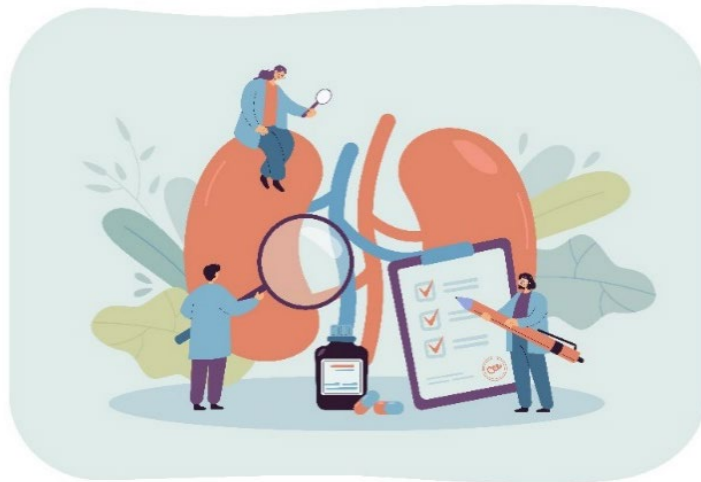


Pediatric Hemodialysis Care Guide

Managing Your Child's Condition



Pediatric Dialysis Program



Introduction

When a child is diagnosed with a serious condition, it is common for parents and caregivers to feel out of control because they do not understand everything that is happening. Understanding the illness and mastering home care skills for your child can help bring back a sense of control.

You might be feeling overwhelmed about your child's diagnosis of end stage renal disease and all the information provided. Don't lose hope! Like other families, you'll learn to manage your child's condition. There's still so much your child can do, and we're here to support you.

This guide provides detailed information on hemodialysis, including treatment, medications, and other resources. We will also include age-appropriate games and activities to help your child understand and follow their treatment.

With this guide, the expertise of your child's healthcare team, and you, our goal is to make the best decisions together for your child's well-being.

A note about this guide

This guide was developed by a Doctor of Nurse Practitioner candidate at the University of Michigan. It's meant to make learning about kidney health and hemodialysis easier for kids and their caregivers. Our goal is to empower and involve young patients and their caregivers in their care journey. This way, they will have a better understanding of their treatment and follow the treatment plan prescribed by their providers.

Meet the members of your Dialysis team

Medical Director: A special doctor who leads the team that takes care of kids with kidney problems. This doctor is very experienced on how to treat these special patients. They make sure everything runs smoothly and safely in the center, so patients can get the best care possible.

Clinical Nurse Director: An advanced practice nurse who oversees operations of the unit. They work closely with staff, make sure safety measures are being followed, and make sure everything runs smoothly for patient well-being.

Nursing Supervisor: A registered nurse who supervises unit employees, unit operations, and clinical leadership.

Nephrologist Attendings: Doctors who are highly trained and experienced in kidney health. They are the leaders of the kidney healthcare team, diagnosing kidney conditions, creating treatment plans, and overseeing patient care. They guide other medical professionals and share their expertise.

Nephrologist Fellows: Doctors who are getting extra training in kidney health after medical school. They work with experienced doctors (attendings) to learn about kidney issues. They see patients, study different kidney conditions, and use their learning to support patient care and kidney treatment research.

Nurse Practitioner: An advanced practice nurse who works with doctors to support patients with kidney issues. They help explain diet, medications, and lifestyle changes to manage kidney conditions. They can also diagnose certain kidney conditions, order tests, and create care plans.

Clinical Nurse Specialist: An advanced practice nurse who specializes in using the latest research to make changes to improve patient outcomes. They also help create and improve healthcare practices and policies for better safety and quality. This means they're always looking for better ways to take care of patients.

Social Worker: A care professional who acts as a guide for non-medical support. They help with challenges that come with health issues, listening to patients' needs and offering emotional support. They connect families to community resources, explain insurance, and plan for future steps in the care journey.

Dietitians: Experts who figure out what kind of food is best for each person and make a special eating plan just for them. This is important because the right food can help keep the kidneys healthy when they're not working perfectly.

Child Life Specialist: A professional who uses games and activities to make kids feel better, explain medical things in a simple way, and help parents understand what's happening.

School Teacher: A specialist who helps patients and their families stay on track with schoolwork and offers educational tools and information to support them.

Administrative Assistant: A professional who keeps everything organized and running smoothly on the unit. They might schedule appointments, answer phones, and help with paperwork.

Nurses: Registered professionals who operate dialysis machines, check on patients, teach them about treatment, and provide support during hemodialysis (a therapy for kidney problems).

Dialysis Technicians: Certified professionals who are trained to access and give hemodialysis therapy under the supervision of a registered nurse.

Clinical Care Coordinators: Healthcare professionals who make sure that patients get the best care by coordinating their medical journey. They work closely with healthcare providers, scheduling appointments, tests, and treatments and making sure everyone is working together. They make sure information is clear, answer questions, reduce stress, and work to get patients timely and organized care

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Understanding Kidney Function and Kidney Disease

What do healthy kidneys do?



Remove waste

Waste products, such as blood urea nitrogen (BUN) and creatinine, are made by the body during normal everyday functions. Healthy kidneys are like little filters that work all day to get rid of this waste from the blood.



Balance fluid

Healthy kidneys know when there is too much or too little fluid in the body. When there is too much fluid, the kidneys make urine (pee) to remove extra fluid your child drinks. When there is too little fluid in the body from sweating, throwing up, diarrhea, or not drinking enough, the kidneys hold in fluid and make less urine.



Control blood pressure

Healthy kidneys help keep blood pressure in a safe range. They release a signal that tells the body when to raise or lower blood pressure. They also help control blood pressure by balancing the fluid in the body.

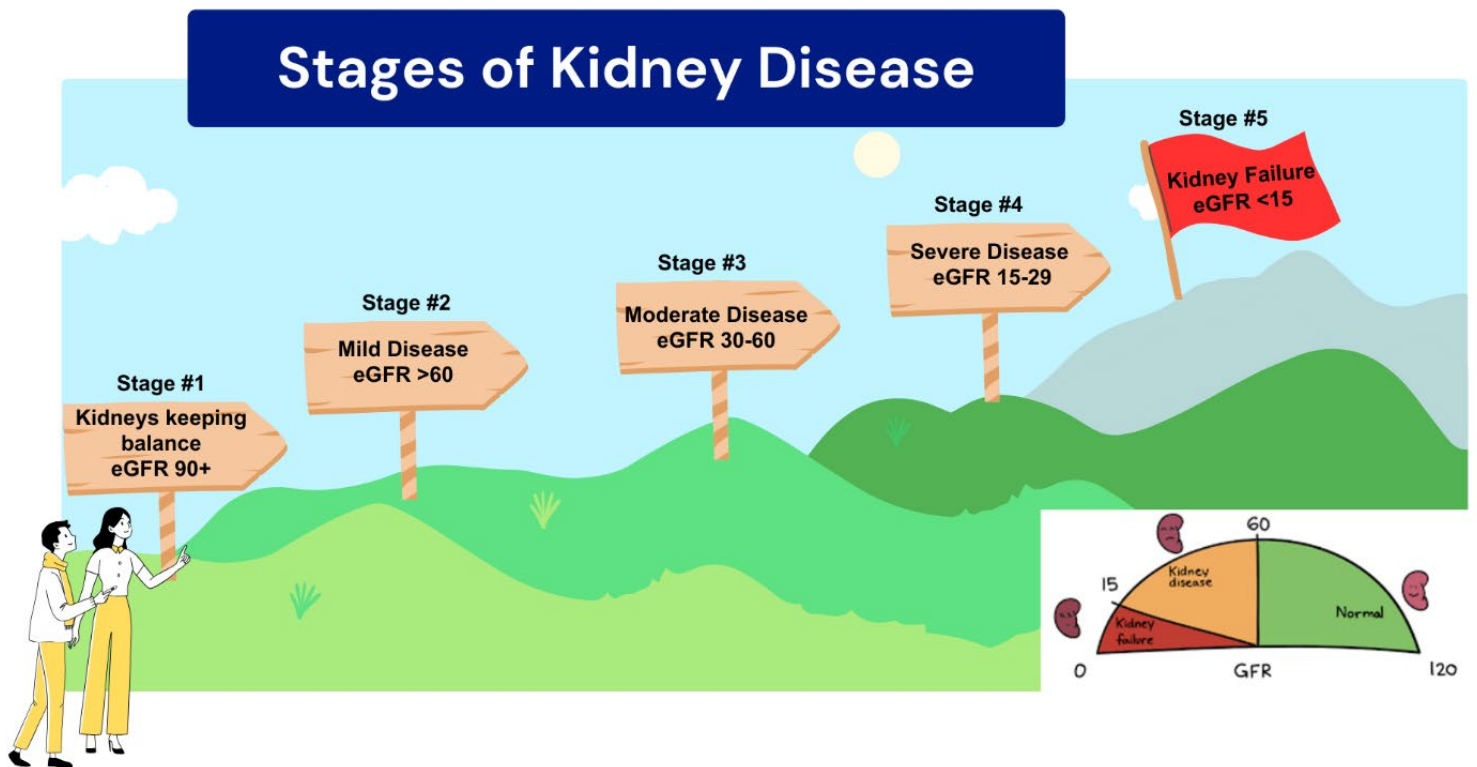


Make red blood cells

Healthy kidneys release a signal that tells the body when to make more red blood cells.

What happens if my child's kidneys don't work?

Kidney disease can be caused by many things. Sometimes patients are born with kidneys that don't function as well as they should. Other times it can be caused by infections or other diagnoses, such as systemic lupus erythematosus or sickle cell disease. The 5 different stages of kidney disease, including the final stage of kidney failure, are described below. No matter the cause of kidney failure, the treatment options are the same.



- **Stage 1:** At the beginning, the kidneys are working well and keeping the body in balance. You might not even know there's a problem. The **estimated Glomerular Filtration Rate (eGFR)** is like a speedometer for the kidneys. It tells us how well they're working. A high number is good, while a low one might mean the kidneys need some extra attention.
- **Stage 2:** The kidneys might show some small signs of not working perfectly, but your child might still feel pretty good.

- **Stage 3:** The kidneys start having more trouble doing their job. Your child might feel more tired or notice changes in how much they pee. It's a sign that the kidneys need some extra attention.
- **Stage 4:** The kidneys are struggling a lot. Your child might feel even more tired, have trouble sleeping, or feel sick to their stomach. You'll need to work closely with doctors to manage your child's kidney health.
- **Stage 5:** The most serious stage of kidney disease. The kidneys are not working well enough to keep your child healthy. They might feel very tired or have trouble breathing, and their body can't get rid of waste like it should. At this point, they'll need special treatments like dialysis or a kidney transplant to help their body stay balanced.

How does kidney disease affect the body?

Waste buildup

When the kidneys don't work as well, they can't clean the blood like they should. This can lead to a buildup of waste, known as **uremia**.

Fluid imbalances

Kidneys help balance the amount of fluid in the body by controlling how much we pee and what's in our pee. When the kidneys aren't working, kids might pee too much or too little or have pee that looks different. When kids stop peeing, extra fluid can build up in their body, which can make it harder for the heart to pump blood throughout the body.

Electrolyte imbalances

Electrolytes are minerals in our body that help keep our body working smoothly. When the kidneys aren't working well, this can lead to too much or too little of certain electrolytes in our blood.

Anemia

Healthy kidneys produce **erythropoietin**, a hormone that makes red blood cells. When the kidneys don't work as well, the body makes fewer red blood cells which leads to **anemia** (a condition where the body doesn't have enough red blood cells to work properly).

Bone disease and problems with growth

Kidneys help keep bones strong by balancing minerals in the body. When they're not doing this job, kids might have weaker bones. Since kids' bodies are still growing, kidney problems can sometimes slow down their growth.

Skin changes

When the kidneys aren't working, the body's skin looks paler and is itchier.

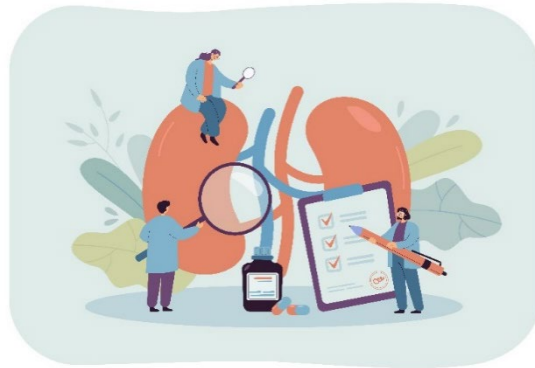
High blood pressure

Kidneys help manage blood pressure. When they're not working properly, blood pressure can go up, which isn't good for the heart.

Hemodialysis

What is hemodialysis?

- **Hemodialysis** is a therapy for kidney problems. It uses a machine to filter your child's blood, removing waste and extra water. Nurses perform this procedure in the Dialysis Unit.
- During hemodialysis, your child will be connected to a dialysis machine using something called an **access device**. There are 2 types of access devices: a **central venous catheter** or an **arteriovenous (AV) fistula**. Your child's access device will be connected to tubes on the dialysis machine that will pull blood from your child's body, clean it, and then return the clean blood to their body.
- Only about 100-300 milliliters (ml) of blood is cleaned outside of the patient's body at any time during treatment. This amount depends on the patient size. For example, a teenager may have 300 ml outside their body being cleaned, but a toddler would only have 100 ml.
 - To help you think about these amounts: a regular soda can is about 355 ml, and a small juice box is about 200 ml. So the amount of blood being cleaned at one time can range from about a half a small juice box to a little less than a soda can.



How often will my child need hemodialysis?

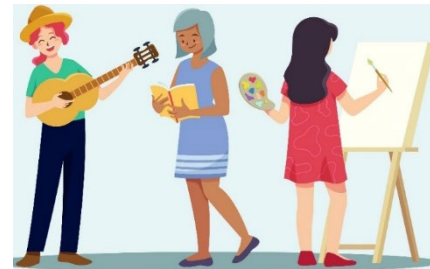
- Your child will come to the Dialysis Unit 3-4 times every week. Each hemodialysis session is 3-4 hours long. This means that during hemodialysis, the blood is cleaned for only about 9-16 hours a week. Keep in mind that healthy kidneys do this job around-the-clock (24 hours

a day, 168 hours per week). This is why staying on schedule and showing up for your child's treatments is really important!

What happens when I bring my child to the unit for hemodialysis?

- Trained dialysis staff will check your child's weight, temperature, and blood pressure before every hemodialysis treatment.
- Your child will be comfortably seated in a recliner or crib.
- During your child's treatment, a nurse will stay with your child to watch for symptoms of low blood pressure (like dizziness or feeling lightheaded), nausea, and vomiting. They will also check their vital signs (blood pressure, heart rate) every 15 minutes.
- During hemodialysis, your child can do activities like watch TV or movies, play games, do homework, or do arts and crafts.

- Art therapists, music therapists, and child life specialists are available to support and engage with your child during hemodialysis.



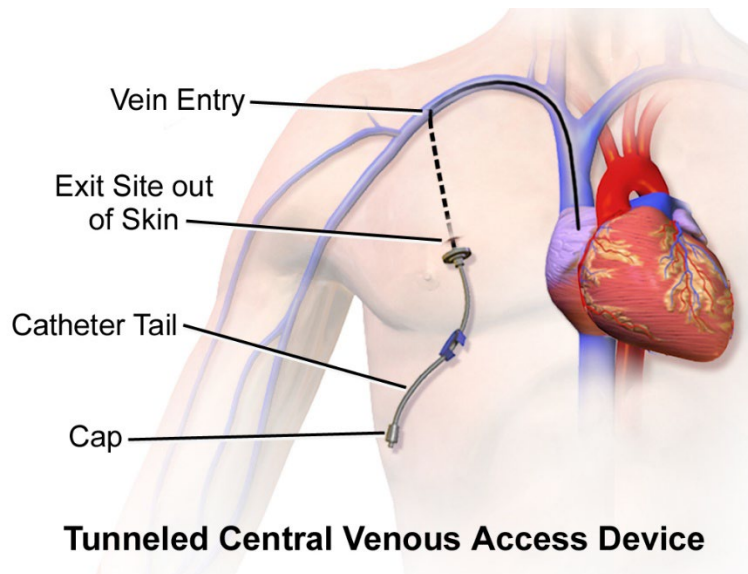
- For school-aged children, we encourage them to focus on their schoolwork during treatments. To help them, we have a school teacher available.
- No food or drink is allowed in the Dialysis Unit. Please keep any food or drink in the triage room or family waiting room across the hall.
- Hemodialysis does not hurt. However, because some of their body fluid is being removed for a short time, they can experience some uncomfortable symptoms. This may include dizziness, nausea, vomiting, headaches, and cramping.
 - If your child experiences these symptoms, a nurse will take steps to reduce these symptoms and help them feel better.



- After treatment, your child’s weight, temperature, and blood pressure will be checked again. If these values are too high or too low, you may be asked to stay in the unit after your child’s dialysis treatment so that the nurses can help fix these values.

Types of hemodialysis access

Central venous catheter



A central venous **catheter**, which is like a soft tube, has 2 **lumens** (lines) on one end that connect to the dialysis machine and transport blood to and from your child. The other end of the catheter is inserted into a blood vessel, and the catheter tip sits in your child’s heart.

Advantages of this access type:

- This option is used by many patients because it’s easy to use for dialysis and because sometimes pediatric patients don’t have big enough blood vessels for the other access type (called an AV fistula).
- A central venous catheter can be used right away, making it useful for urgent dialysis needs.

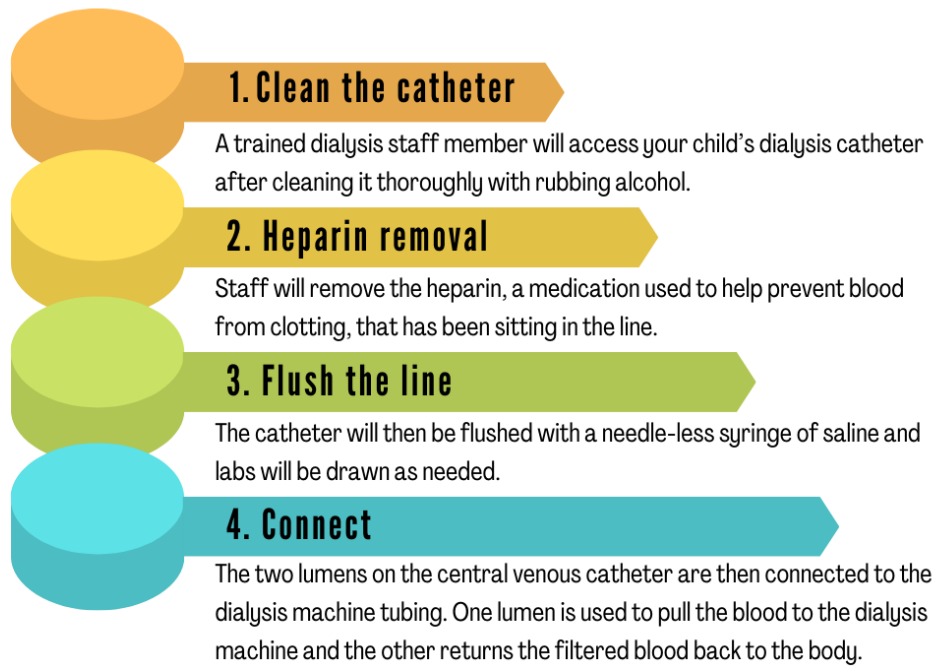
- This access does not require your child to get poked by a needle for hemodialysis.

Disadvantages of this access type:

- There is a higher infection risk with this access type because the catheter is in direct contact with your child's bloodstream.
- There is a possibility of catheter problems or malfunction, like the catheter getting dislodged (knocked out of place), getting a blood clot in the line, getting a kink or fold in the line, etc. If this happens, we would have to replace the line.
- Your child would not be able to play contact sports (football, hockey, etc.) because of the risk of accidentally dislodging the catheter.
- Your child cannot take baths or swim because the line can't be submerged (go under water).

How is it used?

Central Venous Catheter Access



Care instructions for the catheter:

- The Dialysis Unit staff will put a Tegaderm™ dressing over the catheter. This is a clear bandage that lets us see where the catheter enters the body and protects it from getting dirty or wet. It also helps keep the catheter in place.
- Watch for signs of infection, including any redness, swelling, warmth, or discharge (leaking fluid) around the catheter site. If you notice anything unusual, let the healthcare team know.
- Never get the catheter or dressing wet. This includes protecting it from water when showering and avoiding taking a bath or swimming.
- Patients can shower or take a sponge bath. However, the line should always be covered with plastic wrap.
- If the Tegaderm™ dressing starts to lift or get loose, use the supplies we gave you to secure it until the Dialysis Unit staff can replace it. Never change your child's dressing yourself.
- If the dressing becomes **non-intact** (meaning the dressing has lifted past the edge of the dressing into the clear center window), cover the site with Tegaderm™ and call the Dialysis Unit to come in for a dressing change.
- Dialysis staff are the only people who should access a hemodialysis catheter. It must only be used for dialysis (not for blood draws or IV infusions other than those done by dialysis staff) unless it is a life-threatening emergency or ordered by your nephrologist.
- Never take the caps off the end of the lines. If the cap does come off, cover the end of the catheter with an alcohol pad, wrap the pad and catheter end with sterile gauze, and place tape around it. Then call the Dialysis Unit, as blood tests and antibiotics may be necessary.
- Wash your hands or use sanitizer before touching the catheter.
- Avoid twisting or pulling the catheter, getting it stuck on clothing, moving it around, or putting clamps or caps on it.
- Don't use lotion near the catheter dressing sites.

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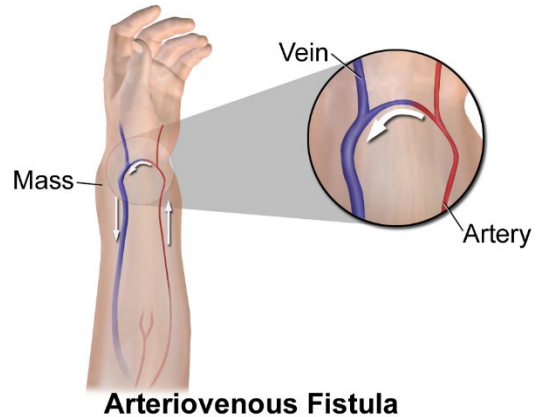
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- Change your child's bedsheets and bed linens weekly, and have them wear clean pajamas every night to reduce the risk of infection.

If the catheter gets pulled out, this is an emergency! Put pressure on the site with sterile gauze and call 911 immediately.

Arteriovenous (AV) fistula

An **arteriovenous (AV) fistula** is created by connecting an artery and a vein through surgery. In children, this is a less common dialysis access type because their veins are usually too small for this procedure.



For those who get an AV fistula, their healing time usually takes several months. During that time, they will use a central venous catheter for dialysis until the AV fistula can heal. Once the surgeons decide your child's AV fistula is ready to be used, we will start accessing it with 1 needle and eventually use 2.

How is it used?

- Before dialysis and accessing an AV fistula, you will put the prescribed numbing cream on your child's fistula site.
- We will access the AV fistula for dialysis using 2 needles that connect to the tubing from the dialysis machine.
- Blood is pulled from the body in one needle and returned after cleaning to the body in the other needle.

Advantages of this access type:

- Studies show that an AV fistula produces the best results for dialysis.

This is because they last longer than other access types and they provide

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better blood flow rates during dialysis to remove waste products and extra fluid from the body.

- It has a lower risk of infection and clotting than catheters.
- It can last for years if it is protected from injury and kept clean.
- The AV fistula is under the skin, so your child can swim, shower, play sports, etc.

Disadvantages of this access type:

- Fistulas can develop complications (medical issues) such as blood vessel **stenosis** (narrowing) or **thrombosis** (clotting). If these develop, your child may need extra procedures or surgeries to fix them.
- There is a risk of bleeding after the needles are removed from the AV fistula after each dialysis treatment.
- Creating an AV fistula requires a surgery, which comes with its own risks.
- AV fistulas need time to develop (while the surgery site heals and the artery and vein connection becomes strong and stable) before they can be used.

Care instructions for the AV fistula:

- Avoid activities that could hurt or put pressure on the AV fistula arm. This includes helping your child to avoid wearing tight clothing, carrying heavy objects, or sleeping on the arm with the fistula.
- Wash the AV fistula area with gentle soap and water regularly. Avoid using harsh chemicals or lotions that could irritate the skin.
- Look for any redness, swelling, warmth, or discharge (leaking fluid) around the fistula. Report any signs of infection to the healthcare team.
- Learn how to feel for the "thrill" (vibration) or listen for the "bruit" (a whooshing sound) over the AV fistula. These are signs of good blood flow. Report any changes to the healthcare team.

- Don't let your child wear tight jewelry, watches, or clothing that could limit blood flow to the AV fistula arm.
- Don't use the AV fistula for blood pressure measurements or blood draws. The AV fistula is a special access for dialysis, and using it for other purposes could harm it.
- Have your child drink plenty of fluids to keep the blood flowing well through the AV fistula.

Fluid Management

Why is fluid management important for children with kidney disease?

- Healthy kidneys balance the amount of fluid in the body by producing urine (pee). But when the kidneys aren't working properly, their body cannot get rid of the extra fluid through urine (either because they don't make as much urine or they can't get rid of urine).
- When a child drinks a lot, their body will make a lot of urine. Dialysis can get rid of some of this extra fluid, but not as well as healthy kidneys do. Drinking too much fluid can also make their hemodialysis procedure more difficult. Because of this, it's important to manage how many fluids your child drinks. Proper fluid control depends on the actions of your child and you!
- For most children with kidney disease, we usually recommend that they **limit their fluid intake**. How much fluid your child should have depends on the cause of their kidney problems. It's very important that you talk with a dietitian to get advice that fits your child's needs.



What is target weight (dry weight)?

Target weight, also called **dry weight**, is your child's weight when all the extra fluid in their body is gone and their labs and blood pressure are in a good range.



Getting your child to their target (dry) weight, and keeping them at their target weight, is extremely important for hemodialysis and their overall well-being.

Your child's target weight is _____


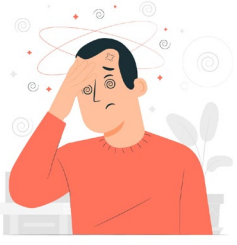
- If your child doesn't make enough urine (pee), they will gain extra weight when they eat or drink.
- Weight changes throughout the day, so you may notice that your child's weight in the evening is higher than it was in the morning.

How do I tell if my child is getting the right amount of fluid?

There are many different tools you can use to make sure your child is not drinking too much or too little.

- **General physical checks:** How does your child look? Do you see swelling anywhere on their body? Do their eyes look sunken or have dark circles around them? Are they acting sluggish or tired?
- **Monitoring (watching) their weight:** What is their weight? How does this compare to their target weight?
- **Monitoring blood pressure:** What is their blood pressure today? Is it higher or lower than normal?
- **Other checks:** Have they been sick with a cold, vomiting, or diarrhea?

All of these tools are good ways to see if your child is getting the right amount of fluids so you can adjust as needed. See the table for common signs of too much or too little fluid.

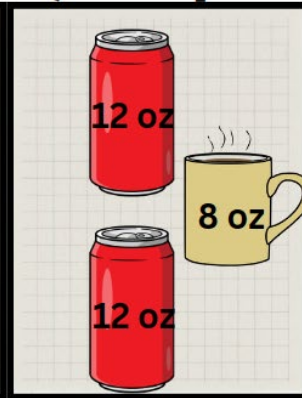
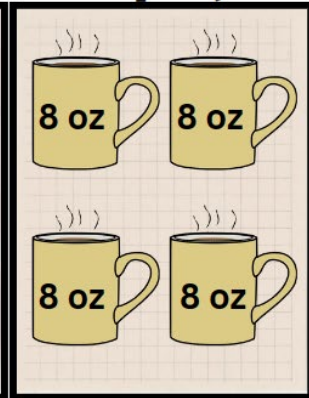
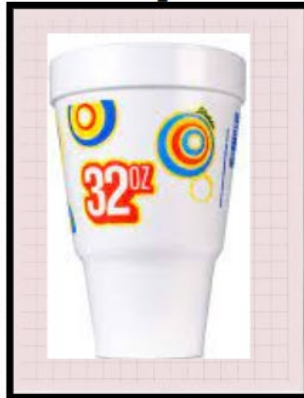
Signs of fluid overload (too much fluid)	Signs of dehydration (not enough fluid)
<ul style="list-style-type: none"> • Tiredness • Swelling • Headache • Feeling short of breath • Itching or irritated skin • Weight increases • Blood pressure increases 	<ul style="list-style-type: none"> • Dizziness • Feeling weak or sick • Muscle cramps • Dark circles around the eyes • Dry lips • Feeling thirsty • Weight decrease • Blood pressure decrease 

How can I keep track of how much fluid my child is getting?

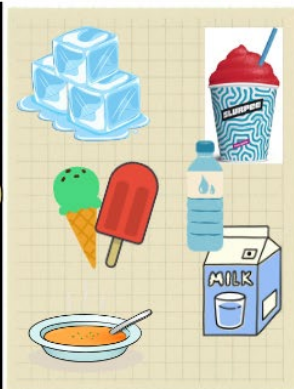
Now that we’ve talked about signs of too much or too little fluid, we want to help you keep track of how much your child is drinking for a healthier balance. We’re including some pictures and tables below to help you understand how much liquid your child is having each day, especially if you need to limit or restrict their intake.

The pictures show how many liters and milliliters are in different drinks. The tables show fluid amount and fluid weight conversions, so you can track how much they’re drinking and how much fluid intake will affect their weight. With these easy tips, you can make sure your child is sticking to the recommended fluid limits.

Examples of 4 cups (32oz) of liquid



Other things that count as a liquid!



Other things that count toward your child's fluid intake:

- Ice cubes
- Milkshakes
- Popsicles
- Milk
- Soup
- Juice
- Slurpees
- Ice cream
- Yogurt
- Water
- Jell-O®
- Fruits (grapes, watermelon, oranges)

Easy measurement conversions

Ounces (oz)		Milliliters (mL)		Cups
4 oz	=	120 mL	=	½ cup
8 oz	=	240 mL	=	1 cup
12 oz	=	360 mL	=	1 ½ cups
16 oz	=	480 mL	=	2 cups
32 oz	=	960 mL	=	4 cups

Liquid weight conversions

- 1 liter (L) is equal to 1000 milliliters (mL), which is about 32 ounces!
- 1 liter (L) is equal to 1 kilogram (kg).
- 1 kilogram (kg) is equal to 2.2 pounds (lbs).

Diet Management

What should my child eat and drink to stay healthy?

- All children need healthy and nutritious food to grow and develop normally. Children with kidney disease often have trouble growing normally. They also have to fight off infections and have problems such as low appetite.
- The diet for children on hemodialysis is very important to help your child feel healthy while also helping to reduce the build-up of wastes between treatments. Your child's **renal dietitian** will help you understand a diet that meets your child's own special needs. Each child's recommendations are different, and they may change throughout the course of treatment based on their blood work, fluid balance, growth progress, and other factors.
- Some general guidelines for a healthy diet are listed in the sections below!



Managing potassium levels

Potassium is a nutrient that helps our bodies with nerve and muscle function. **Children with kidney disease often have too much potassium in the blood, so the amount of potassium they eat or drink should be limited.**

- Both high and low potassium levels can be dangerous to the heart.
 - Low levels can happen after vomiting, diarrhea, with a diet too low in potassium, or when too much potassium is removed by hemodialysis. Symptoms of low potassium include tingling or numbness, feeling tired or weak, and abnormal heart rhythms.
 - High potassium makes the heart work harder and may cause it to stop beating, causing death. Symptoms of high potassium include

muscle weakness (like trouble walking), skipped heartbeats, and cardiac arrest (heart attack).

How much potassium do different drinks have?

Drink	Potassium
Kool-Aid®	0 mg
smartwater®	2.5 mg
Lemonade (made from powder)	3 mg
Root beer (12 oz, or 1 can)	4 mg
Lemon juice (from 1 lemon wedge)	6 mg
Capri-Sun® (1 pouch)	21 mg
Cranberry cocktail	35 mg
Gatorade®	37 mg
Coconut milk	46 mg
Fruit punch	77 mg
Papaya juice	70 mg
Peach nectar	77 mg
Grape juice (100%)	120 mg
Pear juice	260 mg
Apple juice	240 mg
SunnyD® Citrus Punch	304 mg
Oat milk	325 mg
Soy milk	371 mg
Pineapple juice (100%)	320 mg
PRIME sports drink	350 mg
Whole milk	366 mg
Coconut water (unsweetened)	396 mg
Grapefruit juice	400 mg


Drink	Potassium
Skim milk	406 mg
Orange juice (100%)	448 mg
Tomato juice (100%)	488 mg
Goat's milk	499 mg
Prune juice (100%)	684 mg

What foods have high or low potassium?


Read through the tables below to learn about high and low potassium foods. For the tables, a portion size is ½ cup (about the size of 1 scoop of ice cream) unless it says otherwise. We've also include an illustration to show you how to use your hand to estimate (guess) portion sizes.

Visual hand guide to portion sizes


The front of your closed fist is about 1/2 cup




Your fingertip is about 1 teaspoon



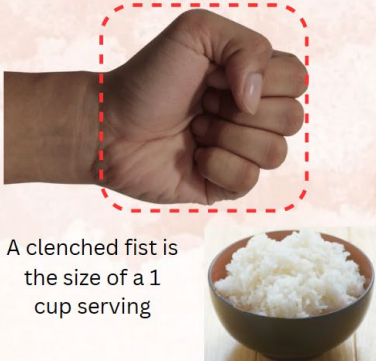
The length of your entire thumb is about 2 tablespoons



Your palm is 3-4oz, which is the standard serving of meat



A clenched fist is the size of a 1 cup serving



High potassium foods		
Fruits	Vegetables	Other foods
<ul style="list-style-type: none"> • Apricots (2 medium or 5 dried halves) • Avocado (1/4 of a whole) • Banana (1 medium) • Cantaloupe • Dates (5 whole) • Dried fruits • Grapefruit juice • Honeydew • Kiwi (1 medium) • Mango (1 medium) • Nectarine (1 medium) • Orange (1 medium) or orange juice • Papaya (½ of a whole) • Pomegranate or pomegranate juice • Prunes or prune juice • Raisins 	<ul style="list-style-type: none"> • Artichoke (1 medium) • Bamboo shoots • Baked, refried, or black beans • Beets • Broccoli • Brussel sprouts • Carrots • Dried beans and peas • Greens (except kale) • Kohlrabi • Lentils • Legumes • Okra • Parsnips • Potatoes (white and sweet) • Pumpkin • Rutabagas • Spinach • Squash • Tomatoes and tomato products • Vegetable juice 	<ul style="list-style-type: none"> • Bran/bran products • Chocolate (1.5-2 ounces) • Granola • Milk (1 cup) • Molasses (1 tablespoon) • Nutritional supplements • Nuts and seeds (1 ounce) • Peanut butter (2 tablespoons) • Potato chips (1 ounce) • Salt substitutes* and salt-free broth • Soy milk (1 cup) • Snuff or chewing tobacco • Yogurt

*Some salt substitutes have potassium chloride and should be avoided. This is why it is important to check food labels!

Low potassium foods		
Fruits	Vegetables	Other foods
<ul style="list-style-type: none"> • Apple (1 medium), apple juice, and applesauce • Apricots (canned) • Blackberries • Blueberries • Cherries • Cranberries • Fruit cocktail • Grapes and grape juice • Grapefruit (½ of a whole) • Lemon and limes • Mandarin oranges • Peaches, fresh (1 small) or canned (½ cup) • Pears, fresh (1 small) or canned (½ cup) • Pineapple and pineapple juice • Plum • Raspberries • Strawberries • Tangerine (1 whole) • Watermelon (1 cup) 	<ul style="list-style-type: none"> • Alfalfa sprouts • Asparagus (6 spears) • Cabbage • Carrots (cooked) • Cauliflower • Celery (1 stalk) • Corn, fresh (1 ear) or frozen (½ cup) • Cucumber • Eggplant • Green beans or peas • Kale • Lettuce • Mixed vegetables • Mushrooms • Onion • Parsley • Peppers • Radish • Rhubarb 	<ul style="list-style-type: none"> • Bread and bread products (not whole grain) • Crackers • Cake (angel or yellow) • Coffee (8 ounces) • Cookies (without nuts or chocolate) • Hard candies • Margarine • Mayonnaise • Noodles or pasta (⅓ cup) • Oil • Pies (without chocolate or high potassium fruit) • Popcorn • Popsicles • Rice (⅓ cup) • Refined cereals • Soda pop • Tea (16 ounces) • Tortilla chips

How can I prepare vegetables to reduce the amount of potassium in them?

Potassium can be removed from some vegetables before cooking with them. Follow these instructions to reduce potassium amounts when preparing potatoes, sweet potatoes, carrots, beets, rutabagas, squash, mushrooms, cauliflower, and frozen greens:

- Let frozen vegetables thaw to room temperature and then drain them.
- Peel your vegetables and put them in cold water so they won't darken.
- Slice potatoes, sweet potatoes, carrots, beets, and rutabagas $\frac{1}{8}$ inch thick (the size of two stacked pennies).
- Rinse fresh or frozen vegetables in warm water for a few seconds.
- Soak vegetables for at least 2 hours in warm water. Use 10 times the amount of water to the amount of vegetables. If you soak your vegetables for longer, change the water every 4 hours.
- After soaking vegetables, rinse them under warm water again for a few seconds before cooking them.
- Cook vegetables with 5 times the amount of water to the amount of vegetables.

How do I feed a baby who has a potassium-restricted diet?

When deciding what to feed a baby who needs to limit their potassium, you can choose from the low potassium foods in the following table. Try to limit or avoid the high potassium foods listed.

Low potassium foods		High potassium foods	
Rice cereal	Applesauce	Bananas	Prunes
Apricots	Peaches	Spinach	Squash
Plums	Pears	Potatoes	Sweet potatoes
Blueberries	Carrots	Avocado	
Green beans	Peas		

Here are some more recommendations on diet and potassium levels for babies and toddlers:

Age:	Potassium recommendations:
6-8 months	<p>Give your child 150 mg or less potassium per meal for 2 meals a day.</p> <ul style="list-style-type: none"> • Once your baby is 6 months old, you may start introducing foods. • Recommended foods include iron-fortified baby cereals (like rice, barley, and oatmeal) and single-ingredient purees (fruits, vegetables, and strained meats). They can eat 2-3 tablespoons per meal for 2 meals per day. • Wait 2-3 days between introducing new foods to make sure your baby does not have an allergic reaction or dietary sensitivity to it.
8-12 months	<p>Give your child 200 mg or less potassium per meal for 3 meals a day.</p> <ul style="list-style-type: none"> • At 8 months old, you can start to give your baby finger foods (soft fruits, cooked vegetables, grains and cereals, chopped protein like turkey and chicken, yogurt, cheese cubes, etc.). • Offer them foods from all food groups (grains, fruit, vegetables, protein, and dairy). They can eat 3-4 tablespoons per meal for 3 meals per day.

Age:	Potassium recommendations:
12-24 months	<p>Give your child up to 600 mg potassium per meal and 100-200 mg per snack.</p> <ul style="list-style-type: none"> • Continue adding variety to your toddler’s diet and offering them new foods. • We recommend giving them 3 meals and 2-3 snacks per day. • Your toddler may need to continue drinking baby formula longer than 12 months of age to help with them with growth and fluids. Please talk with your provider or dietitian before you stop using formula. • Cow’s milk is high in potassium. Your toddler may try drinking almond milk instead, which has much less potassium. Choose unsweetened milk options and limit the amount of milk they drink to 16 oz per day.

How do I read food labels to figure out potassium amounts?

To help you understand how much potassium different foods and drinks have, check on the labels.

- Potassium can be listed as milligrams (mg) or Percent Daily Value (%DV). The %DV will be different for baby foods than non-baby foods, since it is based on the needs of a baby instead of an adult.
- The table and photo included below show you what low, medium, and high amounts of potassium would be on both baby and adult food labels.
 - Please note that it is important to pay attention to serving size. Giving your baby a smaller amount of a high potassium food can make it low in potassium. Similarly, giving more than 1 serving of a low potassium food can make it high in potassium.

Potassium level	Baby foods	Adult foods
Low	Less than 10% DV or 80 mg	Less than 5%DV
Medium	10-20% DV or 80-170 mg	5-10% DV
High	More than 20% DV or 170 mg	More than 10% DV

Nutrition Facts	Oatmeal Cereal	Sweet Potato	Banana
Servings per container	2	2	2
Serving Size	1/2 Packet (15g)	1 Tub (56g)	1 Tub (56g)
Amount Per Serving			
Calories	60	40	40
	% Daily Value	% Daily Value	% Daily Value
Total Fat	1g 3%	0g 0%	0g 0%
Saturated Fat	0g	0g	0g
Trans Fat	0g	0g	0g
Cholesterol	0mg	0mg	0mg
Sodium	5mg	5mg	5mg
Total Carbohydrate	10g 10%	9g 9%	10g 11%
Dietary Fiber	<1g	<1g	0g
Total Sugars	<1g	5g	10g
Includes Added Sugars	<1g	0g	0g
Protein	2g 9%	<1g 2%	0g <small>Not a significant source of protein</small>
Vitamin D	0mcg 0%	0mcg 0%	0mcg 0%
Calcium	65mg 25%	11mg 4%	0mg 0%
Iron	6.75mg 60%	0mg 0%	0mg 0%
Potassium	70mg 10%	140mg 20%	130mg 15%
Vitamin A	0mcg 0%	150mcg 30%	0mcg 0%
Vitamin C	8.7mg 15%	0mg 0%	17mg 35%
Vitamin E	0.6mg 10%	0mg 0%	0mg 0%
Thiamin	0.075mg 25%	0mg 0%	0mg 0%
Riboflavin	0.1mg 25%	0mg 0%	0mg 0%
Niacin	1mg 25%	0mg 0%	0mg 0%
Vitamin B6	0.075mg 25%	0mg 0%	0mg 0%
Folate DFE (folic acid)	12mcg 15%	0mcg 0%	0mcg 0%
	7mcg	0mcg	0mcg
Vitamin B12	0.125mcg 25%	0mcg 0%	0mcg 0%
Zinc 1mg	1mg 30%	0mg 0%	0mg 0%

OATMEAL CEREAL INGREDIENTS: WHOLE GRAIN OAT FLOUR AND OAT FLOUR (CONTAINS WHEAT), POTASSIUM PHOSPHATE, VITAMINS AND MINERALS: CALCIUM CARBONATE, VITAMIN C (ASCORBIC ACID), IRON (ELECTROLYTIC), ZINC SULFATE, VITAMIN E (ALPHA TOCOPHERYL ACETATE), NIACINAMIDE, VITAMIN B2 (RIBOFLAVIN), VITAMIN B1 (THIAMIN MONONITRATE), VITAMIN B6 (PYRIDOXINE HYDROCHLORIDE), FOLIC ACID, VITAMIN B12.
CONTAINS: WHEAT.

SWEET POTATO INGREDIENTS: SWEET POTATOES, WATER, ASCORBIC ACID (VITAMIN C) TO MAINTAIN COLOR.

BANANA INGREDIENTS: BANANAS, CITRIC ACID, VITAMIN C (ASCORBIC ACID).

MADE WITH BANANAS FROM COSTA RICA

GERBER PRODUCTS CO.
FREMONT, MI 49413, USA

CEREAL MIXING INSTRUCTIONS:
Completely cooked and ready to serve. *Just add liquid.*

Baby's First Cereal Feeding:
Mix 1 Tbsp. cereal with 4-5 Tbsp. of breastmilk or infant formula.

Easy-to-Mix Directions:

- Pour or spoon desired amount of cereal in bowl
- Stir in liquid (breastmilk or infant formula) to desired consistency.
- Serve as is or warm in the microwave.
- Always test temperature before feeding.
- Discard any unfed cereal.

Microwave Guidelines for Heating:

- Warm unheated liquid at MEDIUM (50% power) for 15-30 SECONDS.
- Mix heated liquid with cereal.
- Stir to even out temperature.
- TEST TEMPERATURE before feeding.






Managing calcium and phosphorus levels

Calcium and phosphorus are nutrients that keep bones healthy and blood vessels and muscles working properly. Children need a balance of calcium and phosphorus for healthy bones and growth. Unhealthy kidneys have a hard time

balancing calcium and phosphorus. **For kids with kidney disease, it's important to limit high phosphorus foods.**

- High phosphorus can cause calcium to leave the bones (making them weaker and easier to break) and move into areas that it does not belong, such as the heart and blood vessels. High phosphorus can also cause itching.
- Foods high in phosphorus include dairy products and dried beans, protein, seeds (sunflower, pumpkin, etc.), nuts, whole grains, and dark soda.
- Phosphorus can also be called “phosphate” or “phosphoric acid” on food labels, so avoid or limit foods or drinks with these ingredients!

























Phosphorus

Low Phosphorus Alternatives	High Phosphorus Foods to Avoid
 <ul style="list-style-type: none">✓ 8 ounces of nondairy creamer 4 ounces of milk✓ 1 ounce of cream cheese✓ 1/2 cup of sherbert 1 popsicle✓ 1/2 cup of mixed vegetables or green beans✓ 1/2 cup of custard or pudding with nondairy creamer✓ 1/2 ounce cup of light salt/low fat popcorn✓ 1/2 ounce of hard candy, fruit flavors, or jelly beans✓ 2/3 cup of cream of wheat or grits✓ 1/2 cup of non-bran cereal, shredded wheat, rice cereals, or corn flakes	 <ul style="list-style-type: none">✗ 8 ounces of milk✗ 1 ounce of hard cheese✗ 1/2 cup of ice cream✗ 1/2 cup of lima or pinto beans✗ 1/2 cup of custard or pudding made with milk✗ 2 ounce of peanuts✗ 1/2 ounce of a chocolate bar✗ 1/2 cup of bran cereal   

Eat more protein
















Protein is a nutrient that helps the body build and repair muscle, heal from injury, fight infections, and grow. Children on dialysis may require twice the usual amount of protein each day compared to someone without kidney disease. This is because they lose some protein during each treatment session. Check out the images below for good sources of protein for your child!


GOOD SOURCES OF PROTEIN

Poultry			Meat		
 Roast Chicken / Turkey	 Grilled Chicken Sandwich	 Chicken Rollup	 Pork Tenderloin	 Fresh Ham	 Lamb Chop
 Baked Chicken	 Chicken Kabobs		 Beef Steak	 Hamburger Patty	 Roast Beef
Fish & Seafood			Dairy & Eggs		
 Fresh Fish	 Frozen Fish	 Canned Fish	 Cheese	 Cottage Cheese	 Milk
 Shrimp	 Crab	 Clams, Oysters & Scallops	 Eggs	 Greek Yogurt	 Omelette
 Lobster					



PLANT BASED SOURCES OF PROTEIN

 1/2 c cooked Lentils 9 g Protein = 1 oz	 1/2 c cooked Beans ~7 g protein = 1 oz	 1/2 c Edamame 11 g Protein = 1.5 oz	 1/2 c Lima Beans ~7 g Protein = 1 oz	 1 c Green Peas 8 g Protein = 1 oz
 1/2 c Hummus 6 g Protein = 1 oz	 3 T Nutritional Yeast 12 g Protein = 1.5 oz	 1/2 c cooked Steel Cut Oatmeal 5 g Protein = 1 oz	 1 c cooked Wild Rice 6-7 g Protein = 1 oz	 1/2 c cooked Quinoa 6-9 g Protein = 1 oz
 1/4 c Seeds (Pumpkin, Hemp, Sunflower, Chia, Sesame, Flax) 7-9 g Protein = 1 oz	 1/4 c Nuts (Pistachio, Walnut, Cashew) 7-9 g Protein = 1 oz	 2 T Nut Butters 6 g Protein = 1 oz	 Soy Pattie ~ 10-19 g Protein = 2-3 oz	 1/2 c Tofu 10 g Protein = 1.5 oz


Nephrology
INTERNAL MEDICINE
Michigan Medicine, University of Michigan

Managing sodium levels





















Another name for sodium is salt. Damaged kidneys can't filter sodium out of the body as well as healthy kidneys. This is a problem, as high levels of sodium in the body can cause thirst, high blood pressure, swelling, and fluid weight gain.

- A healthy goal is to eat and drink less than 2000 mg of sodium per day (a teaspoon of salt), or about 500-700 mg per meal.
- Depending on your child's needs, your dietitian may recommend either reducing sodium in their diet or having them take sodium supplements (things with more salt).

Your child's goal is _____ mg sodium per day.

What foods have high sodium?

HIGH SODIUM FOODS

Snack Foods	Meats & Proteins	Other
 Salted Potato Chips	 Salted Pretzels	 Hot Dogs
 Salted Popcorn	 Bacon	 Pizza
 Salted Nuts	 Sausage Links/Patties	 Instant Hot & Ready-to-Eat Cereal
 Salted Crackers	 Canned Meats	 Processed Cheese & Cheese Spreads
	 Deli Meats	 Canned Soups & Vegetables
		 Frozen Entrées
		 Dining Out
		 Pickles & Relishes
		 Olives
		 Salt
		 Sauces: BBQ, Teriyaki, Tartar, Soy, Spaghetti Sauce, Broths & Bouillon

Finding Sodium Content on a Food Label

Read ingredient labels — some lower sodium foods contain potassium chloride as a substitute for salt. These should be avoided.

Nutrition Facts	
Serving Size 5 oz (140g)	
Servings Per Container about 6	
Amount Per Serving	
Calories 290	Calories from Fat 180
% Daily Value*	
Total Fat 20g	31%
Saturated Fat 7g	36%
Cholesterol 60mg	20%
Sodium 780mg	32%
Total Carbohydrate 30g	10%
Sugars 28g	
Protein 15g	
Vitamin C 10%	Iron 4%
<small>Not a significant source of dietary fiber, vitamin A, and calcium.</small>	
<small>* Percent Daily Values are based on a 2,000 calorie diet.</small>	
<p>Serving Size:</p> <p>Always look here first. Make sure you know how much you are getting in your serving size.</p>	<p>Sodium:</p> <p>Always look for the "mg" and <i>not</i> the "%".</p>

What are some other food choices that have lower levels of sodium?

Some low sodium options and salt substitutes include:

- Low sodium canned foods
- Unsalted snacks (popcorn, pretzels, tortilla chips, or corn chips)
- Salt-free seasoning (like onion powder, garlic powder, or black pepper)
- Kirkland Organic No Salt Seasoning
- Fresh herbs and spices (garlic or onion)
- Vinegars and oils
- Lemon and lime juice
- Fresh foods (beef, veal, pork, or poultry)

How can I spice up my cooking without sodium?

- Use herbs and spices.
- Be creative and experiment with new and exciting flavors (see the tables below for different spices you can use).
- Buy spices and herbs in small amounts so they don't sit around too long. When they sit on the shelf for years, they lose their flavor.
- Use no more than ¼ teaspoon of dried spice or ¾ of fresh spice per pound of meat.
- Add ground spices to food about 15 minutes before the end of the cooking period.
- Add whole spices to food at least 1 hour before the end of the cooking period.
- Mix herbs with oil or butter, set for 30 minutes to bring out their flavor, then brush on foods while they cook or brush meat with oil and sprinkle herbs 1 hour before cooking.
- Crush dried herbs before adding them to foods.
- Salt substitutes are not always good alternatives. If you are told to limit potassium in your child's diet, be very careful about using salt substitutes. Check with your child's doctor or dietitian before using salt substitutes, since most contain potassium.

Spice	Cooking suggestions
Allspice	Use with beef, fish, beets, cabbage, carrots, peas, or fruit.
Basil	Use with beef, pork, or most vegetables.
Bay leaf	Use with beef, pork, or most vegetables.
Caraway	Use with beef, pork, green beans, cauliflower, cabbage, beets, asparagus, and in dips or marinades.
Cardamom	Use with fruit and in baked goods.

Spice	Cooking suggestions
Curry	Use with beef, chicken, pork, fish, green beans, carrots, and in marinades.
Dill	Use with beef, chicken, green beans, cabbage, carrots, peas, and in dips.
Ginger	Use with beef, chicken, pork, green beans, cauliflower, and eggplant.
Marjoram	Use with beef, chicken, pork, green beans, cauliflower, and eggplant.
Rosemary	Use with chicken, pork, cauliflower, peas, and in marinades.
Thyme	Use with beef, chicken, pork, fish, green beans, beets, and carrots.
Sage	Use with chicken, pork, eggplant, and in dressing.
Tarragon	Use with fish, chicken, asparagus, beets, cabbage, cauliflower, and in marinades.

Medication Management

Why does my child have to take all these medications?

Medications are sometimes needed to help your child when their kidneys are not working properly. It is important to take the prescribed medications as instructed by your dialysis team. It is also important to carry a list of the names, purposes, and doses of each medication with you at all times in case of an emergency.

What should I know about managing my child's medications?

- Never stop any medications, or change any doses, unless the kidney doctor or nurse practitioner tells you to.
- Bring a list of all of your child's medications to the clinic visit each month so the team can make sure their list matches.
- Always check with your kidney doctor or nurse practitioner if another doctor prescribes a medication for your child, as some medications need to be adjusted based on kidney function.
- Refill all your medications before the bottle is empty.
 - Please let a clinical care coordinator know at least **48 hours before** you need a prescription refill.
- It is important to talk to your child's healthcare provider before starting any new supplements or medications. Some supplements and medications may have ingredients that could be harmful to your child's kidneys. Your healthcare team knows your child's health situation, and they can offer personalized advice on what is safe and helpful. They can also recommend the right dose (amount) and watch for any side effects.

What are the different types of medications that my child may take?

Erythropoietin stimulating agents (ESAs)

Medication brand names:

- EPOGEN® (epoetin alfa)
- PROCRIT® (epoetin alfa)
- RETACRIT® (epoetin alfa-epbx)
- ARANESP® (darbepoetin alfa)

What do these medications do?

Generally, ESAs help with anemia.

- Healthy kidneys make a hormone called **erythropoietin**, which tell the bone marrow in the body to make red blood cells. Many children on dialysis will need extra erythropoietin because their bodies don't make enough of it naturally.
- **Hemoglobin** is a protein in the blood that contains iron and transports (moves) oxygen through the body. Your child's hemoglobin level is 10-12 grams per deciliter (g/dL). If your child's hemoglobin level is low (less than 10 g/dL), we may train you on how to give this medication to your child.

Directions for taking ESAs:

- All erythropoietin products must be stored in the refrigerator.

Iron

Medication brand names:

- Venofer® (intravenous or injection form)
- Ferrlecit® (intravenous form)
- Ferrous sulfate (oral, or taken by mouth, form)
- iFerex (oral form)
- Fer-In-Sol® (oral liquid)

What do these medications do?

Generally, iron medications help erythropoietin stimulating agents (ESAs) work.

- **Iron** is a mineral that works in your body to help make red blood cells. Your body must have iron for the ESAs to work.

Directions for taking iron:

- There are 2 ways your child can take their iron supplement: orally (by mouth) or intravenously (IV). If your child cannot tolerate the oral forms, we may give them the intravenous form of iron during their dialysis clinic visit.
- Do not take this medication at the same time as phosphate binders, antacids, or milk.
- It is best to take iron 30-60 minutes after eating food to replace the body's iron stores that are used up in making red blood cells.

Phosphate binders

Medication brand names:

- TUMS® (calcium carbonate)
- Renvela® (sevelamer powder)
- Renagel® (sevelamer tablet)
- Phoslo® (calcium acetate)
- Velphoro® (sucroferric oxyhydroxide)

What do these medications do?

Phosphate binders protect your child's bones and teeth from losing calcium.

- Phosphorus is a mineral that is found in bones, teeth, and blood, and it is normally removed by the kidneys. When the kidneys are not working properly, phosphorus is not removed. As phosphorus increases in the

blood, it causes the parathyroid gland to release a hormone which removes calcium from the bones and teeth, making them weak.

- To prevent this from happening, phosphate binders create a bond with phosphate to prevent it from being absorbed by the body.

Directions for taking phosphate binders:

- To be effective, phosphate binders must be taken with meals or snacks.
- School-age children will need to have phosphate binders set up with school officials for lunch time. Your dialysis team will help you with this.

Vitamin D

Vitamin D types and brand names:

- Calcitriol (Rocaltrol®)
- Paricalcitol (Zemplar®)
- Ergocalciferol
- Doxercalciferol (Hectorol®)
- Cholecalciferol (vitamin D3)

What do these medications do?

Vitamin D helps the body absorb calcium.

- For calcium in food to be absorbed, the body needs a special type of vitamin D that the kidneys produce. In kidney failure, this vitamin is not produced, so the body cannot absorb the calcium from food and it pulls it from the bones and teeth instead.

Blood pressure medications

What do these medications do?

All of the blood pressure medications listed below work in similar, but slightly different, ways. They are used to help decrease blood pressure and decrease

how hard the heart works. Your dialysis team will determine the best blood pressure medication for your child based on these factors.

Directions for taking blood pressure medications:

- Your dialysis team will tell you whether to take these medications before or after dialysis.
- You may be asked to take your child's blood pressure at home before giving the medication.
- Your kidney doctor or nurse practitioner will give you the proper range for your child's blood pressure. We will ask you to report blood pressures higher or lower than this range.

Lisinopril

- Medication type: angiotensin-converting enzyme (ACE) inhibitor
- This medication relaxes bloods vessel by blocking a substance in the body that would normally cause the blood vessels to tighten.
- This medication is usually taken daily.
- Side effects: Some patients have a cough, but this is very rare in children.

Amlodipine

- Medication type: calcium channel blocker
- This medication works by relaxing blood vessels so blood can flow more easily and your child's heart does not have to pump as hard.
- This medication is taken once or twice a day (as told by your child's doctor or nurse practitioner).
- Side effects: Some patients have swelling, but this is rare in children. Patients who are on this medication for a long time might have overgrowth of their gums, so it is important that they brush their teeth twice a day and see their dentist.

Isradipine

- Medication type: calcium channel blocker
- This medication works by relaxing blood vessels so blood can flow more easily and your child's heart does not have to pump as hard.
- Typically your care team will give you specific blood pressure readings for when your child should take this medication. Sometimes their doctor may tell you to give them this medication without taking their blood pressure.
- Side effects: Some patients may experience flushing (the skin gets red and feels warm) and feel like their heart is racing.

Labetalol

- Medication type: beta blocker
- This medication works by relaxing blood vessels and slowing the heart rate to improve blood flow and reduce blood pressure.
- If your child is diagnosed with diabetes, you may need to watch their blood sugar closely, as this medication can hide the signs of low blood sugar.
- This medication should be taken twice a day.
- Side effects: Some patients may feel very tired and have lower energy levels if their heart rate gets too low.

Minoxidil

- Medication type: vasodilator
- This medication works by relaxing blood vessels, which can help improve blood flow and reduce blood pressure.
- Typically your care team will give you specific blood pressure readings for when your child should take this medication. Sometimes their doctor may tell you to give them this medication without taking their blood pressure.

- Side effects: Most patients don't have any problem taking this medication. If patients take it for a long time, it can cause extra hair growth.

Multivitamins

Some multivitamin brands:

- Dialyvite® (pill)
- Nephronex® (liquid)
- Nephrocaps® (soft gel pills)

What do multivitamins do?

Vitamin supplements are used to replace the vitamins that are removed by dialysis. These vitamins are necessary for general health.

Directions for taking multivitamins:

- Vitamins should be taken after dialysis.
- Please check with your child's kidney doctor or nurse practitioner before taking any over-the-counter vitamins to make sure they are kidney friendly (safe for children with kidney disease).

Heparin

Heparin is a medication that stops blood from clotting. We may give it to your child to keep things flowing smoothly and safely during treatments like hemodialysis, where blood needs to move in and out of the body through a catheter. We may also give it at the end of treatment as a "heparin lock" to prevent clotting of your child's dialysis catheter between dialysis treatments.

Growth hormone

Sometimes, we may give children with kidney disease a special treatment called **growth hormone therapy**. This is because patients with kidney failure will not

respond as well to their body’s natural growth hormone. Before starting this therapy, there are a few important things to think about (such as making sure their bones are strong and healthy, that they’re getting all the right nutrients, and other factors). Your dialysis team will work with you to determine if and when growth hormone therapy is appropriate.

Over-the-counter medications

Not all **over-the-counter medications** (medications you can buy in a store or pharmacy without a prescription) are safe for patients with kidney disease. Below is a list of medications that are generally safe to use. Be sure to check with your dialysis team if you have any questions before using an over-the-counter medication.

Medical issue	Safe medications to use	Important instructions
Pain or fever	<ul style="list-style-type: none"> ● Acetaminophen (Tylenol®) ● Ibuprofen 	<ul style="list-style-type: none"> ● Acetaminophen is the preferred medication. ● Call your dialysis nurse before you use ibuprofen.
Cough or congestion	<ul style="list-style-type: none"> ● Guaifenesin (Mucinex® and plain Robitussin®) ● Dextromethorphan (Robitussin® DM and Mucinex® DM) 	<ul style="list-style-type: none"> ● Do not give cold and cough medication to children under 4 years old. ● Only the plain and DM forms of Robitussin® are safe. ● Never give your child the decongestant form of these (like Mucinex® D). ● Never give your child Vicks® Nyquil™ or similar products.

Medical issue	Safe medications to use	Important instructions
Allergies	<ul style="list-style-type: none"> ● Certirizine (Zyrtec®) ● Chlorpheniramine (Chlor-Trimeton®) ● Diphenhydramine (Benadryl®) ● Fexofenadine (Allegra®) ● Loratadine (Claritin®) 	<ul style="list-style-type: none"> ● Benadryl® may cause drowsiness. ● Never give your child the decongestant form of these medications (like Claritin-D® or Zyrtec-D®). ● Never give your child Vicks® Nyquil™ or similar products.

Blood Pressure Monitoring

Why is blood pressure monitoring important?

- High blood pressure, often called **hypertension**, occurs when blood moving through the arteries places too much force against the artery walls. Having the extra pressure on your child's arteries and organs for a long period of time (months or years) can seriously damage their organs, including their eyes, heart, brain, and kidneys.
- Low blood pressure, or **hypotension**, can create problems during dialysis. Blood pressure may drop at any time during treatment. This can be caused by having less fluid in the bloodstream.
- Noticing high or low blood pressure early by monitoring (checking) your child's blood pressure often, and then taking action to improve their blood pressure, can help their overall health and lower their risk of poor outcomes.

Why do we need to do a 24-hour blood pressure monitor at home?

It's important for the dialysis team to be able to monitor your child's blood pressures at rest, with activity, and before and after taking medications. This helps us treat their symptoms and identify problems early. This can also help us identify if they are on the best blood pressure medication for their current readings, since different blood pressure medications can work in different ways.

What are the causes and symptoms of high blood pressure (hypertension)?

Causes:

- Too much fluid in the body (too much fluid intake between dialysis treatments)
- Not enough blood pressure medication

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- Blood pressure cuff is not on their arm correctly
- Using the wrong size cuff to measure their blood pressure
- They're moving or crying during their blood pressure reading

Symptoms:

- Headaches
- Nosebleeds
- Difficulty breathing
- Flushing (feeling warm)
- Swelling (edema)
- Dizziness
- Chest pain
- Blurry vision

What are the causes and symptoms of low blood pressure (hypotension)?

Causes:

- Too much fluid removed during dialysis
- Not enough fluid in the body
- Diarrhea or vomiting, leading to dehydration
- Too much blood pressure medication

Symptoms:

- Dizziness
- Nausea or vomiting
- Tiredness
- Being more thirsty
- Not being able to concentrate
- Blurry vision

- Cold, clammy skin

How do I measure my child's blood pressure (BP)?

Check your child's BP right before giving them any blood pressure medication. Pay attention to the hold threshold that your provider gave you (in other words, don't give your child their blood pressure medication if their blood pressure is lower than the threshold number your provider told you).

Follow these steps:

1. Place the BP cuff over their bare skin (or over a thin shirt) around their upper arm, just above the elbow.
 - The lower edge of the cuff should be about 1-2 inches (2.5-5 centimeters) above the bend of their elbow.
 - Make sure the cuff is snug but not too tight. You should be able to put 1-2 fingers between the cuff and their arm.
2. Have your child sit with their back resting on the back of a chair with both their feet flat on the floor (if possible).
3. Position their arm level with their heart, and support the arm by propping it up with pillows, on a table, or on the side of a couch or chair.
4. While the machine is taking their measurements, remind them to keep the arm with the BP cuff still. Moving or talking while the machine is measuring can cause a wrong measurement.
5. If you get an unusual reading, readjust the cuff and try measuring again.

If your child ever has high or low BP symptoms with a "normal" blood pressure reading, don't hesitate to contact the on-call nephrologist or dialysis unit.

Your child's goal blood pressure is: _____

- They have **low blood pressure** if their reading is less than _____ . If their numbers are below their goal, recheck their BP in 30 minutes. If they are still below the goal and they have symptoms, page the on-call nephrologist at (734) 936-4000 or call the dialysis unit at (734) 232-7373.
- You have **high blood pressure** if your reading is greater than _____ . If their numbers are above this, recheck in 30 minutes. If they are still above the range, have them take rescue high BP medication and recheck in 1 hour. If they are still above the goal and they have symptoms, page the on-call nephrologist or call the dialysis unit.

Lifestyle Changes

What kind of lifestyle changes will we need to make for a child with kidney disease?

Vacations

When planning a vacation, please talk with a dialysis social worker at least **1 month** before. They will help you find a dialysis center where you're going that will meet your child's dialysis needs.

School

- All our patients on hemodialysis are expected to go to school as much as possible. Except for when they occasionally get sick, there are usually no medical reasons for your child to be out of school. We will do the best we can to set a schedule that helps them go to school as often as they are able. For most kids, this would be going to school either before or after dialysis treatments and on days when dialysis isn't scheduled.
- We offer some services to help with schooling for your child:
 - **Dialysis school teacher:** The Pediatric Dialysis Unit at Mott Children's Hospital has a teacher that works with the students regularly during hemodialysis sessions. They can help with homework or even give your child different learning activities to complete. Our teacher can be in constant communication with your child's school to help coordinate learning and also establish a 504 plan or IEP (more on this below).
 - **Tutors:** Our unit will bring in college students from the University of Michigan each fall and winter to help kids with homework, or to play with them if they've finished their homework already.
- We can help you set up some accommodations for your child's schooling.
 - **504 plan:** This is a list of **accommodations**, or supports, a school will provide for the student to have access to education. Examples

of accommodations are more time for taking tests, note taking help, or other supports based on the needs of the student. It's called a 504 plan because it comes from Section 504 of the national Rehabilitation Act. According to the official State of Michigan website (Michigan.gov), in order to have a 504 plan, "a student must have a physical or mental impairment which substantially limits one or more major life activities and either have record of the impairment or be regarded as having such an impairment." Your child meets this requirement if they are have kidney disease and are on hemodialysis.

- **Individualized education program (IEP):** Your child needs an IEP if they need services that may include things like excused absences for appointments, setting up a medication plan during school hours, having a private classroom, technology help, extra time with a teacher, adapted curriculum, etc. Eligibility for this is defined under the Individuals with Disabilities Education Act (IDEA). Qualifications include physical health impairments, emotional impairment, cognitive impairment, specific learning disabilities, and speech or language impairment. Your child may or may not qualify for this.

Dentist visits

If your child has a hemodialysis catheter and they have a dental appointment, please let your nurse or clinical care coordinator know. Your child will need to take an antibiotic 30-60 minutes before any dental procedure.

Sports

- Your child can't play contact sports (football, dodgeball, soccer, etc.) while they are on hemodialysis. Encourage your child to stay active in other ways.

- Patients with a hemodialysis catheter are not allowed to go swimming. However, if your child has an AV fistula, they may go swimming once it's healed.
- Talk with your doctor about sports or activities your child is interested in to see if they are safe for a dialysis patient.

Adherence

What is adherence, and why is it important?

- The dialysis team may use the terms “adherence” or “compliance” often. **Adherence** means following your provider’s instructions for your child’s care. Once your child starts dialysis, it is very important that you follow dietary (food and drink) guidelines, have them take their medications properly, and monitor their fluid restrictions. Setting up consistent, good habits early is important to make sure your child does well medically, and it will help to prevent future problems.
- Patients who consistently follow their care team’s recommendations are more stable on dialysis and better prepared for kidney transplant. Adherence is a major factor when a patient is considered for a kidney transplant, and families must be able to prove their ability to follow care team instructions before they move forward with a transplant.

What kinds of things am I expected to do for adherence?

Here are specific expectations we will be watching for:

- You must know all of the medications your child is taking, including their doses and how often they take them. Depending on your child’s age, they may be expected to know them as well.
- Medications must be taken on time and refilled on time.
- You must bring your child’s medications to the unit before their monthly clinic visit.
- You must show up to dialysis on time. You should arrive 15 minutes before your listed start time so you can start treatment on time. If you arrive late to dialysis, you will lose time on therapy which can negatively affect your child’s health. If you think this will be a problem, please talk with a dialysis staff member.
- You must go to the monthly outpatient clinic appointments.

- You and your child must follow the fluid and diet restrictions.
- Your child must follow the unit rules about schoolwork in the unit for at least 1 hour during each hemodialysis treatment.

Here are some questions to think about:

- If age appropriate, does my child know why they are taking each medication?
- What routine can we set up at home that will help remind us to take all the medications on time?
- Does our family understand the fluid restriction? Does my child have a good idea of how much 1 liter is?
- Do we have any challenges to making all the dialysis and clinic appointments?

What are some suggestions for helping with adherence?

We asked other patients and families what they do to help them remember all of the requirements and how to do them. Some ideas and suggestions used by other patients and families include:

- Take medications the same time every day.
- Set an alarm (on a clock, cell phone, or watch) as a reminder to take medications.
- Carry around a small pill box or container with a few phosphorous binders. This way you'll have them in case you eat an unexpected meal or your child eats while they are away from home.
- Talk with your school about your child's need to have some medications available as needed and how that system will work.
- Post written reminders on sticky notes in places you routinely go in the morning or evenings (like the bathroom, front door, car) as reminders for medications.

- Set up a pill box. Encourage your child, when ready, to start to manage their own medications under your supervision.
- Keep the pill box near things you use every day.
- Buy some cups that you know the exact fluid volume of, and only use those to help you monitor how much fluid they drink in a day.
- Create a chart to help you monitor their fluid intake (you can use a whiteboard or print charts). If you need help with this, please ask your dialysis social worker (they have some charts available).
- Try to get the whole family involved and educated. For example, maybe all family members can decrease their sodium intake at meals to support this same behavior for your child.

You can also try filling out this monthly dialysis report card to track how your child is doing. You'll review this every month during your clinic visits with the provider, nurse practitioner, clinical care coordinator, nurse, social worker, and dietitian.

Blood pressure control

How good is my blood pressure this month?

	Goal	Last month	This month	Score
BP				

Comments or changes: _____

Dialysis adequacy

How good is my dialysis therapy this month?

	Goal	Last month	This month	Score
Kt/V	Greater than 2 (standard Kt/V) Greater than 1.4 (single pool Kt/V)			

Comments or changes: _____

Weight and fluid control

Daily fluid restriction: _____ Dry weight: _____

	Goal	Last month	This month	Score
Weight gain between dialysis	More than 2 kilograms			

Comments or changes: _____

Bone disease

	Goal	Last month	This month	Score
Phosphorus	4.5-5.5			
Calcium	8.0-10.4			
Parathyroid hormone	150-300			

Comments or changes: _____

Anemia management

	Goal	Last month	This month	Score
Hemoglobin	10-12			
Hematocrit	33-35			
Iron saturation	20-50%			

Comments or changes: _____

Medication changes this month:

If you have any other questions about adherence, please feel free to talk with the dialysis social worker.

Insurance and Benefits

Having a child on hemodialysis means they may qualify for some or all of the following insurance or benefits programs. You can read more about each of these in the sections below:

- Children’s Special Health Care Services (CSHCS)
- Michigan Medicaid
- Medicare
- Social Security disability programs

Children’s Special Health Care Services (CSHCS)

All children on hemodialysis who live in Michigan automatically qualify for CSHCS. Your child’s medical condition, not your income, determines if you qualify for this program. Depending on your family size and income, there may be a monthly cost involved.

CSHCS is optional, so you will need to decide if this would be right for you and your family. There is no penalty or issue if you decide not to enroll (join this program), and your child can enroll and disenroll (leave the program) multiple times as long as they continue to meet requirements.

What are the benefits of CSHCS?

CSHCS works with you to make sure that your child gets the very best care.

They help you with:

- Paying specialty medical bills
- Coordinating services from multiple providers
- Learning about specialty providers like doctors, hospitals, and clinics
- Coordinating health insurance benefits
- Covering co-pays or deductibles
- In some cases, CSHCS can cover other insurance’s premiums

- Sometimes CSHCS can offer transportation (car rides), gas mileage reimbursement (paying for your gas), and lodging assistance (helping you find a place to stay) related to medical care from specialists
- CSHCS can also pay for items you bought in the past, if needed.

How do I enroll in CSHCS?

- If you are interested in enrollment, contact the nephrology social worker. The social worker will need to submit medical information about your child to start the enrollment process.
- In a few weeks after the social worker sends in the information, you'll get a packet of information by mail with a parent application enclosed. Complete the application and send it to the address listed on the application.
- When CSHCS gets the application and approves it, they will send an approval letter to the home with your CSHCS ID number listed on it. You will not get an insurance card. Please bring in this approval letter to your next dialysis appointment so that we can enter the insurance information into our billing system.
 - If you have Michigan Medicaid, CSHCS will automatically become part of your Medicaid plan and you will not receive anything in the mail.

If you have further questions, you can call the CSHCS Family Phone Line at (800) 359-3722.

Michigan Medicaid

This is state-issued health care coverage for low-income people and families. This includes families with children, pregnant people, and people under the age of 21. It also offers help to people who are blind or disabled, and people age 65 and over.

Do we qualify for Medicaid?

- Medicaid can help cover medical expenses for pregnant individuals, those with medical needs, people over 65, and individuals with disabilities. Your child may qualify based on family income guidelines set by the state.
- Even if your family income is above the Medicaid limit, your child might still qualify for the program. In such cases, you may need to pay for some part of the medical expenses each month, called a deductible.
- If you're a legal resident but not a US citizen, your child may still be eligible for Medicaid. Non-citizens without immigration documents can typically only receive emergency medical services.

How do I apply for Medicaid?

- You will apply through the Department of Human Services (DHS). Each Michigan county has its own DHS office available, which is where you will go to apply.
- You will need to fill out an assistance application. This is a form that is about 8-10 pages long, including instructions. You can get this application from your local DHS office. Your social worker may also be able to give you an application.
- You can also apply online at: NewMIBridges.michigan.gov

What is on the Medicaid application?

The Medicaid application will ask you for the following information:

- Your address, with directions to your home
- Any assistance you have received from state programs in the past
- All people living in your home and their relationship to you
- U.S. citizenship or resident status
- Employment status

- Earnings and income information
- Account balances of checking, savings, retirement savings, or other funds
- Information about ownership of land, trust funds, life insurance or annuities
- Information about vehicles (cars, trucks) you own
- A list of your monthly household costs for the following:
 - Rent or mortgage
 - Homeowners insurance and property taxes
 - Utility bills such as heat, electric, sewer, water, garbage, etc.
 - Child support or alimony
 - Out-of-pocket medical costs for medical and dental care, medications, dentures, hearing aids, and transportation to medical appointments
 - Information about past insurance coverage

You will also need to take the following things to DHS with your application:

- Proof of income (like a pay stub or income tax form 1040 or W2)
- Bank statements for any accounts you have
- Information about your cars (the make, model, and year so they can determine the value)
- Your social security card
- 2 forms of ID (like a driver's license and birth certificate)
- Proof of Michigan residency (proof that you live in Michigan, like a utility bill with your name and address on it, a telephone bill, or a rent or mortgage receipt)

Medicare

Any patient with kidney failure or end-stage renal disease (ESRD)

qualifies for Medicare as long as their parents or guardians have the required amount of work credits defined by Social Security. Medicare is a federal health insurance program that has different parts that help cover specific services. You can learn more online at:

www.medicare.gov/basics/children-and-end-stage-renal-disease

Medicare Part A covers hospital insurance, including:

- Inpatient care in hospitals
- Inpatient care in skilled nursing facilities
- Hospice care
- Some home health care

Medicare Part B covers medical insurance, including:

- Doctor's services
- Outpatient hospital care
- Other medical services that Part A doesn't cover, like physical and occupational therapy

Medicare Part B has a monthly premium (cost that you have to pay). The premium rates can change every year. Medicare typically sends a bill for your Part B premium every 3 months. Medicare Part B premiums may be covered by Children's Special Health Care Services.

Medicare Part D is the prescription drug coverage part of Medicare. Some plans have no premiums, while others have premiums that are not included in the Part B premium.

How do I apply for Medicare?

- Once your child starts outpatient dialysis at the University of Michigan, a 2728 form (which includes information on your child's medical condition so they can apply for Medicare benefits) will automatically be completed

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and signed by you and your dialysis doctor. We will give this form to you along with a booklet explaining the above information in more detail.

- To enroll, you will need to visit your local Social Security office, call Social Security at (800) 772-1213, or apply online (www.ssa.gov) once you receive this form and information in the mail.

When will Medicare benefits start?

For hemodialysis patients, it will typically start after 3 months of hemodialysis treatments.

Are we required to enroll?

- No, you do not have to enroll in Medicare immediately. You have the option of deferring enrollment (waiting to enroll in Medicare later). Just be aware that, if you have private insurance, you may want to talk about Medicare enrollment with your benefits office. Some private insurance companies require Medicare enrollment, or they have a penalty (fee) for not enrolling within their specific timeline. If your child has insurance coverage at this time and you are not having any issues with the current insurance, copays, or premiums, you may want to consider deferring Medicare enrollment until the time of their kidney transplant.
- Medicare enrollment will be required at the time of kidney transplant, as it is very important to cover the cost of transplant medications. We will talk more about this with you at the time of kidney transplant if your child has not yet enrolled.

Does Medicare coverage end?

Yes. Your Medicare benefits will end 12 months after your child stops dialysis treatments, or 36 months after the month your child has a kidney transplant.

Social Security disability programs

There are 2 Social Security disability programs that include children. These programs provide financial support in the form of monthly payments.

Supplemental Security Income (SSI) program

A child younger than 18 years old may receive monthly payments based on disability if:

- They have an impairment or combination of impairments that meets the definition of disability for children (being on hemodialysis qualifies for this).
- The income and resources of the parents or guardians and the child are within the program's allowed limits.

Social Security Disability Insurance (SSDI) program

A person 18 years and older may receive monthly benefits based on disability if:

- They have an impairment or combination of impairments that meets the definition of disability for adults (being on hemodialysis qualifies for this).
- Their disability began before age 22.
- Their parent or guardian worked long enough to be insured under Social Security and is receiving retirement or disability benefits, or their parent or guardian has died.

Under both of these programs, the child or person must be unable to do any "substantial" work because of a medical condition that has lasted or is expected to last for at least 12 months or to result in death.

How do I apply for SSI or SSDI?

If you are interested in applying for either program, please talk with the dialysis social worker.

Preparing for Kidney Transplantation

A **kidney transplant** is an operation that replaces your child's current kidney with a healthy kidney from another person. The kidney can come from someone who is alive (a **living donor**) or dead (a **deceased donor**). A kidney transplant is a treatment option, not a cure for kidney disease.

What are the steps for getting a kidney transplant?

The process of getting to a kidney transplant will look different for every patient. The timing of the process will change, but it will always follow the same process.

Step 1: Referral to transplant

- The dialysis team will make a request for the University of Michigan Transplant Center to see your child so they can decide if they are eligible for a kidney transplant. After we make this referral, they will call you to schedule appointments with them.

Step 2: Transplant evaluation appointments

- During these appointments, you will meet many people from the transplant team, including the transplant surgeon, transplant nephrologist, dietitian, transplant social worker, and the transplant nurse coordinator. These can be very long days for you and your child, so bring snacks and coffee! Appointments can last for about 4 hours, and then you may have your regularly scheduled hemodialysis after.

Step 3: Finding donors and completing the transplant requirement checklist

- After your appointments with the transplant team, they will give you a list of appointments and items that you need to complete before your child can be added to the transplant list. During this time, we are happy

to help coordinate appointments, vaccines, or anything else you may need. This is also the time to start referring friends and family to the donor office for testing (to see if one of their kidneys could be donated to your child).

Step 4: Listing your child for transplant

- Once you've completed all the required items for a transplant, your child can be listed when the team feels it is safe to do so. If your child is on the deceased donor list, you will wait for a call for a kidney to match them. If you have a living donor, we can schedule the transplant surgery.

Caregiver Advocacy and Self-Care Practices

How can I be a good advocate for my child?

- Share with your child's care team the most effective way to communicate with your child, and how best to give them directions and requests.
 - What works well (related to their schedule, medication plan, diet, etc.)?
 - What doesn't work well?
- Ask questions.
 - Keep track of any questions that you or your child have while at home, and bring the list of questions to your dialysis appointments. Never be afraid to ask questions!
 - Do you need extra help or advice?
 - Is something not working well?
- Remember that you are a part of the care team.
 - If you see something happening that is not in the best interest of your child, or if you have any questions, say something! Your team wants to know when they can be doing something better or differently.
- Empower your child.
 - Encourage your child to ask questions, make suggestions, and interact with the dialysis team. This can help your child feel more comfortable with the care team and give your child a sense of control. As a parent, you may be tempted to jump in to answer questions and provide information, but try to let your child take the lead and fill in only when needed.
- Comfort your child.
 - If your child gets nervous during tests or procedures, make sure that you're available to comfort them. You can ask to hold your child's hand during a procedure or test. The child life specialist can

also make suggestions for other simple ways to comfort your child when they are nervous or afraid.

- Understand, and stay informed about, your child's care.
 - Ask questions if you feel confused. Understanding your child's medical care plan helps you feel confident in your ability to manage your child's care. Remember, you are an important member of the dialysis team!
- Stay organized.
 - There is so much information to remember! Staying organized and having all your resources in one place can greatly reduce your risk of feeling overwhelmed and stressed.

What is caregiver burnout?

It is common for many caregivers to experience **caregiver burnout**. This can look different for different people, but what is most important is being able to recognize how you are being impacted by the stress of being a caregiver.

Caregiver burnout can cause issues in many aspects of your life, including the relationship with your medical team, your personal relationships, and your professional life.

Common signs and symptoms of caregiver burnout

Emotional and mental symptoms:

- Not feeling like yourself
- Feeling frustrated, sad, angry, helpless, or overwhelmed regularly
- Feeling like you are alone and isolated, like no one can understand what you are going through.
- Losing interest in doing things that you normally love to do

Physical symptoms:

- A large loss or gain in weight

- Sleeping too much or not enough
- Regular head and body aches

What are some ways to care for myself and avoid burnout?

- Find a support system.
 - This can include friends and family who can come spend time with you or talk with you over the phone. This can also be community members, religious groups, or support groups.
- Learn and communicate.
 - The better understanding you have of your child's illness, the better you are able to make sense of their symptoms, understand the need for medications, and stay involved with the medical team. It is important to communicate with the medical team when you have questions or concerns about your child's diagnosis and medical management. This can help reduce your stress.
- Take time for yourself.
 - This can seem impossible to do, but it is important. Ask your support system to help you take at least 1 hour a week to do something fun or relaxing that you enjoy. Some ideas are taking a long walk, going to the salon, having dinner with a friend, exercising, taking a nap, reading a book, working on a scrapbook, or journaling.

Contacting the Unit: When to Call and What to Expect

If you have any dialysis concerns about your child while you are at home, please feel free to contact the dialysis unit for help.

- Keep in mind that a doctor or nurse practitioner may not always be available to return your call.
- Different requests and concerns have different levels of seriousness and urgency.

Please refer to this page so you know how to call and when you can expect to hear back from the unit.

911 emergency calls

Call 911 if your child experiences any of these symptoms:

- They are difficult to arouse (you are having a hard time waking them up or getting them to respond to you)
- They have any mental status changes (they are not behaving normally)
- They lose consciousness (pass out or faint)
- They have a seizure

Once your child has gotten emergency care and their condition is stable, please contact the dialysis unit to let them know what happened.

Immediate response calls

You can expect a response **within 2 hours** if you call the dialysis unit about your child having any of these symptoms:

- Signs of severe dehydration or low blood pressure (if their systolic or top blood pressure number is less than 80, or they have dizziness, lightheadedness, or sweating)
- Signs of severe fluid overload (which may include high blood pressure, very fast heart rate, or difficulty breathing)

- Fever of 100.4° F (38° C) or above

Urgent calls

You can expect a response **within the next 24 hours** when you call the dialysis unit about any of the following concerns:

- Your child has a persistent systolic (top number) blood pressure measurement over their goal.
 - If you get a high systolic blood pressure measurement, have your child sit down and relax for 30 minutes. Then measure their blood pressure again. If the systolic measurement is still higher than their goal, we consider this a “persistent” high measurement.
- You have blood pressure medication questions.
- Your child has mild fluid overload symptoms (including puffiness and swelling).

Know that it is normal for your child to occasionally have some cramping and headaches after their hemodialysis treatment. These symptoms can appear with fluid shifts, and they may have these symptoms for several hours after treatment. They are not a cause for concern, and you don't need to contact the dialysis unit.

Routine calls

You can expect a response **in 24-72 hours** (depending on the day of the week) if you call the dialysis unit about any of the following concerns:

- Scheduling questions
- Dry weight change concerns
- Questions for the school teacher, dietitian, or social worker
 - We do understand that some calls with the social worker or

dietitian may be urgent, so please let us know so we can meet your needs.

Emergency Preparedness

We want to help prepare you for some emergency situations, so you'll know what to do and who to call. Read below for more details on some issues that may come up and how to handle them.

Pediatric Dialysis Unit: (734) 232-7373

Hours: Monday to Saturday 7:00 AM – 5:00 PM

After Hours Paging Operator: (734) 936-4000

(ask to page the on-call pediatric nephrologist)

If the dressing becomes non-intact (meaning the dressing has lifted past the edge of the dressing into the clear center window of dressing):

- Cover the site with Tegaderm™ and call the dialysis unit immediately.
 - If it is after hours, page the on-call nephrologist.
- You will need to come in to have the dressing changed to reduce the chances of infection.

If the Tego® cap comes off the catheter:

- Cover the end of the catheter with an alcohol pad, then wrap it with sterile gauze and place tape around it to hold it in place.
- Call the dialysis unit or nephrologist on call.
- We may ask you to come to the ER so that the dialysis nurse can draw blood and start antibiotics.

If the catheter gets pulled out:

- **This is an emergency.** Put pressure on the site with sterile gauze and call 911 immediately.

If there are signs and symptoms of a potential catheter infection:

Infection is a possible concern for your child, because they have an object inserted in their body (central catheter). It is very important to understand the signs and symptoms of a possible infection.

Some possible symptoms of an infection:

- Temperature greater than 100.4° F (38° C)
- Rigors (shaking or chills)
- Unusual irritability
- Low blood pressure
- Unexplained high blood pressure
- Soreness, redness, or drainage (leaking fluid) around the catheter site

If you think your child may have a catheter infection, call the dialysis unit. If it is after hours, page the nephrologist on call and go to the Emergency Room.

Resources and Support

- **American Association of Kidney Patients (AAKP)**
 - 1-800-749-2257
 - aakp.org
- **American Kidney Fund**
 - 1-800-638-8299
 - www.KidneyFund.org
- **Dialysis Patient Citizens**
 - 1-866-877-4242
 - www.DialysisPatients.org
- **National Kidney Foundation**
 - 1-800-622-9010
 - www.kidney.org
- **Medicare**
 - 1-800-MEDICARE (1-800-633-4227)
 - www.medicare.gov
- **Social Security Administration**
 - 1-800-772-1213
 - www.ssa.gov

Online resources

- LifeOptions.org
- MyKidneyLifePlan.org
- mei.org
- KidneySchool.org

Disclaimer: This document contains information and/or instructional materials developed by University of Michigan Health for the typical patient with your condition. It may include links to online content that was not created by U-M Health and for which U-M Health does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition, or your treatment plan.

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