Caring for Your Child
with kidney disease and dialysis
Welcome

Welcome to the Primary Children’s Hospital (PCH) Dialysis Center. The children’s dialysis center first opened at the University of Utah hospital in 1981. Our new, state-of-the-art center opened at Primary Children’s Hospital in 2015. We have treated thousands of children diagnosed with kidney disease.

Many families feel scared and overwhelmed when their child first receives a kidney disease diagnosis. Our team of trained healthcare professionals is here to provide your child with excellent medical care.

At Primary Children’s Dialysis Center, our goal is to help children with kidney disease live the healthiest lives possible. To achieve this goal, a child and their family must carefully follow the treatment plan from the dialysis healthcare team.

This handbook provides important information about kidney disease, treatment options such as transplant and dialysis, and other useful resources. The more informed you are, the better you can support your child and their healthcare needs.
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What is Kidney Disease?

Sometimes kidneys slow down and stop doing all the things they need to do. When this happens, it is called kidney disease or kidney failure. This condition may get worse and causes other health problems, but kids living with it can still live an active, happy life. You can take steps now to keep your child’s kidneys as healthy as possible.

“When life gives you every reason to be negative, think of all the reasons to be positive. There’s always someone who has it worse.”

— Larry, father of a child living with kidney disease
Types of kidney disease

Kidney disease can either be **acute** (short-lasting) or **chronic** (long-lasting). Both types are very serious and need immediate medical attention.

**Acute kidney disease:**
- Can come on suddenly but get better with medical treatment
- May or may not require dialysis
- Is often treated for only a short time
- Can be caused by drug overdose, heart failure, infection, injury, and poisoning

**Chronic kidney disease (CKD):**
- Is long-lasting, and kidneys will not get better over time
- Requires medical treatment for your child’s entire life
- Can be caused by birth defects, urine backing into the kidneys, inflamed kidneys, genetic diseases, and systemic diseases like lupus and diabetes

What do healthy kidneys do?

Healthy kidneys:
- Carry waste products and toxins out of the body
- Help make red blood cells
- Help maintain strong bones
- Regulate blood pressure
- Remove extra fluids
- Restore needed body chemicals

Most people are born with 2 kidneys, but a person can live a healthy life with only 1 good kidney.

Steps to help your child

There are 4 critical steps to help your child live the healthiest life possible. Your child needs to:

1. Receive dialysis as prescribed
2. Follow their diet plan
3. Take their medication as prescribed
4. Attend all scheduled appointments

What are waste products?

Waste products include excess fluid, minerals, and chemicals. When too much of any waste product is left in the body, it can make a person sick. Some of the most common waste products healthy kidneys take out of the body include blood urea [yoo-REE-uh] nitrogen (BUN), creatinine [kree-AT-n-een], potassium [puh-TAS-ee-um], and phosphorus [FOS-fer-us].
Healthy kidneys

Your child’s kidneys are about the size of their fists. They are located on either side of the lower back, above the waist. The main job of kidneys is to make urine. Urine carries waste products and toxins out of the body.
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-tn] (EPO) that helps your bone marrow make red blood cells. When you have kidney disease, your kidneys don’t make enough EPO. This causes your red blood cell count to decrease and makes you more likely to get anemia. Symptoms include feeling tired, weak, depressed, or short of breath. If not treated, anemia can lead to heart disease.

**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. Calcium and phosphorus imbalance will also negatively impact growth.

**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.

To reduce your risk of bone disease:

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

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.
SECTION 1 | What is Kidney Disease?

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

When you have CKD, your body may have 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 if recommended.
- Read food labels carefully, especially salt substitutes which may contain potassium chloride.

Fluid buildup
With CKD stage 5, 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 thirst with hard candy or gum.
- Meet with your pediatric renal dietitian to learn how much fluid you can have 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.
Kidney Disease Treatment

You may feel overwhelmed by your child’s diagnosis of kidney disease. This is natural. The good news is that when your child follows their kidney disease treatment plan, they can continue to live an active, happy life.

There are 3 treatment options for kidney disease:

1. Dialysis [dye-AL-ih-sis]
2. Kidney transplant
3. Conservative care

Your child’s treatment plan will also include prescribed medication as recommended and a personalized diet. Our healthcare team will work with you and your child to find the best treatment option for your child.

“I love my nurses. They’re so nice, and they take good care of me! The first time I met them, I knew they were going to be my friends. When I first started [treatment] I was scared and had a lot of pain, but all the nurses played games with me to get my mind off my pain. Sometimes they would hold my hand, and that made me happy.”

— Nellie, age 7
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 [dy-AL-i-SAYT] fluid) when your kidneys aren’t making urine.

Types of dialysis

There are 2 main types of dialysis:

1. **Hemodialysis** [hee-moh-die-AL-uh-sis] (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 (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.

2. **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]. 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

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.
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.

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.

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

Dialysis works by diffusion and ultrafiltration

Diffusion [di-FY00-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 and is one of the functions of the kidneys that dialysis replaces.
Hemodialysis (HD)

A blood thinner is added to prevent clotting

Blood pump

Blood is pumped out of the fistula

Dialyzer (Membrane)

Used dialysate with waste is removed

Fresh dialysate is added to cleanse the blood

Dialysate

Air detector and trap

Clean blood is returned to the body through the fistula

Fistula (Access)

Blood is pumped out of the fistula

3 things to make HD work:

1. **Access**, a fistula or a graft surgically placed in the arm

2. A **membrane**, the dialyzer, that has small hollow tubes with microscopic holes that let wastes and fluid out, but keep red blood cells and nutrients in

3. **Dialysate**, the fluid inside the machine that is drained out after your blood is cleaned
# Hemodialysis access types

HD requires a surgery to connect an artery to a vein in your child’s arm. This allows access to their bloodstream for HD treatments. Access to your child’s bloodstream can be achieved either with a **fistula** [FIS-CH00-luh] or a **central venous catheter**.

## Fistula

A fistula is a permanent access for HD created by surgically connecting a vein and an artery in the arm. This creates a bigger vessel which allows for an increased bloodflow for dialysis.

If your child’s treatment plan includes HD, they usually need a fistula in their arm. It’s ideal for your child to get a fistula a few weeks or months before HD treatments begin so it has time to heal.

- A vascular surgeon will make your child’s fistula in the operating room.
- Once the fistula has healed, your child can swim or soak in a bath.
- Protect the fistula from damage or clots by never allowing blood pressure to be taken on the fistula arm.
- Don’t let your child wear tight-fitting clothing or jewelry around the fistula arm.

## Central Venous Catheter (CVC)

If a fistula is not a good option for your child, they will receive a central venous catheter (CVC). You may also hear it called a central line catheter. It is a small tube put through the skin into a vein so your child can receive fluids, nutrition, and medication. CVCs can stay in place for weeks or months.

There is a high risk of infection with a catheter. It is important to care for it properly between treatments, such as keeping it clean and dry. Your child’s healthcare providers will show you how to care for a fistula or CVC.

Dialysis is a part of your child’s life, but it does not define who they are.
Catheter care or access checks
By taking good care of your access, it will last longer and you will prevent problems such as infection and clotting. Check your dressing every day at home.

Basic hemodialysis catheter care
The 6 steps below will guide you through basic HD catheter care.

1. Keep the catheter dressing clean, dry, and intact. (Do not pull on your skin, catheter, or catheter ports.)

2. Make sure the area of the insertion site is clean and your care team changes the dressing as needed at each dialysis session.

3. Keep an emergency dressing kit at home, in case you need to change your dressing in between treatments. Never remove the cap on the end of your catheter. Air must not enter the catheter.

4. Cover your dressing every time you shower or bathe. Make sure your catheter ports are covered with “Press ‘n Seal.” Secure the edges of Press ‘n Seal with tape.

5. Wear a mask over your nose and mouth anytime the catheter is opened to prevent bacteria from entering the catheter and your bloodstream. Professionals changing the dressing should wear a mask and gloves as well.

6. Keep the caps and clamps of your catheter tightly closed when not being used for dialysis. Only your care team should use your dialysis catheter to draw blood or to give medications or fluids.
Basic peritoneal dialysis access check
The 6 steps below will guide you through basic PD catheter care.

1. **Check the abdomen** for any redness, tenderness, unusual swelling, or drainage.

2. **Feel along the tunnel** for warm areas, hardening, or tenderness.

3. **Clean the access daily.** This is especially important after showering, bathing, swimming, or any time the access becomes wet or soiled.

4. **Anchor the access securely** to avoid pulling at the exit site, or injury and irritation.

5. **Cover the exit site with a dressing or bandage.**

6. **Check all drain fluid for clarity.**
Medication and diet

Dialysis does some jobs that are normally done by healthy kidneys. Medications and a special diet are necessary to fill in for work dialysis cannot do.

Medication

In addition to dialysis treatment, your child will need medication to keep their body healthy. Medications do some of the jobs dialysis can’t do for the kidneys. Each child may need different types of medications, and they may change over time. Your child’s healthcare team will regularly test your child’s blood to make sure the medications are working properly. They will let you know when changes are needed.

Common medications for kids living with kidney disease include:
- Vitamin and mineral supplements prescribed by your provider
- Blood pressure medication
- Erythropoietin (kidney hormone that helps produce red blood cells)
- Growth hormones
- Iron
- Phosphorus binders (help your child absorb less phosphorus)
- Vitamin D

Diet

What your child eats helps them maintain healthy fluid, electrolyte, and mineral levels in their body. Your child must eat enough of the right foods so they will grow, gain weight properly, and maintain appropriate lab values. You and your child will meet with our pediatric renal dietitian to create a special food plan for your child. It may seem like a chore at first, but after a while the diet will become easier for you and your child. The dietitian can offer tips and resources to help you with the diet. If your child is unable to meet their nutritional needs, they may require nutrition supplements by mouth and/or tube feedings.
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.

Electrolytes in Balance

- **Phosphorus (P)**
  - Normal range: 2.5 to 4.5 mEq/L
  - **Too much**: Thirst, fatigue, bone pain, stomach upset, confusion, seizures, changes in heart rhythm
  - **Too little**: Numbness of fingertips and around the mouth, twitching, cramps, shortness of breath

- **Sodium (Na)**
  - Normal range: 135 to 145 mEq/L
  - **Too much**: High blood pressure weakness, seizures, coma
  - **Too little**: Brain swelling

- **Chloride (Cl)**
  - Normal range: 96 to 106 mEq/L
  - **Too much**: Itchy skin, bone or joint pain, and/or development of serious skin sores
  - **Too little**: Muscle weakness, coma, death

- **Calcium (Ca)**
  - Normal range: 8.8 to 10.4 mEq/L
  - **Too much**: Trouble breathing, sleepiness, problems with heart rhythm, death
  - **Too little**: Nausea, vomiting, weakness, painful foot cramps, tiny muscle twitches or tremors

- **Potassium (K)**
  - Normal range: 3.5 to 5.3 mEq/L
  - **Too much**: Cardiac arrest, sudden death, or may have no symptoms
  - **Too little**: Weakness, fatigue, muscle cramps, change in heart rhythm

- **Magnesium (Mg)**
  - Normal range: 1.4 to 2.1 mEq/L
  - **Too much**: Confusion, paralysis, or may have no symptoms
  - **Too little**: Weakness, fatigue, muscle cramps, change in heart rhythm
What is a kidney transplant?

The result of a kidney transplant is that your child’s body responds as it would if they had their own healthy kidneys. It is not a cure for CKD as your child will need follow-up care. Most patients will have multiple transplants during their lifetime. A transplant can extend your child’s life. 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 you need to know about a transplant

Your child might not be able to have a kidney transplant if they have one of several medical issues (see the In Focus box on page 25). A kidney transplant is a surgery that can only be successful if your child is 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.

Your child might have to wait months or years for a kidney that is a good “match” for their 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. 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).

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

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

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.** Your child (and a living donor, if applicable) will have every major system in your body tested.
   - **Support qualification.** Team members will verify that your child has 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 your child, 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 child’s 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 child’s transplant status regularly.
   - **Maintain** a positive outlook and live healthy while you wait.
   - **Think ahead.** Prepare your home for the 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 your child is 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 your child and 4 to 5 days for a living donor. Your child 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 child’s recovery. Be patient while healing occurs. Follow recommendations for activity.
   - **Follow orders.** Have your child take medications as instructed and have blood drawn as directed.
   - **Be prepared for change.** Your child may experience physical and emotional changes. Talk with the transplant team about the changes.
How do we get a kidney?

A healthy family member, friend, or even a stranger could donate a kidney for your child (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 3½ 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 child’s 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 your child 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, your child 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 your child reaches CKD stage 5. 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](http://optn.transplant.hrsa.gov).

For more information about Intermountain Healthcare’s living donor program, visit [intermountainhealthcare.org/services/transplant-services/become-donor](http://intermountainhealthcare.org/services/transplant-services/become-donor). You may also contact Intermountain’s Transplant Services by calling 801-507-3380.

“**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, the transplant team will run tests to see if this is a safe and beneficial option for your child. 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 your child 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:

- **Size**: Children are candidates for transplant evaluation once they’re at an appropriate size, as determined by the transplant team.
- **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, tobacco use within 3 months, or alcohol or substance use.
- **Following your child’s treatment plan (adherence)**. All treatment options are complex and require significant involvement by parents or other family members. Your healthcare team is here to support you. *Adherence is a necessity. Your child’s care and health are our top priority and will require your commitment.*

Having a history of not following doctors’ instructions about your child’s 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 your child takes care of themselves. 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 child’s doctor prescribes** to keep their body from rejecting the new kidney. Your child will need to take these every day without fail.
- **Live healthy.** Have your child eat healthy, not smoke, get regular physical activity, achieve and maintain an appropriate weight to reduce their 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 child’s immune (disease-fighting) system knows that their new kidney is not the one they were born with and will normally try to reject it (unless the donor was an 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 child’s natural immune response, making it less likely that it will reject the new kidney.

When your child has their transplant surgery, they will get a powerful anti-rejection medication. They will need to continue to take maintenance doses of these medications every day from that point on as long as they have their transplanted kidney. **Remembering to take their prescribed anti-rejection medication every day is critical to the health of their 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 your child takes any medication at a different time than prescribed.) At 6 to 12 months after the 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 the transplant doctor before your child takes 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 child’s 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 27).
- **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 your child, avoid direct sunlight and tanning booths, wear sunscreen, and be extra aware of changes in their 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 we call our transplant doctor or other care team members?

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

- 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

Before transplant your child needs to be up-to-date on all vaccinations according to Centers for Disease Control and Prevention guidelines.

Vaccines to avoid include:

- 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 (unless instructed by your team)
- Mumps
- Rubella
- Oral polio
- Live Japanese encephalitis vaccine
- Yellow fever

Changes to your child’s vaccination schedule may occur based on your medical team’s recommendations.

Some live vaccines can be harmful if your child has 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 child’s doctor to see what vaccines your child should have. 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 child’s doctor to see what vaccines you should have beforehand.
How will having a transplant affect my child’s lifestyle?

Having a kidney transplant is the treatment option that allows your child the most similar lifestyle to what they experienced when their own kidneys were healthy. Once they recover from surgery, they will be able to continue to work, attend school, travel, and enjoy most of the same activities and hobbies. They will, however, need to modify some activities to protect their 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 your child healthy.

Make healthy choices

Possible side effects of post-transplant medications are weight gain and developing diabetes or heart disease. However, you can reduce your child’s risk if your child:

- **Maintains a healthy weight.** Follow a healthy diet with the help of their dietitian.
- **Controls 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 their blood pressure every day.
- **Remains physically active** (as directed by their doctor).
- **Avoids exposure to second-hand smoke, or smoking.**
- **Controls their diabetes.** Follow their care plan for medications, diet, and glucose monitoring.

Intermountain resources for a healthy lifestyle
Safely return to school, sports, work

After your child recovers from surgery, they can likely return to most of their previous activities. However, their doctor may suggest certain precautions.

Your child will likely be able to return to school (or work) within 2 months following surgery. If their job previously required heavy lifting or some exposure to germs, they might need to talk with the transplant social worker or others on their transplant team about some career counseling to discuss other job options. Remember, your child will need to protect their 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 your child can safely drive. The medications they will be taking when they leave the hospital can make them dizzy or have blurred vision, which makes driving dangerous.

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

Return to normal family life

After the transplant, you will likely be able to resume normal activities. Patients should talk with their doctor about any concerns they have related to sexual activity, fertility, or pregnancy.

Travel smart

Your child may be asked to limit or avoid travel for a period of time after surgery. Talk with the transplant team about any travel plans your child has while recovering and adjusting to life with a kidney transplant.

Where can I find more information?

For more general information about transplants, visit: UNOS.org — “What Every Patient Needs to Know”

Adherence

All treatment options are complex and require significant parental involvement. Your healthcare team is here to support you and to help your child attend appointments, take medications, and follow their specific diet. Adherence is a necessity. Your child’s care and health are our top priority and will require your commitment. Your care team will provide you with Intermountain’s patient handout, Pediatric Dialysis: Adherence to the treatment plan.

Conservative care

Conservative care does not include dialysis treatments. Instead, it focuses on improving quality of life, using medication and diet, to keep a child comfortable during their final days. Your child’s healthcare team can provide you more information on this approach.
The Dialysis Center

The dialysis center has been serving children with kidney disease for more than 35 years. Our professional, highly trained healthcare staff provide your child with the best medical care.

Location
Primary Children’s Dialysis Center
Primary Children’s Hospital
Eccles Outpatient Building
81 N. Mario Capecchi Drive
Salt Lake City, Utah 84113

The dialysis center is in the south end of the third floor in the Eccles outpatient building, across the street from Primary Children's Hospital.

Contact information
Dialysis center: 801-662-7600
Main hospital: 801-662-1000

“Be strong, be happy, and remember that you can always talk to your team.”
—Manu, 17-year-old living with kidney failure
Hours

The dialysis center’s hours are Monday through Friday, 6 am to 4 pm.

Dialysis treatments are scheduled on Monday, Wednesday, and Friday. The last dialysis appointment of the day is scheduled to begin before noon.

The center is closed on Christmas Day (December 25th) and New Year’s Day (January 1st). If either holiday falls on a Monday, Wednesday, or Friday, the dialysis center will adjust the treatment schedule to accommodate patients.

Staff

Our staff provides your child with the best medical care. Your child’s healthcare team will work with you and your child to develop a treatment plan. Each team member plays an important role in your child’s treatment plan.

Nephrologist. Pediatric nephrologists are doctors who specialize in treating kids with kidney disease and kidney failure. Our nephrologists will lead your child’s healthcare team in developing a treatment plan that is right for your child.

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone Number</th>
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<tbody>
<tr>
<td>Registered nurse</td>
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</table>

Registered nurse. Registered nurses are trained to provide many levels of care. They often set up and monitor dialysis treatments. They will review medications and make sure your child’s treatment plan is being followed. Our nurses will talk with other members of your child’s healthcare team to make sure your child’s medical needs are being met.

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone Number</th>
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<tbody>
<tr>
<td>Dialysis technician</td>
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</tbody>
</table>

Dialysis technician. Dialysis technicians are trained to operate dialysis machines. A dialysis technician may set up and monitor your child during their in-center dialysis treatments.

<table>
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<tr>
<th>Name</th>
<th>Telephone Number</th>
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<tbody>
<tr>
<td>Child life specialist</td>
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</table>

Child life specialist. Child life specialists are experts in child development who ensure life remains as normal as possible for kids in the dialysis center. Our child life specialists will work with your child and family to decrease stress and anxiety.

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone Number</th>
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<tbody>
<tr>
<td>Social worker</td>
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</tbody>
</table>

Social worker. Social workers are trained to help people during difficult times in life. Our social workers help you and your child with challenges that may come from living with kidney disease and maintaining dialysis treatments. Your child’s social worker can connect you to resources that can help.

<table>
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<tr>
<th>Name</th>
<th>Telephone Number</th>
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<tbody>
<tr>
<td>Dietitian</td>
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</table>

Dietitian. Dietitians know what foods and drinks each patient needs to stay healthy. After considering labs, nutrition, and fluid needs, our renal dietitian provides a dietary plan for each dialysis patient. Your child’s dietitian will work with you to plan a safe, healthy, and satisfying diet for your child.

<table>
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<tr>
<th>Name</th>
<th>Telephone Number</th>
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Dialysis center expectations

Our goal is to provide all our patients with the best medical care, so we ask our patients and their families to follow a few simple rules. Doing this ensures your child has a safe, healthy, and timely experience every time they visit our center.

Monthly dialysis clinic
Once a month, your child will be required to have a dialysis clinic appointment and meet with the team’s social worker, dietician, nurse, and physician. The team will review labs, medications, and medical records with you and may also revise your child’s care plan.

Be on time
It is very important that your child is on time for their dialysis treatment appointments. If your child is late, the next child’s treatment can be delayed. We value all our patients and want to provide timely care for each child. Please arrive 10 minutes before your child’s scheduled appointment to make sure their treatment can begin on time.

Do not eat
To protect themselves and others, kids are not allowed to eat during their dialysis treatments. Give your child a snack before they arrive for their treatment and pack a small snack for your child to eat when they finish their treatment. To respect our young patients, visitors may not eat in the center either.

Have all vaccinations
All patients must be up-to-date on all vaccinations, which keep your child, other patients, and our healthcare staff safe and healthy. Your child can begin dialysis treatments if they don’t have all their vaccinations. However, you must get your child all required vaccinations within three months of starting the treatments. Coordinate the vaccinations with your child’s primary care provider.

Respect the one-visitor rule
Your child may have one visitor at a time during treatment. This helps us make the treatment area a healthy and quiet environment for all our patients. Children younger than 18 years may visit, but they must have an adult or guardian at the hospital while they are in the dialysis center. Please make other plans for siblings or take them to the Kids’ Clubhouse on the first floor of the Eccles outpatient building. The Kids’ Clubhouse is open Monday to Thursday from 8:30 AM to 6 PM and Friday from 8:30 AM to 3 PM.

Use your locker
Your child will have a secure locker to store personal items, including their blood pressure cuff and pillow. Please help us keep our center clean by putting all personal items in your child’s locker before leaving for the day.

Complaints
The dialysis center staff are committed to providing the very best medical care and keeping your child safe. We want you and your child to understand their diagnosis and treatment plan, and we encourage you to ask questions and speak up if something doesn’t seem right. Be an advocate for your child’s care. We will do our best to address your concerns or complaints.

If you have concerns or complaints the dialysis center management has not addressed, contact Primary Children’s quality resource department at 801-662-6315.

If the Quality Review (QR) department does not resolve your concerns, you have the right to contact the Health Services Advisory Group ESRD Network 15 at 800-783-8818 and make a formal grievance.
Living Healthy

Healthy bodies and healthy minds equal happy, active kids. You and your child’s caregivers help your child maintain good health. You can help by:

• Using good hand hygiene [HYE-jeen]
• Empowering your child
• Being prepared for emergencies
• Ensuring they, along with other family members, are up-to-date on all vaccines

“Trust your team, and don’t forget to communicate how you are feeling.”

—Sarah, mother of a child living with kidney disease
Use good hygiene

Germs can make people sick and cause infections. Using good hygiene can help kill germs and prevent illness.

1 **Wash hands well.** Germs live on the skin, including under nails and between fingers. Scrubbing your hands well with soap and warm water will help get rid of germs. You can also protect your child’s dialysis access from germs by washing your hands often and encouraging your child to do the same.

2 **Clean household surfaces.** Germs can live on all objects, including countertops, floors, door handles, computers, phones, and open medical supplies. Clean all surfaces you touch or that may touch your child’s catheter, dialysis equipment, and supplies.

3 **Wash soiled bedding and clothing.** Germs live and spread on all bedding items and clothing. Washing your child’s bedding — sheets, pillowcases, and blankets — weekly or when they become dirty will help kill germs. Make sure your child also wears clean clothing to help keep germs away.

Empower your child

Teach your child to be aware of their body and feelings. Our child life specialists and other healthcare providers’ goal is to help your child feel comfortable talking about their kidney disease. To do this:

- Help your child understand their emotions and find ways to get through emotional times.
- Take time every week to ask your child some caring questions to find out how they are feeling.
- Teach your child to speak up when they don’t feel right.
Emergency preparedness

Natural disasters, such as earthquakes, floods, and bad winter storms, can cause power outages and bad road conditions that last for several days. During this time, your child may not be able to have regular dialysis treatments.

You must be prepared to keep your child healthy when disasters happen.

The dialysis team will do their best to coordinate with other dialysis centers to provide safe and needed care if an environmental disaster or emergency makes it impossible for you to go to the dialysis center. When patients can’t have dialysis for several days, they must follow an emergency plan diet to keep their nutrients, electrolytes, and fluids balanced. This diet is more limited than their normal kidney care diet to keep toxins in the blood from building up too fast. Some food your child normally eats may not be allowed.

If the center is closed due to a natural disaster, extreme weather event, or emergency, or if your child has an urgent dialysis-related problem:

- Call the main hospital at 801-662-1000.
- Ask to speak to the dialysis nurse on call.
- Wait on the line while the nurse is contacted.
- Coordinate with the on-call nurse an immediate plan for care.

If your child has stopped breathing or is unresponsive, immediately call 911.

For all other medical concerns, contact your child’s primary care doctor or pediatrician.

Your emergency plan

Your child’s dietitian will help you create an emergency plan diet for your child. To prepare for emergencies after a natural disaster:

- Know your child’s weight. Kids who weigh less than 80 pounds (36 kilograms) need smaller amounts of food and liquids.
- Plan meals that can be stored and prepared with little or no refrigeration.
- Buy single-serving cans of food and juice boxes for easy portion control.
- Store food and drinks in a strong, secure box.
- Keep your child’s emergency food box in an easy-to-access location.
- Make sure other family members or caregivers know where the emergency box is located.
- Replace the food and drinks in the emergency box every year with fresh supplies.
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.

“The nurses at Primary Children’s Hospital Dialysis Center are among the most compassionate and loving nurses I’ve ever seen.”

—Denise, mother of a child living with kidney disease
Social work

A hospital can be a frightening and frustrating place for both you and your child. It is normal to have these feelings, and a PCH medical social worker can help.

Social work support is available 24 hours a day, 7 days a week. A social worker from the dialysis center healthcare team meets and speaks with all of our patients and their families regularly.

Social workers are trained, licensed professionals with graduate degrees in social work. They offer help with mental, physical, and social concerns. They also provide hospital and community resources and help you and your family work through challenges.

Your child’s social worker can:

• Help you talk to your child’s healthcare team about questions, concerns, or support
• Offer counseling, support group information, or refer you to community mental health services
• Give you guidance when you feel your child’s rights are not being properly addressed
• Help with problem-solving, prioritizing, or setting goals
• Give you information on housing, transportation, financial aid, and community resources
• Support you when you feel stressed, vulnerable, overwhelmed, or alone
Insurance

Kidney treatment is expensive. Luckily, many kids on dialysis qualify for Medicare, Medicaid, and Social Security, which can help pay for many treatment expenses. Your child’s social worker can help with insurance, but here are a few common questions and answers.

What is Medicare?
Medicare is a health insurance program provided by the federal government. It is usually for Americans 65 years or older. However, pediatric patients on dialysis for chronic kidney disease who are receiving Social Security can apply for Medicare.

What does Medicare cover?
Medicare helps pay for many, but not all, kidney disease treatment expenses. Kids on dialysis can apply for Medicare Parts A, B, and D.

- **Part A**: Covers treatment costs when your child stays in the hospital, including transplant surgery expenses. Most people do not pay a premium for Part A. You will pay a deductible and coinsurance.

- **Part B**: Covers some treatment costs when your child is not in the hospital. You will pay a monthly premium, a deductible, and coinsurance unless you have Medicaid and are signed up and qualify for the qualified Medicare beneficiary (QMB) program. Part B helps with costs for outpatient care, including clinic visits, dialysis, lab tests, and medication during dialysis.

- **Part D**: Covers some costs of kidney disease medications your child takes regularly. Premiums and copays will vary.

How do I sign my child up for Medicare?
Your child’s social worker can help you sign up for Medicare and get all the forms you need to apply. Enroll your child by calling the Social Security Administration (800-772-1213) or visiting your county’s local Social Security office. You don’t need to sign up for Medicare Parts A, B, and D at the same time, but it can be helpful.

When does Medicare coverage begin?
If your child is on PD, Medicare coverage will begin immediately after you apply.

If your child is on HD and you have private health insurance, Medicare coverage will begin 3 months after your child starts HD treatments. If you do not have private health insurance, Medicare coverage will begin once your application is processed.

Will Medicare send me a bill?
Medicare Part B only pays for some expenses. You will receive a monthly bill for your premium (the amount you must pay to keep Part B coverage). If you, as a parent, have Medicare, you may qualify for the QMB program that can help cover premium costs. You must pay the premium on time every month. If you do not pay, Medicare will cancel coverage.

What if we have private health insurance?
Private health insurance will help cover expenses Medicare does not cover, but each insurance plan is different. Sometimes private insurance requires you to apply for Medicare when you qualify for the coverage. Your employer often provides private health insurance, but you can also buy insurance plans through Healthcare.gov. Ask the hospital finance assistance counselor or your child’s social worker for more information.

What if we do not have private health insurance?
Medicare will pay for many of your child’s kidney treatment expenses. Your child’s social worker will help you find other resources to cover treatment costs Medicare doesn’t pay for. This may include applying for grants and community assistance programs or Medicaid disability assistance.
**What is Medicaid?**
Medicaid is a federal insurance program run by individual states. Each state has its own Medicaid eligibility rules. In Utah, you may qualify for Medicaid if you meet the income requirements, which look at family size and your assets (savings, home, and more than one car). Qualifications can change according to your disability rating. If you are on Medicaid and applying for Medicare, you should also apply for the QMB program to help cover Medicare premiums. To apply for Medicaid, meet with a hospital Medicaid specialist, visit the Department of Workforce Services (DWS) website, or go to the DWS offices in your county.

**Will Medicaid send me a bill?**
Some people will qualify for Medicaid under the Medicaid “spend down” rule. In this case, you must pay for a portion of your child’s monthly medical care. Once you have paid your portion of the monthly medical expenses, Medicaid will cover the remaining expenses. This system is similar to a monthly deductible.

**What about Social Security?**
Two Social Security programs can help cover medical care costs: Social Security Income (SSI) and Social Security Disability (SSD).
SSI is a program for people 18 years or younger. Qualifying for SSI depends on household income and how old the child who needs services is. A medical review board looks at all applications; it can take three to six months for a decision.
SSD is similar to SSI, but it is for people 19 years or older. To qualify, you must meet the income requirements, and a doctor must confirm that the person in need can’t work because of a medical disability. A medical review board will review the application. It can take three to six months for a decision.
To apply for SSI/SSD, visit SocialSecurity.gov or call 800-772-1213.
Transitioning to adult care

Young adults that are transitioning to adult healthcare providers need to develop certain skills to manage their own care and support their needs. The development of these skills will start at age 12 or 13 years to help support more independence as they get older. They will learn about:

- All their medications and what they do
- Their treatment and disease process
- The basics of healthcare insurance

Your child will have the ability to ask questions about their condition and how it will affect their life. Anticipate that your child will transition their care between ages 18 and 21 years to an adult care team.

Insurance words to know

- **Claim**: A request to have a medical bill paid. Either you or your provider may send claims to your insurance company.

- **Coinsurance**: The percent or amount of the bill you need to pay. You usually pay a deductible (see below) before paying coinsurance. With Medicare, your coinsurance is usually 20% of the cost, while Medicare pays the other 80%.

- **Copayment (copay)**: A preset cost you pay for medical services and prescription medications.

- **Deductible**: The amount you pay for medical services before the insurance company begins to pay. After you meet the deductible, you must pay a percentage of your medical costs, known as coinsurance. You must 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, has waiting periods before paying medical expenses.

- **Lifetime maximum**: The total amount a healthcare plan will pay over your lifetime. For people who need dialysis, this can be important to think about.

- **Medicare assignment**: Approved amounts from Medicare for how much is paid for a covered service, called an assignment.

- **Out-of-pocket expenses**: 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 for everything covered by your plan for the rest of that year.

- **Payer**: The company paying the medical bills. If you have coverage through two 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 tells what they will pay and what you must pay.

- **Premium**: The amount you pay to an insurance company to get and keep insurance.

- **Qualified Medicare beneficiary (QMB)**: A program for people enrolled in both Medicare and Medicaid that helps pay for Medicare premiums.
### 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.

<table>
<thead>
<tr>
<th>Website name</th>
<th>URL</th>
<th>What this site offers</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Association of Kidney Patients</td>
<td>aakp.org</td>
<td>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.</td>
</tr>
<tr>
<td>American Kidney Foundation</td>
<td>kidneyfund.org</td>
<td>This non-profit organization provides charitable assistance to kidney patients to pay for health insurance premiums and other treatment-related expenses.</td>
</tr>
<tr>
<td>Centers for Medicare and Medicaid Services</td>
<td>medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf</td>
<td>Medicare offers a free, downloadable booklet, Medicare Coverage of Kidney Dialysis &amp; Kidney Transplant Services, for patients which explains how Medicare pays for a kidney transplant and dialysis services and provides resources for assistance.</td>
</tr>
<tr>
<td>Home Dialysis Central</td>
<td>homedialysis.org</td>
<td>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.</td>
</tr>
<tr>
<td>Kidney School</td>
<td>kidneyschool.org</td>
<td>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: Help! I Need Dialysis.</td>
</tr>
<tr>
<td>National Kidney Foundation</td>
<td>kidney.org</td>
<td>This organization has a wealth of online resources and a regular newsletter. It is dedicated to the awareness, prevention, and treatment of kidney disease.</td>
</tr>
<tr>
<td>Renal Support Network</td>
<td>renalnetwork.org</td>
<td>This non-profit, patient-run support organization offers advocacy and education programs. The website allows users to access the KidneyTalk podcast, a newsletter, a peer support phone line, recipes, resources, and more.</td>
</tr>
<tr>
<td>United Network for Organ Sharing (UNOS)</td>
<td>unos.org</td>
<td>UNOS is the private, non-profit organization managing the U.S. organ transplant system. It offers a free booklet, Talking about Transplantation, which is available to download at this location.</td>
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</tbody>
</table>
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.

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.

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 “cycler.”

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

cycler: Used in peritoneal dialysis (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.
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.

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).

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).

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).

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

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.

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).

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.

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

**O**

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

**P**

**Palliative care**: A 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).

**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 or finding financial resources.

**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).

**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.