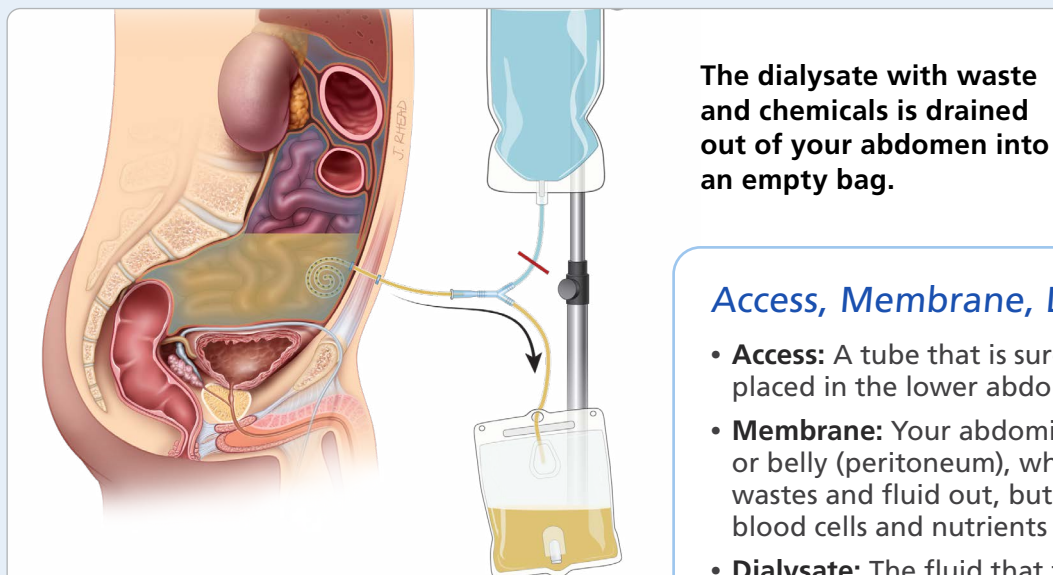
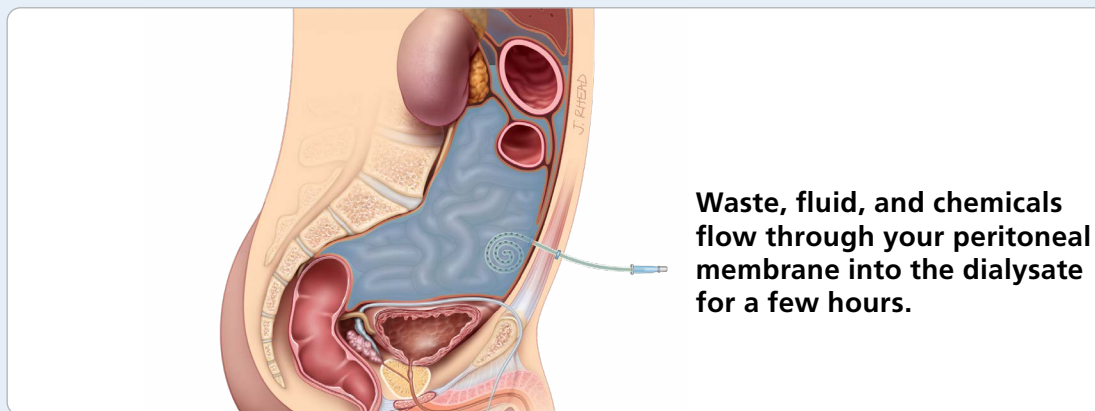
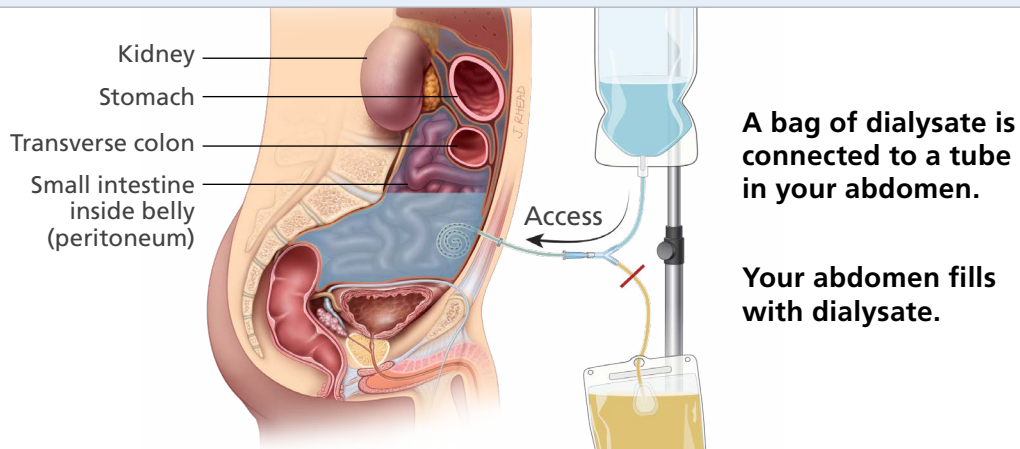
Look for a box titled, "**Access, Membrane, Dialysate,**" to see how this works for each dialysis type in the sections that follow.



"My dialysis care team was amazing! They provided so much information and support. They helped me understand my choices and how dialysis could impact my lifestyle and schedule."

Evelyn, peritoneal dialysis patient

Continuous Ambulatory Peritoneal Dialysis (CAPD)



Access, Membrane, Dialysate

- **Access:** A tube that is surgically placed in the 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 the peritoneum through the access tube. It stays there for some time, and is drained through the access tube after the blood is cleaned.

What I need to know about peritoneal dialysis

Peritoneal dialysis (PD) cleans your blood from the inside of your body using the lining of your abdomen (belly) as a filter and a special fluid mixture called dialysate to collect wastes.

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

The peritoneum acts as a specialized filter, removing waste products and excess fluid while keeping in red blood cells and nutrients. **Dialysate** (cleansing fluid) enters your body through a small tube, where it will stay for several hours while cleaning your blood. The fluid is then drained out and discarded. The drawing below shows this process.

How does it work?

A **catheter** (small tube) in your abdomen allows dialysate to flow in and out. The draining and refilling of dialysate are called an **exchange**. Exchanges are done in 1 of 2 ways:

- 1 Continuous Ambulatory Peritoneal Dialysis (CAPD).** You 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 abdomen. This is done usually 4 times a day with each exchange taking at least 30 minutes to finish. You can be active while the fluid dwells in your abdomen.
- 2 Continuous Cycling Peritoneal Dialysis (CCPD).** A machine slowly pumps the fluid through the tube into your abdomen and out again after a period of time (for about 6 to 9 hours), all while you sleep.

With either method, dialysate stays in your body for several hours, slowly drawing waste products and extra fluid out of your blood and into your peritoneum. The dialysate with the waste and extra fluid is then drained out of your body through the tube and disposed of. The peritoneum is then refilled with fresh dialysate.

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



Why would I 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 you clean your blood more often.
- **No needles or need to cover your arm.** Unlike HD, you just hook up tubing that is hidden under your clothes.
- **Lots of flexibility.** You control much of your treatment schedule and can continue to work, do sports, or travel and still do your dialysis.
- **Fewer dietary restrictions.** You will be able to eat more things and drink more fluid with more frequent PD treatments.
- **Fewer medications.** With PD, you will likely take (and pay for) fewer medications than with HD.

Many people find that PD helps them keep other treatment options open. It can preserve kidney function longer and better prepare you for a transplant. Those who learn to successfully do home dialysis self-care and can work longer to maintain employer-provided health insurance are in a better position for a kidney transplant.

What about side effects?

Peritoneal dialysis may cause side effects, including:

- Weight gain, especially around the abdomen
- A feeling of fullness, especially when carrying the solution in your abdomen
- Increased blood sugar levels in people with diabetes
- Changes in blood pressure
- Infection at the catheter site of the peritoneal membrane

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

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

What about access for PD?

Before beginning peritoneal dialysis, you will need to have surgery (lasting 15 to 30 minutes) to place a soft, flexible tube (about the size of a drinking straw) through the wall of your abdomen and into the peritoneum. You will have either a local or light anesthesia (sedation). The surgeon will make a tiny cut about an inch below your belly button, insert the tube “cuffs” that hold the catheter in place and 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 get the most from my PD treatments?

- Don't 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 on taking care of yourself.
- Be an active participant in your care.
- Take care of your access.

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 the transfer set.
- Apply any antibiotic creams prescribed by your doctor.
- Avoid swimming in public pools and freshwater sources.
- Avoid bathing in a tub. Shower instead.
- Keep the catheter protected from being pulled or snagged.
- Avoid pressure or strain on your abdomen. Practice safe lifting techniques. Use your legs and don't bend at the waist.

When should I call my doctor?

Call your doctor right away if you have any of these signs of infection:

- Swelling, redness, soreness, or a thick, yellowish-white discharge around the catheter exit site
- A fever of 100.3° F (38.0° C) or higher
- Abdominal pain
- Cloudy PD solution (after it's drained)
- Nausea or diarrhea

Call your PD nurse right away if your catheter appears damaged or is leaking.



Which peritoneal dialysis option is best for me?

For each treatment option below, check the statements that apply to you. Then, show your responses to your doctor and discuss them. You and your doctor will make a decision together based on your condition and medical needs and your preferences.

	I might CHOOSE this because I:	I might NOT CHOOSE this because I:
Continuous Ambulatory Peritoneal Dialysis (CAPD)	☐ Want to be able to shift my treatment time around to allow for work, errands, and other daily tasks ☐ Prefer not to be hooked up to a machine while I sleep ☐ Feel safer being awake and watching what's happening during my treatment ☐ Worry that nighttime treatment will interfere with my sex life or my sleep and/or sexual activity	☐ Only want to do my treatments at night ☐ Can keep my environment cleaner at night ☐ Work where I am unable to do treatments during the day ☐ Need to care for small children or pets during the day so my risk of infection would be higher
Continuous Cycling Peritoneal Dialysis (CCPD)	☐ Don't want to do treatments during the day ☐ Like that my treatments would take less time during daytime hours ☐ Don't mind having a machine in my bedroom	☐ Am afraid that something might go wrong with the machine while I'm asleep ☐ Worry that having nighttime treatments will disturb my partner's sleep or my own ☐ Worry the tubing could get tangled ☐ Don't want to risk losing nighttime intimacy with my partner

What 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 while keeping the red blood cells and nutrients you need. Only about 8 to 10 ounces (about 1 to 1½ cups) of blood being cleaned by the dialyzer at any one time. The blood is continuously circulated so that it is cleaned and returned to your body during treatment.



“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

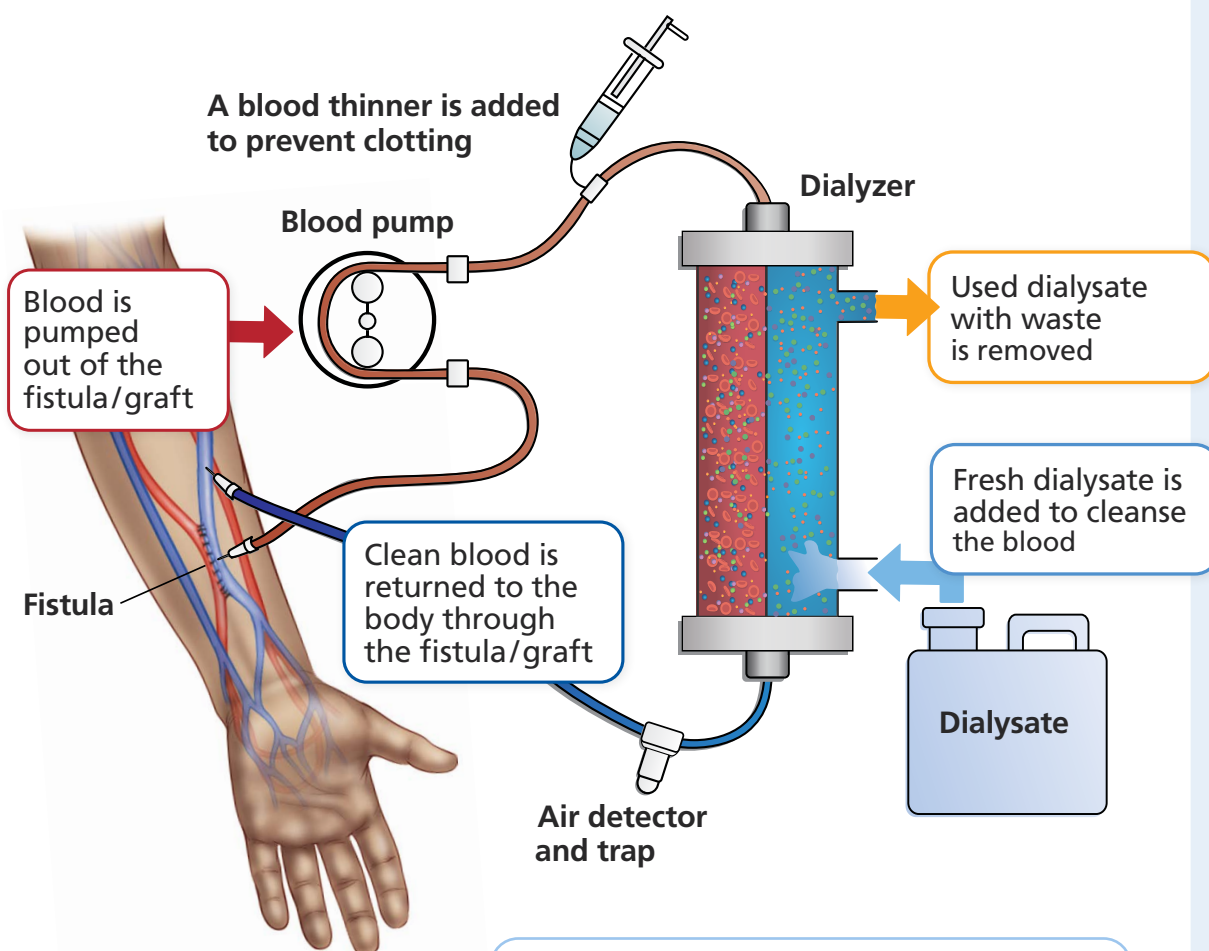
How does it work?

During each hemodialysis treatment, a technician, nurse, or you will insert 2 needles into your fistula or graft to connect you to the dialysis tubing (see [page 41](#) and [page 42](#)). The machine has a pump that moves blood from your arm through the dialyzer and back as it is cleaned. One needle allows the blood to be removed from your body while the other one is used to return it after the blood goes through the dialyzer. This continues throughout the entire treatment.

There are 2 parts to the dialysis system:

- 1 A dialyzer** is made up of small, hollow tubes (the membrane) with very tiny holes that allow fluid and waste to pass through, but not red blood cells and nutrients.
- 2 The dialysis machine** moves the cleaning fluid (dialysate) through the dialyzer, allowing particles that pass through the membrane to be collected in the fluid and later drained.

Hemodialysis (HD)



Access, Membrane, Dialysate

- **Access:** A fistula or graft (see [page 41](#) and [page 42](#)) surgically placed in the arm
- **Membrane / dialyzer:** Small, hollow tubes with microscopic holes that let wastes and fluid out, but keep red blood cells and nutrients in
- **Dialysate:** Fluid that passes by the membrane, collects the fluid and wastes to clean the blood, and then goes into the drain

Where and when would I have HD treatments?

Depending on the type of hemodialysis program you choose, this process can take 12 to 24 hours each week for the rest of your life.

Treatment times vary depending on whether you do your treatments at home, a dialysis center, or while you sleep (either at home or in a center). Your doctor will set and adjust your treatment times to meet your body's needs. You will have regular blood tests to see how well the treatment is working (learn more about these tests on [page 45](#)).

If at home, you will need to do treatments 4 to 5 days a week, typically for 2 ½ to 3 hours each. For home hemodialysis, you and a family member or other caregiver will attend training sessions for 3 to 5 weeks to learn how to use the equipment and manage treatments. During training, you will have your treatments at the center.

Learn more detailed information about what you would need to consider for home hemodialysis in the **In Focus** box on [page 43](#).

If at a dialysis center, you will need to have treatments for 4 hours, 3 times a week.

If you choose to go to a center for your hemodialysis, you will typically not need any training, but you will need to:

- **Be on time** for every appointment
- Attend dialysis treatments **during the workday**
- **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 needs to 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.

Both short, daily dialysis treatments (at home) and nocturnal HD (at home or at a center) help people live about 3 times longer than standard, in-center HD because the treatment is gentler with fewer side effects.

What are potential side effects or complications?

The potential side effects or complications that can occur with dialysis include:

- Muscle soreness
- Chest pain
- Cramps
- Itchy or dry skin
- Shortness of breath
- Faintness or dizziness
- Lack of appetite
- Nausea or upset stomach
- Feeling washed out or drained
- Numbness in the hands or feet
- Problems with the access site

If you experience any side effects or complications, talk with your doctor.

Your care team will work with you to create an individual plan to help manage them.

What I need to know about 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 to make a stronger place for the needles to be placed and your blood to be circulated and cleaned under pressure.

What is access surgery?

Hemodialysis access requires surgery **several weeks to months before you begin treatment** to allow time to heal. Access surgery creates a link between a major artery and vein through either a **fistula** or a **graft**.

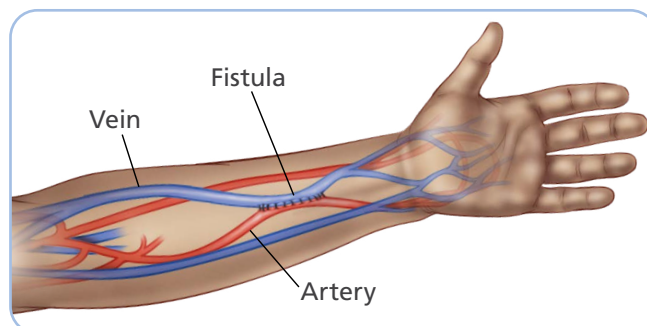
During the access surgery, the surgeon connects the artery to the vein. You will be asleep during surgery. After the surgery, you will stay in the hospital for a few hours until your doctor feels you are ready to go home. You may be given pain medication at the hospital. Discuss at-home pain management with your doctor. You will need someone to drive you home on the day of the surgery.

What if I can't wait for surgery?

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

Because the catheter is both in and outside of your body, **your risk of death, due to catheter infection, is higher with this type of access.**

Discuss access options with your doctor long before you need dialysis.



What is a fistula?

A fistula directly connects a large vein to a nearby artery — typically in your arm.

Once the fistula is in place, 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 dialysis. To help your fistula mature, your doctor may suggest squeezing a rubber ball or doing other exercises.

A fistula is 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.

When should I call my doctor?

Call your doctor 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 graft or fistula.
- A change in feeling in the arm or hand with the access. Signs of a problem include numbness, weakness, tingling, lots of swelling in the arm, or your hand feels cold.

What is a graft?

A graft is like a fistula but uses a small, man-made tube to connect the artery and vein.

Doctors recommend this option for those whose blood vessels are not large enough or strong enough for a fistula.

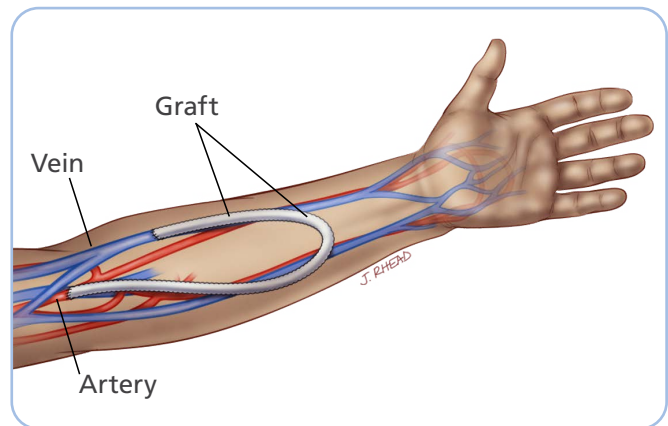
A graft is not as good of an option as a fistula because:

- It typically only lasts for 3 to 5 years before it needs to be replaced.
- There is a greater risk of infection and blood clots.

When you have a graft placed under the skin, you will have bruising, swelling, and discomfort in your arm. After about 2 weeks, the swelling will go down, and the access will be ready to use. During this process, you will want to:

- Keep your arm extended and elevated above your heart.
- Manage pain as directed.
- Keep the dressing clean and dry.
- Avoid putting pressure on your arm.

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



How do I care for my HD access?

Caring for your HD access 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. Only use the access site for dialysis, and carefully wash the site before each treatment. Your care team will show you how.

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 3 to 4 hours.
- ☐ Between treatments, check your access 3 times a day for the thrill (buzz). If there is none, call the dialysis center or your doctor.
- ☐ Watch for signs of infection: Presence of drainage at the skin's surface, fever, or tenderness or warmth over the access.

DON'T

- ☐ Lie on your access.
- ☐ Wear tight clothing, jewelry, or watches on that arm.
- ☐ Carry anything heavier than a gallon of milk with your access arm.
- ☐ Sleep with your access above your head or under your pillow.
- ☐ Allow your access area to be used to measure blood pressure, draw blood, or get intravenous (IV) solutions.
- ☐ Pick or irritate any scabs or abrasions on your access (helps prevent infections).
- ☐ Play excessive contact sports, such as football, unless protection is provided.
- ☐ Carry purses or shoulder bags on the side of your access.

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 dialysis clinics.
- Ability to plan dialysis around work or other activities.
- More frequent dialysis treatments — this means your treatments are shorter and you'll have less waste and fluid buildup in your body. You may feel better.
- Easier travel. Some machines are small enough for domestic travel.
- Fewer dietary restrictions.

Before considering home hemodialysis, ask yourself these questions:

Can I manage my own treatment? After 3 to 5 weeks of training, you and your caregivers will be responsible for your treatment. This includes setting up and caring for the equipment, placing needles, keeping treatment records, and ordering and storing the supplies. During dialysis, you might need to have someone present the entire time to ensure your safety.

Do I have the right space for home dialysis? Your home needs to be clean. 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 for the supplies — a month's supply of dialysate could mean storing dozens of boxes.

Which hemodialysis option is best for me?

For each treatment option below, **check the statements that apply to you.** Then, show your responses to your doctor and discuss them. You and your doctor will make a decision together based on your condition and medical needs and your preferences.

	I might CHOOSE this because I:	I might NOT CHOOSE this because I:
Home-Based	☐ Want to do treatments at home ☐ Like to travel ☐ Want fewer dietary restrictions and medications to take ☐ Have someone at home to help me with my treatments ☐ Want to have a more normal lifestyle ☐ Don't have reliable transportation to and from a center during the work week ☐ Like that it will only be 1 to 2 hours of recovery time after each treatment	☐ Am uncomfortable managing my treatments ☐ Don't have someone to help me with treatments and go through the training ☐ Am worried about possibly having to make possible electrical and plumbing changes in my home to accommodate home dialysis ☐ Don't have room for the machine and supplies at home
Daytime In-Center	☐ Want a few days off from dialysis treatment each week ☐ Prefer the option with the least time spent having treatments ☐ Feel safer with healthcare providers doing my treatments ☐ Want to be around other people during my treatments ☐ Have someone who can take me to and from the center during the workday	☐ Don't want to be tied down to being at a center at a specific time on specific days ☐ Have no dialysis facilities nearby, or have trouble getting there ☐ Prefer more privacy during my treatments ☐ Need to continue to go to work each day ☐ Prefer to have fewer dietary and fluid restrictions ☐ Worry about how long it takes to recover from each treatment (6 to 8 hours typically)
Nighttime In-Center (if available in your area)	☐ Can't do treatments during the workday ☐ Want to do treatments while I sleep ☐ Don't want treatment every day ☐ Have reliable transportation to and from the center at night ☐ Want fewer dietary restrictions and medications to take	☐ Want to be home at night in my own bed ☐ Don't have a way to get to the center at night ☐ Don't live near a dialysis facility, or this is not offered at the facilities near me ☐ Work nights or frequently care for children or animals overnight ☐ Feel like it might be hard to sleep at a center

Routine lab tests and dialysis

For those on dialysis, the nephrologist and kidney care team will perform regular lab tests to answer these questions:

- Is your blood getting cleaned effectively?
- Are your electrolytes (calcium, sodium, potassium, and phosphorus) in balance? (See [Section 1](#) for information on what these electrolytes do for you.)
- Do you have anemia? (See [Section 1](#) for information on how anemia impacts your health.)
- Is your diabetes under control? (If not, you may get sicker.)

You will have blood tests every month, before and after a dialysis treatment, to see how well your blood was cleaned. Your care team may adjust your dialysis prescription to meet your body's specific needs. Review your lab results with your nephrologist and care team. Knowing your “numbers” will help you and your doctor make the best decisions about your care.

In order to keep track of routine lab work, you will want to know the results you and your doctor are looking for. Read the **In Focus** information below. It covers the most common lab tests your doctor may order to monitor your health.

In Focus

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

What you and your doctor needs to know	Name of blood test your doctor orders	Compare your test results to these goals*
Are my calcium, phosphorus, potassium, and sodium levels in balance?	Blood electrolyte levels	Potassium: 3.5 to 5.5 mEq/L
		Calcium: 8.4 to 9.5 mEq/L
		Sodium: 135 to 145 mEq/L
		Phosphorus: 3.5 to 5.5 mEq/L
Is my blood getting cleaned effectively?	Kt/V (formula for clearance, time, and volume)	Peritoneal dialysis: Greater than or equal to 1.7 Home hemodialysis: Greater than or equal to 2.0 Hemodialysis: Greater than or equal to 1.2
	Urea reduction ratio (URR)	Greater than 65 %
Do I have anemia (reduced red blood cells)?	Hemoglobin (Hgb)	10.0 to 12.0 gm/dL
Is my diabetes under control?	Hemoglobin A1c (A1c)	Less than 7.0 gm/dL

* What are the abbreviations in the last column? Some measurements in the last column tell you and your doctor how much of something is in your blood.

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

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

gm / dL: grams per deciliter

Support and Resources

Dealing with kidney failure, or end-stage renal disease (ESRD), may feel overwhelming at times, but your care team can help you manage most aspects of your care and treatment — making informed decisions as well as providing support and assistance to you and your loved ones.

Your ESRD care team

- **Nephrologists** are doctors who specialize in treating kidney disease. A nephrologist will diagnose your kidney disease, prescribe treatments and medications, and refer you to other providers for specialized care. They will help oversee your treatment through regular follow-up appointments.
- **Advanced Practice Providers** are either nurse practitioners (NP) or physician assistants (PA) who are trained and educated similarly to physicians. They can prescribe medication and testing. They work closely with your nephrologist to manage your care.
- **Medical directors** are administrators that help run dialysis centers. They also work to balance the needs of patients and care staff.
- **Nurses** provide many levels of care. At the dialysis center, a nurse will carry out and monitor your dialysis treatment. They also help coordinate treatment with other care team members and may also train you on caring for yourself.
- **Kidney care navigator** is a resource for the patient and their support system. They provide education and help patients make informed treatment decisions based on their preferences and health situation. They are a point of contact for questions regarding your diagnosis and treatment plan, and will follow the patient throughout the continuum of their CKD.
- **Dialysis technicians** work with nurses to care for you during in-center dialysis treatment. They will initiate, manage, and record medical information during your treatment.
- **Registered dietitian nutritionists (RDNs)** are nutrition experts trained in medical nutrition therapy (MNT). An RDN can help you create a diet plan that helps meet your individual needs.
- **Social workers** can provide you and your family with counseling, support, and education. They help you communicate with your care team and assist you with financial, emotional, and social needs.

Social worker services

You and your social worker will complete an assessment which includes the following:

- Family and support systems
- Financial and insurance information
- Complete medical history
- Education and work history
- Legal documentation (Power of Attorney or Living Will)

Other services your social worker may provide:

- Vocational rehabilitation evaluation (for people interested in working, going to school, volunteering, or returning to other activities)
- Assistance with getting or keeping insurance
- Information about other resources and services
- Education about your rights and responsibilities
- Education about advance directives
- Supportive counseling for you and your family

If you are considering a transplant, you must meet with a social worker and transplant coordinator from the transplant team. That social worker will evaluate you and your situation to make sure you are prepared for the challenges you may face following a transplant.

Friends and Family — What can you do?

Supporting someone with chronic kidney disease often means doing new things — and not doing others. If your loved one has ESRD, you may be wondering what you can do to help them. The lists below give a few ideas.



DO

- **Recognize the ways your disease affects your loved one and you.** The adjustments you make may not be easy, and the emotions you feel may be intense. However, ignoring them never helps, though honesty and humor often do.
- **Try some healthier new habits — like being physically active and having a better diet — along with your loved one.** With you as an active partner, your loved one will probably find it easier to live a healthier lifestyle. You'll benefit, too, from healthier daily habits.
- **Offer support and comfort.** Managing ESRD is a lifelong challenge, and your loved one will go through many ups and downs. On a "down day," go out of your way to show love and concern. You don't have to try to fix every problem. Sometimes just listening, or offering a hug, is the best thing you can do.
- **Learn how you can help your loved one with treatment options like transplant (see [Section 3](#)) and dialysis (see [Section 4](#)).**

DON'T

- **Don't act like a police officer.** Trying to control someone's behavior rarely works, and it can damage your relationship.
- **Don't lead them into temptation.** For example, if your loved one is trying to cut down on sodium, do them a favor by not keeping salt in the house or keeping the salt shaker off the table or by encouraging them to eat salty restaurant food. And never encourage them to stray from their self-management plan. "It's all right to skip a few days of physical activity." "Have another burger." If you find yourself saying things like this, ask yourself why.
- **Don't tell everyone about your loved one's condition.** Not everyone is comfortable talking about their health. Talk to your loved one about when and how they want to discuss their health with others.

You are the most important team member

Lots of people have ESRD, but there's no one exactly like you. And no one cares more about your health than you do. That's why you need to take an active role in your care. You can help your care team figure out what you need for your unique situation and personality. **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.** The more you know, the better decisions you'll make. And your team members can offer better advice if they know what you're interested in, and what you don't understand.
- **Be open and honest.** To develop a care plan with you, 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 in your care plan doesn't feel right for you, don't ignore it. Talk to your healthcare providers. You might need to adjust your plan.

Don't be afraid to talk

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

- **Money.** Dialysis, medications, supplies, and office visits can get expensive. But there are ways to make sure that money doesn't get in the way of good care.
- **Sex.** Some dialysis 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, clean environment, and staff wearing gloves, gowns, and masks.
- **Medical terms and concepts.** Don't worry if you don't understand something. Kidney disease is complicated! We are here to help you know everything about 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 your feedback and leadership.

"My care team helped me work through all the questions and worries I had when I started dialysis. It would have been overwhelming without them!"
—Kayla, hemodialysis patient



Paying for treatment

An important part of managing kidney disease is knowing what treatment will cost you. Insurance coverage is different for each patient. Work with your social worker to determine which insurance, Medicare, and /or Medicaid options are available to you.

Your social worker will help you understand:

- How to get insurance or keep your insurance
- What treatments and costs are covered
- Other ways to pay for non-covered (out-of-pocket) expenses

Insurance words you need to know

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

- **Claim:** A request to have a medical bill paid. Either you or your provider may send claims to your insurance company.
- **Coinsurance:** The percent of the bill you will need to pay. You usually pay a deductible (see below) before you start paying coinsurance. With Medicare, your coinsurance payment is typically 20 % of the cost while Medicare pays the remaining 80 %.
- **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 (see above). You will have to pay the full deductible amount again at the beginning of each year, usually on January 1.
- **Effective date:** The date when an insurance policy begins to cover you. Some insurance, including Medicare, have waiting periods before they begin to pay medical expenses.
- **Lifetime maximum:** The total dollar amount a health care plan will pay over your lifetime.
- **Medical Nutrition Therapy (MNT):** This type of therapy involves meeting with a registered dietitian nutritionist (RDN) to develop a personalized eating plan for managing a healthy amount of sodium, protein, potassium, phosphorus, and calcium in your diet.
- **Medicare assignment:** Medicare sets approved amounts to how much is paid for a covered service, called an assignment.
- **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.
- **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.
- **Policy:** A contract issued by an insurance company that spells out what they will pay and what you are responsible for paying.
- **Premium:** The amount you pay to an insurance company to get and keep insurance.

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 with ESRD

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 a person who meets either of the first 2 requirements

Lastly, if you qualify for Medicare only because of permanent kidney failure, your treatment must include dialysis or a transplant. While conservative care for ESRD is not covered by Medicare, hospice care is usually a covered benefit.

Medicare can be complicated. In rare circumstances, one might not qualify or be disqualified for Medicare. Be sure to talk to a local Social Security office about your specific situation.

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: www.ssa.gov.

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. 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.

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 tells us that being employed or otherwise feeling productive helps ESRD patients feel better physically and emotionally.
- You can maintain your employer's group health plan, which often pays for some costs that Medicare does not.

Ask your social worker about career counseling and job training.



Understanding Medicare Coverage

If you enroll in Medicare for ESRD treatment, there are some special rules and situations that you need to be aware of:

- **You can have a group healthcare plan and Medicare.** For the first 30 months of treatment, Medicare is the secondary payer. This is known as the “coordination period.” Make sure your provider knows you have a group healthcare plan and that services are billed correctly.
- **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 usually begins 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. **You have up to 2 months from the date coverage starts to have the transplant.** If your transplant is delayed more than 2 months, coverage back-dates 2 months from the day of the transplant.
For example: If you are first admitted to the hospital in June for a pre-transplant evaluation, you have until August to complete the transplant. During this 2-month window, your treatments are covered by Medicare. If the transplant is delayed until September, Medicare will cover expenses that started in July. Any treatment you received in June will not be covered by Medicare.
- **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.
- **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 transplant
 Medicare coverage can resume again if your treatment needs change. Work with your social worker to complete the necessary Medicare application and supporting documentation.
- **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 a one-on-one meeting 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 can help answer some of your questions. If you are not comfortable researching medical information online, ask for help from a medical or regular librarian, or from your social worker.

Website name	URL	What this site offers
American Association of Kidney Patients	aakp.org	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.
American Kidney Foundation	kidneyfund.org	This non-profit organization provides charitable assistance to kidney patients to pay for health insurance premiums and other treatment-related expenses.
Centers for Medicare and Medicaid Services	medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf	Medicare offers a free, downloadable booklet, <i>Medicare Coverage of Kidney Dialysis & Kidney Transplant Services</i> , for patients which explains how Medicare pays for a kidney transplant and dialysis services and provides resources for assistance.
Home Dialysis Central	homedialysis.org	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	kidneyschool.org	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	kidney.org	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	renalnetwork.org	This non-profit, patient-run support organization offers advocacy and education programs. The website allows users to access the <i>KidneyTalk</i> podcast, a newsletter, a peer support phone line, recipes, resources, and more.
United Network for Organ Sharing (UNOS)	unos.org	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

The list below provides definitions for some of the terms in this book, as well as some others you may hear in the course of your treatment for ESRD.

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.

attenuated: A term used to identify a weaker or lower-strength vaccine.

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

calories: The energy in the foods and drinks that our bodies use to function and sustain life.

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.

conservative care: Care which manages the symptoms of kidney failure without the use of dialysis or transplant. This can include medical, emotional, spiritual, social, and practical care for both patient and family (see **hospice** and **palliative care**).

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

continuous cycling peritoneal dialysis (CCPD): A type of peritoneal dialysis that can be done while you sleep using a machine called a "cyclor."

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.

cyclor: Used in peritoneal dialysis (CCPD type), this is a small machine that does exchanges for you while you sleep (see also continuous cycling 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 in the hospital or community 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 take care of the dialysis machine and other equipment at the dialysis center.

dialyzer: The artificial kidney which removes waste products and extra fluid from your blood; a filter for 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, 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 (see also hemodialysis).

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 (see also hemodialysis).

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, 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 2 to 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 (see also hemodialysis).

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 spiritual support to patients and families as well as palliative care for patients in the home, in a hospital, or in a hospice center (see also palliative care).

I

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

K

kidney care navigator: A nurse who helps to coordinate, support, and guide your CKD treatment plan.

kidney disease: The loss of some or all 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 to keep you alive, requiring either a kidney transplant or dialysis treatment (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 transplant (see also kidney transplant).

M

MAWDS: An Intermountain lifestyle-based patient education acronym. It stands for Medications, Activity, Weight, Diet, and Symptoms.

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.

Medigap: A Medicare supplement insurance which you purchase and is issued by private companies. You have a 6-month window after getting Medicare to obtain Medigap.

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).

obstetrician: A medical doctor who specializes in managing pregnancy, labor, and birth.

P

palliative care: A type of care focused on helping patients who do not opt for dialysis or transplant to cope with their illness through pain relief and stress reduction.

peritoneal cavity (also called abdominal cavity): A fluid-filled 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 removes waste products and extra fluids from the body, and then is drained out (see also dialysis, dialysate, catheter, and abdominal cavity).

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

phosphorus: A mineral (which is not properly filtered in those with kidney disease) that can weaken bones. It is found as a preservative in many foods such as dark sodas, fast food, and other processed foods.

potassium: A mineral (which is not properly filtered in those with kidney disease) that can cause heart problems. 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 but can be in excess if you have kidney disease, making you feel thirsty and take in more fluids than your body can process; 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 include weakness, numbness, blurred vision, confusion, and slurred speech.

supplements: Vitamins and minerals added to your diet and taken as pills or liquids rather than coming from the food you eat.

T

transplant center: A hospital where patients who want to have a kidney transplant go for evaluation and/or the surgery itself (see also kidney transplant).

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 besides the actual surgery.

transplant surgeon: A physician who performs transplant surgery.

U

urine: A yellow 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 evaluates patients at several months before they start hemodialysis and performs the surgery to place a fistula 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.

To find this booklet and other patient education, go to:
intermountainhealthcare.org