MODIFIED: MAY 2026

Hemodialysis Care Manual

A guide for patients and families

Children's Hospital Colorado

This book belongs to:

_____

Compiled and approved by Children's Hospital Colorado Kidney Center.

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General Information

Kidney Center at Children's Hospital Colorado

Location

13123 E. 16th Avenue Aurora, CO 80045

The hemodialysis unit is in the Kidney Center on the 4th floor of the main hospital.

Important phone numbers

- Anschutz Medical Campus: 720-777-1234
- Kidney Center: 720-777-6263
- Hemodialysis room: 720-777-2875
- Kidney Center dietitian: 720-777-4609 or 720-777-0481
- Kidney Center social worker: 720-777-2982 or 720-777-7085
- Family navigator: 720-777-6556

The Kidney Center Hours

Monday, Wednesday and Friday: 7 a.m. to 6:30 p.m.

Tuesday and Thursday 7 a.m. to 4:30 p.m.

If you have questions or concerns about your child after hours, when the Kidney Center is closed, call 720-777-0007. The operator will connect you with a dialysis nurse who can help answer questions or concerns.

If your child has medical problems not related to their kidneys, please call your child's main (primary care doctor) for support.

When should you call the Kidney Center team?

- If you are going to be late for your scheduled treatment
- Before hemodialysis if you or your child are sick
- If your child has a fever of 100.4 ºF (38ºC) or higher
- If you notice your child has swelling, high or low blood pressures or shortness of breath
- If you have concerns about your child's hemodialysis catheter, graft or fistula

For life threatening emergencies, call 911.

General Information

Hemodialysis schedule

Your child has a specific treatment schedule with assigned days and times. Please be on time to your appointments. If you are not here on time, we may ask you to come another day for treatment.

- Your child is scheduled for hemodialysis treatments 3 times every week, either **Monday/Wednesday/Friday** or **Tuesday/Thursday/Saturday**.
- Each treatment lasts 3-4 hours.

Your child's treatment days are:

☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday ☐ Saturday

Your child's treatment start time is: _____

Unit rules:

- Only 2 visitors are allowed at a time
  - Visitors under the age of 13 must have an adult with them.
- You may have your cell phone in the hemodialysis room.
  - Please talk with a Kidney Center staff member if you want to take photos.
  - **Don't take photos of other patients**.
- Recording is not permitted in Children's Hospital Colorado.
- To keep you and your child safe, please stay at least 6 feet away from your child when nurses are starting or stopping dialysis.
- Please stay outside of the nurses' station at all times.
- Patients and visitors must wear appropriate child friendly clothing.
- Please do not sleep in the waiting area.
  - There are areas for resting within the hospital if needed.
- Please call 720-777-2875 as soon as possible if your child is sick.
  - They may have to wear a mask during their treatment to prevent getting other people sick.
- A variety of movies and games are available to your child during dialysis. Please use headphones so that all may enjoy their chosen movie or game.
- Parents and visitors cannot eat or drink in the dialysis room.
  - Please use the cafeteria or the Kidney Center waiting area while your child is on dialysis.
  - If your child needs fluid removal during dialysis, they may have eating and drinking limits.

Kidney Center Team

Welcome to hemodialysis

Together, you and the Kidney Center team at Children's Hospital Colorado have decided that hemodialysis is right for your child.

We know this can be a stressful time, and we are here to support you every step of the way. Our **Hemodialysis Program** makes sure your child receives dialysis treatment with the full support of our hospital resources and a dedicated team of experts, including you and your child.

Meet your dialysis team

The Kidney Center team is a group of experts who work together to meet your child's healthcare needs. Children's Hospital Colorado is a teaching hospital, so you may also work with students, resident doctors, and nephrology fellows.

Your child's primary care doctor will continue to be a part of the medical team, so it is very important that your child continues to see them for regular checkups and non-dialysis related health concerns.

Your care team may consist of these team members:

- **Pediatric nephrologists:** These are kidney doctors who focus on treating children. This doctor will assess your child's medical needs, oversee your child's care, order necessary medicines and determine your child's dialysis needs.

  My child's main nephrologist is: _____

- **Nurse practitioner:** This is a nurse with advanced education and training that works closely with your nephrologist to oversee your child's dialysis treatment and care plan. They may advise on treatment, order medicines and give input on labs.

- **Dialysis nurses:** These specialized nurses start, watch and complete your child's dialysis treatment. They will also help you understand kidney failure, dialysis, medicines and lab results. Every nurse will be involved in your child's care but you may be assigned 1 nurse as your "primary nurse" who will go to your monthly family meetings.

- **Clinical manager:** This is a nurse that leads the care team and oversees the dialysis center. They can help with any dialysis concerns and scheduling needs.

- **Other team members** include renal dieticians, psychologists, social workers, patient care technicians, child life specialists, art therapists and family navigators.

Overview of the Kidneys

Functions of the Kidney

The kidneys are bean-shaped organs and are about the size of your fist. Most people are born with 2 kidneys, but it is possible to live a healthy life with only 1. The kidneys are located on either side of the backbone at waist level and help keep your child's body healthy.

Function	Description
Remove water	The kidneys control how much water is kept in your body.
Control blood pressure	The kidneys help keep blood pressure within a safe and normal range. Blood pressure is the pressure blood exerts on the walls of the blood vessels. The systolic (top) number is the pressure when the heart beats, and the diastolic (bottom) number is the pressure when the heart rests.
Remove waste and balance electrolytes	The kidneys take waste products out of the blood and make sure it has the right amount of some minerals.
Balance acids and bases	The body needs the right amount of acids and bases to work best. Healthy kidneys know how much acids and bases to keep or remove so that the body stays healthy.
Make red blood cells	Kidneys release a hormone called erythropoietin (EPO). EPO sends a message to the bone marrow to make more red blood cells. Red blood cells carry oxygen to the whole body. A low red blood cell count is called anemia.
Keep bones healthy	The kidneys balance minerals to make sure that bones stay healthy. By keeping normal phosphorus, calcium and vitamin D levels, the kidneys help to make sure your child's bones stay healthy and strong.
Support growth and development	Kidneys help control the levels of many chemicals in the body. Some of these chemicals affect growth. These include acids, bases, electrolytes, minerals, hormones and special proteins. By balancing these, healthy kidneys help children to grow and develop normally.

Complications of Kidney Disease

Fluid overload and edema

Healthy kidneys remove fluid from the body by making pee. When kidneys don't work as well, extra fluid needs to be removed through dialysis. The Kidney Center team will tell your child how much fluid they can drink. **It is important that your child only drinks the amount of fluid ordered.**

What happens when there is too much fluid in the body?

- High blood pressure
- Swelling in part of the body
- Trouble breathing
- Higher anxiety

If your child has trouble breathing, call 911 or go to the closest Emergency Room.

High blood pressure

High blood pressure (hypertension) is common in kidney disease. If your child's blood pressure is high, they may need to drink less fluid and avoid salty foods. Salty foods may make your child want to drink more.

Each dialysis session keeps your child's body from holding onto too much fluid. If changing your child's diet and how much fluid they drink does not work, the nephrologist may order blood pressure medicines.

Uremia

Uremia happens when there's a buildup of waste products in your child's blood. This usually happens when the kidneys aren't working well. When these waste products build up in the blood, they can cause the following:

- Headache
- Drowsiness or confusion
- Nausea or throwing up
- Bad taste in the mouth
- Difficulty concentrating
- Fatigue
- Loss of appetite
- Thirst
- Liquid poop
- Itching

Dialysis removes waste products from your child's body and may help make them feel better.

Anemia

Anemia happens when your child has low red blood cells. This is common in children with kidney disease. Blood tests help the care team know if your child has anemia. Anemia can be treated with:

- Dialysis
- Epoetin Alfa (EPO), which is a medicine that helps the body build red blood cells
- Iron supplements
- Blood transfusions

Bone disease

Children with kidney disease are at risk of getting bone disease. When kidneys are not working, phosphorus builds up in the blood and calcium levels begin to drop. This results in weak bones that fracture and break easily.

To keep bones healthy,

- Limit eating foods that have phosphorus (examples: processed/packaged foods or snacks, dark sodas, fried foods)
- Take “phosphorous binders” as ordered by your doctor
- Take vitamin D and/or calcium supplements as ordered by your doctor

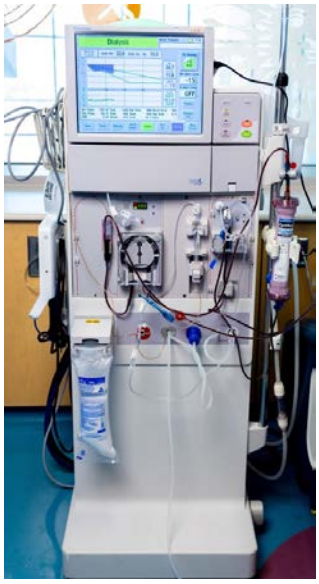
What is Hemodialysis?

Hemodialysis (HD)

During hemodialysis, your child's blood is pulled out through a tube (catheter, fistula or graft) and passes through a filter (dialyzer) to be cleaned. As the blood goes through the filter, waste products and extra fluid are taken out then the clean blood is given back to your child through the tube. This process takes about 3-4 hours, and your child may need it done 3 times a week.

Dialysis clearance is the process of taking waste products and electrolytes out of your child's blood. Many factors affect how fast this is done, such as:

- Dialyzer size
- Type of dialysate solution. Dialysate is a solution made up of water and electrolytes that passes through the dialysis filter to remove extra fluid and waste from the blood.
- How fast your child's blood moves through the dialyzer
- How long the treatment is



Blood tests

Your child will get blood tests every month to see how well their dialysis is working. You may hear the team talk about "Kt/V", which tells us how well waste products are being removed by dialysis. This is done every month, and the nephrologist will use this information to decide if changes are needed to the dialysis plan.

Measurements

- **Blood pressure and heart rate:** The nurse measures these before, during and after your child's dialysis treatment. This information helps determine how slowly or quickly to remove fluid from your child's body. It is also important to help monitor your child's progress.
- **Temperature:** This helps check for infection. You may check your child's temperature at home if they don't feel well. Please call us if your child has a fever greater than 100.4˚F (38˚C).
- **Weight:** This tells us your child's fluid status. The nurse will weigh your child before each treatment.
    - A **dry weight** is your child's weight when they do not have extra fluid in their body. It is measured by watching your child's weight changes, blood pressure and how they feel during dialysis. Your child's dry weight may change over time as they grow.
    - At every treatment, the nurse will try to remove enough fluid to get your child to their dry weight. Some children still make a lot of pee and may not need fluid removed during dialysis.

Fluid

The amount of fluid your child can drink depends on how much they pee and how much fluid is taken off during each dialysis treatment. The dietitian will help figure out how much fluid is safe and will teach you how to keep track of the fluid your child drinks.

Some things you can do to keep track of fluid:

- Measure all fluids such as water, milk, juice, sodas, coffee, tea, other beverages and soup broth.
- Measure foods that are liquid at room temperature such as gelatin desserts, Popsicle® type treats, yogurt, pudding and ice.
- Limit eating fruits and vegetables that have a high fluid content.
- Avoid foods cooked in water such as hot cereals, pasta and rice.

Tell the nurse if your child has any of the following symptoms:

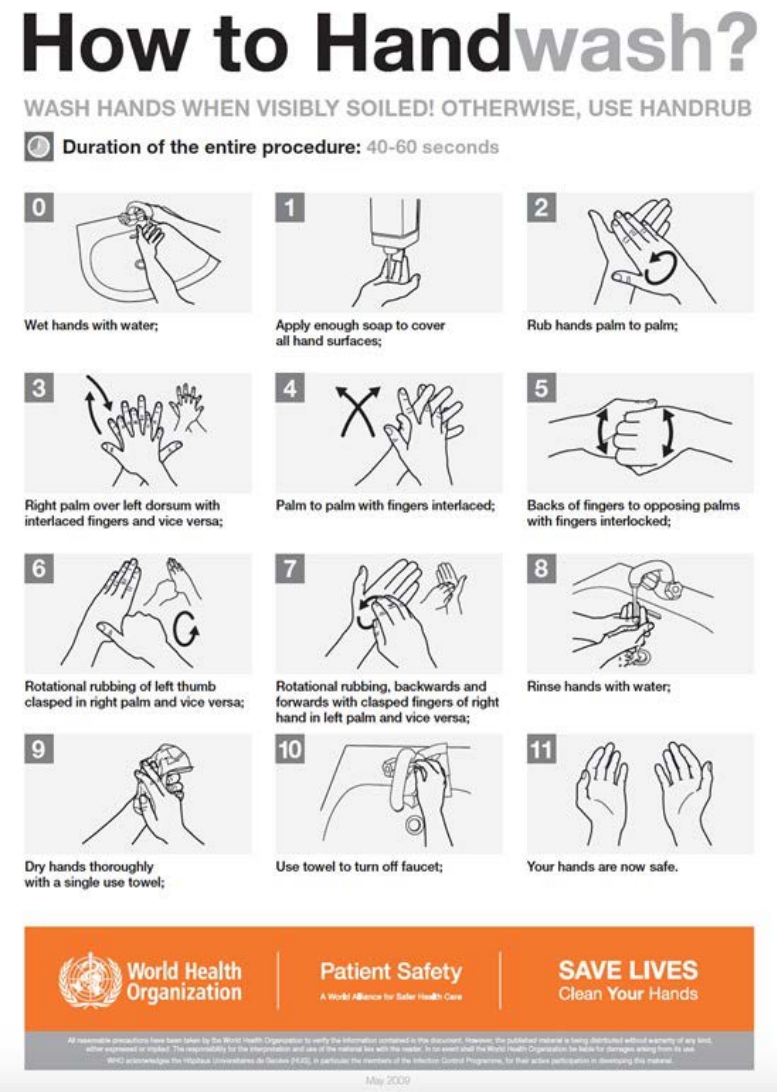
Symptoms showing there's **not enough** fluid in your child's body	Symptoms showing there's **too much** fluid in your child's body
• Low blood pressure • Muscle cramps • Headache • Dizziness/light headedness	• High blood pressure • Swelling (edema) • Difficulty breathing or pain in their chest • Headache

Infection Control

Your child needs everyone's help to keep them free from infection!

The best way to prevent infection is to wash your hands often.

- Wash your hands with soap and water for at least 40-60 seconds every time you and your child enter the Kidney Center.
- Wash your hands with hand sanitizer for 20-30 seconds when you leave the Kidney Center.
- Wash your hands before and after central line dressing changes (if applicable).
- Before and after each dialysis treatment, use clean hands to wash your child's fistula or graft area (if applicable).



What else can I do to prevent infection?

Your child should get a dose of antibiotics 1 hour before every dental exam/procedure. Please contact your child's kidney doctor to ask for a prescription for antibiotics before their dental visit.

Hemodialysis Access

What is a central line?

A central line is also called a central venous catheter (CVC) or line. It is like an intravenous (IV) line but longer. The line goes under the skin in your child's chest and into a large blood vessel that leads to the heart. Your child will have a central line called a hemodialysis catheter.

- The central line is put in during surgery.
- There is a small fabric cuff that sits underneath the skin. Once healed, it will help the line stay in place.
- There are 2 openings on the end of the tube. During dialysis, blood is taken out of the body from one opening and returned to the body through the other.
- The central line goes straight to the heart, so it's important to be very careful when caring for the line to make sure it does not get an infection. Your nurse will show you how to care for the central line.

Increased risk of infection

Children with a central line have a higher chance of getting an infection. It's important to follow the instructions from your care team when caring for the line to help prevent an infection. Even if you do all the right steps in caring for your child's central line, it can still get infected. **Call your child's doctor right away if your child has fever, redness at the line site or any type of illness.** We will help you with what to do next.

What is a central line-associated bloodstream infection (CLABSI)?

A central line-associated bloodstream infection (CLABSI) is an infection that can happen when bacteria or other germs get into the blood of a child with a central line. If a child gets an infection, they may get a fever and chills and become very sick. The area around the central line may or may not look red and irritated with an infection.

This infection is considered an emergency, even though it is well treated with medicines.

How are CLABSIs treated?

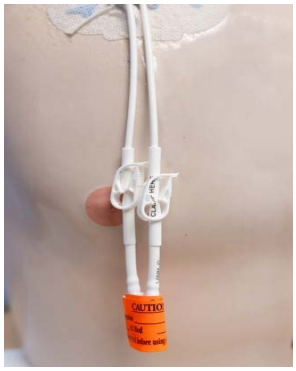
This type of infection is treated with medicines through the central line, usually antibiotics. Sometimes, the central line may need to be removed.

What can you do to lower the risk of CLABSI?

Wash your hands and wear gloves

- Clean your hands and put on clean gloves before you touch the line or handle supplies. This helps prevent an infection.
- Use soap, running water and friction for 15 seconds to wash your hands. Use a clean towel or paper towel to dry your hands.
    - If your hands are not visibly dirty, you can use hand sanitizer. Scrub using friction until your hands are dry.

Keep the line clean and dry



- Keep the dressing clean and dry. Don't let your child scratch, rub or remove the dressing.
    - Avoid activities that may get the line or dressing wet (this includes swimming).
    - If the line accidentally gets wet or dirty, call the dialysis nurse.
    - If the dressing is coming up on 1 side, reinforce it by putting a clear dressing on the edge and call the dialysis nurse right away.
- Keep the clamps on your child's line closed and taped. If they are unclamped, re-clamp and tape them securely then call the dialysis nurse.

Line care

- The dialysis nurses will do the dressing changes 1 time a week during dialysis or more often if the dressing gets wet or dirty.
- The stitches placed after surgery will keep the catheter in place. After 8 weeks, the stitches may be removed. The fabric cuff will hold the catheter in place.
- The dialysis nurses will change the caps, and tubing at the scheduled times.
- If using a device that secures the line, change to a clean one every day.
    - Gus Gear vest: Wash it every day. You should have 2 vests to allow for daily washing.

Personal care

- Brush teeth 2 times a day: Use a soft bristle toothbrush or toothette.
    - Talk to your child's care team before going to the dentist.
- Take a bath or shower every day.
- Put on clean clothes and underwear every day.

Keep your child's living area clean

- Change bed sheets every week.
- Change towels used for bathing at least 2 times a week.

Protect the central line

- Your child can continue normal activities but try to avoid rough-housing or forceful movement. We want to make sure the line does not accidentally get pulled out.
- Do not have fake nails, gel, shellac or chipped nail polish.
- Do not let anyone touch the line unless they are familiar with how to use it.
- Never use scissors near the line. Please only use the provided clamps near the line. These should only be used when there is a tear in the line, causing it to leak. Your nurse will show you how to use them.

Helpful tips about central line care

- **If your child is allergic to any of the supplies, please let your nurse know. We can help find a product that works best for your child.**
- If you go to another hospital, take a copy of the steps of how to care for the hemodialysis catheter with you. It is okay if they choose to follow their own procedure instead.

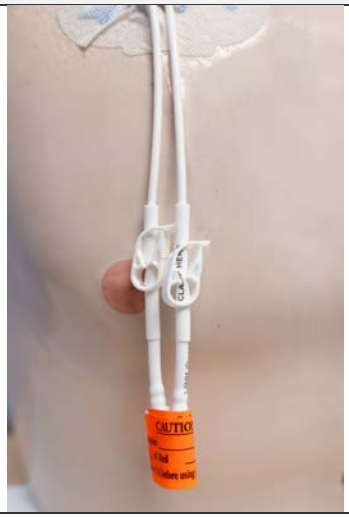
Emergencies

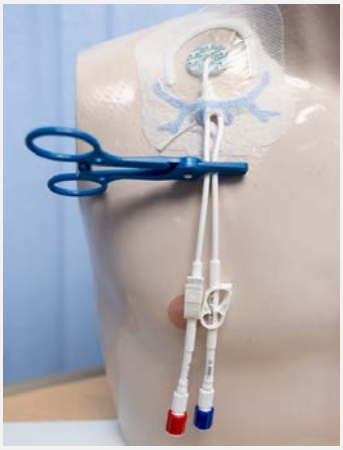
Always have an emergency kit with your child. This should include:

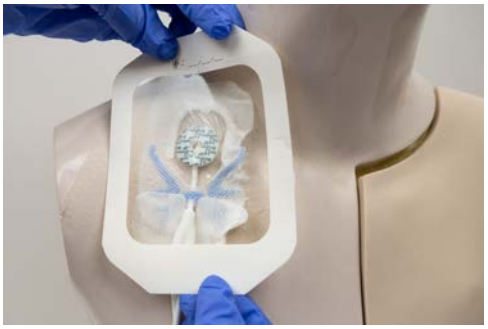
- Clean gloves
- Clear dressings (small and large)
- Blue clamps
- Masks
- Gauze
- Tape

What to do in case of an emergency

Emergency	How to respond
Fever above 100.4 °F (38 °C)	Call your dialysis doctor or go to the Emergency Room right away.
Pain, redness or drainage at the line site	Call your dialysis doctor or go to the Emergency Room right away.
Sudden pain in the neck, chest or shoulder or trouble breathing	1. Make sure the line is clamped. 2. Have your child lie on their left side with their head down. 3. **Call 911.**



Emergency	How to respond	
Central line falls out	If the line gets longer, shorter or falls out, do not push it back in or pull it out the rest of the way. 1. Hold pressure to the site with a sterile gauze. Put a sterile dressing over it. 2. Go to the Emergency Room right away or call 911.	
Injection cap comes off	1. Make sure the line is clamped. 2. Take a sterile gauze and wrap it tightly around the end of the open line. Secure it with tape. 3. Call the dialysis nurse and go to the closest Emergency Room.	
Leaking from the line	1. Clamp the line above the leak using a blue clamp. 2. Wrap gauze around the line. 3. Call the dialysis nurse right away and go to the Emergency Room.	

Emergency	How to respond	
Blood on the dressing	• If the blood is **not** leaking out from under the dressing, watch to see if the bleeding gets worse. • If blood leaks outside of the dressing, put light pressure over the site with a gloved hand and 4X4 gauze. Call the dialysis nurse.	
Dressing lifting on one side	1. Reinforce the dressing by putting a clear dressing on the side that is lifted. 2. Tell your dialysis nurse so they can change the dressing at your next visit.	
Dressing is lifting on more than one side or is completely off	If the dressing is still attached, leave it on. 1. Put a mask on. 2. Wash hands and put on clean gloves. 3. Put a clear dressing over the line site. 4. Go to the closest Children's Hospital Colorado facility for a new dressing.	

Bathing and Showering

General information

For baths: Only fill the tub to your child's waistline or lower to make sure the water is away from the central line.

For showers: Keep the water spraying on your child's back, away from the central line.

How do I cover the central line to keep it dry?

- There are 2 things that are available to cover the dressing during a bath or shower:
  - **Aquaguard®:** This is available in the hospital and sometimes supplied at home from the home care agency.
  - **GLAD Press'N Seal®:** This is more commonly used at home. You can buy it at the store.

- Always cover your child's hemodialysis catheter site, even if the dressing will be changed after the bath or shower.
- If your child is wearing a Gus Gear vest, take it off before their bath or shower. Make sure their skin is dry before putting on a clean vest.

Using GLAD Press'N Seal®

1. Take a piece of GLAD Press'N Seal that will be large enough to completely cover the site. (Fig. 11.1)
2. Wrap the caps with GLAD Press'N Seal to make sure they stay dry.
3. Pull the caps up to the dressing, so they are not hanging out of your covered area.

4. Put GLAD Press'N Seal over the central line dressing, covering the dressing and caps. (Fig. 11.2)
5. You may need to use some tape around the edges to make sure the GLAD Press'N Seal forms a tight seal on the skin.
6. Pat dry the body and site with a clean dry towel, before removing the GLAD Press'N Seal.
7. Remove the GLAD Press'N Seal after the bath or shower is finished.
8. If central line dressing seems wet, call the dialysis nurse right away.

Swimming

- Children may not swim or soak in any water. Your child should only participate in activities when the chance of getting soaked or wet is low. Examples include:
    - Fishing on a boat or shoreline
    - Riding on a boat (not rafting)
    - Water table or water sensory play with minimal splashing
    - Being around a body of water (not going under water)
- Always cover the hemodialysis catheter site during these activities.

If your child's dressing gets wet or is peeling up, call your dialysis nurse to talk about the next steps.

Securing the Hemodialysis Catheter

What is Gus Gear?

Gus Gear is a soft fabric vest that is used to protect a central line placed in your child's chest. It helps prevent the line from accidentally being pulled out, breaking, or becoming dirty.

Your child may use Gus Gear if:

- They have a central line in their chest.
- They can appropriately fit in the largest GusGear vest (size 6).

How do I care for my child with Gus Gear?

Watch your child closely

- Check the central line site in the morning, at bath time, at bedtime, and if your child has any discomfort around their central line.
- Call the doctor right away if your child has signs of infection:
  - Redness
  - Drainage
  - Swelling
  - Pain
- Take the vest off right away if your child:
  - Shows signs of sensitivity (redness, irritation, hives)
  - Shows signs of skin breakdown
  - Develops a pressure sore. To help prevent this, move the tubing often so it is sitting in a different place.
- Starts a type of chemotherapy called Thiotepa

Take the vest off your child before bath time

- Make sure their skin is dry before putting the vest back on.
- Don't let the vest get wet or dirty. Take the vest off right away if it is wet or dirty and put on a clean vest.

Wash the Gus Gear vest every day

- Vest can be machine washed with **cold** water.
  - If a washing machine is not available, you can hand wash the vest with soap and water.
  - Let the vest air dry. **Don't put it in the dryer.**

How do I use the Gus Gear vest?

Scan QR code or visit the website for Gus Gear Lock 2000 Vest Instructions.

https://gusgear.net/wp-content/uploads/2026/01/LOCK-2000-Vest-IFU-PDF-version-JAN-2026.pdf

Scan the QR code or visit the website below to watch videos about how to use the vest.

https://gusgear.net/lock-2000-vest-video-instructions/?v=0b3b97fa6688

For questions and more information, scan the QR codes or visit the website below.

https://clinical.gusgear.com/lock-2000-vest/

What is a Fistula and Graft?

Fistulas and grafts can be a great option that you and your child may want to consider. They allow for:

- Easier showering and bathing
- Swimming
- Lower risk of infection
- Lower risk of blood clots
- More efficient dialysis

Arteriovenous (AV) fistulas

Arteriovenous (AV) fistulas are created inside the arm during surgery. The surgeon connects an artery and vein together creating a very large blood vessel called a fistula. The fistula can be used for dialysis once it has healed from surgery.

- During dialysis, the nurse will put 2 needles into the fistula.
- One is used to remove blood and the other is used to return the blood.
- After dialysis is over, the needles are taken out, and the nurse will hold pressure on it to stop the bleeding.
- A Band-Aid is put over the needle sites before your child goes home.

Grafts

Grafts may be another option if your child's veins are too small to create a fistula. The surgeon will use a small tube to connect the artery and vein. This will create a large blood vessel called a graft. The graft is used for dialysis. As with fistulas, the nurse will put 2 needles into the graft for removing and returning blood during dialysis.

If your child would like to have a fistula or graft created, be sure to consider the following:

- Your child must have surgery to get the fistula or graft placed. Ask the surgeon about the risks and benefits for your child.
- It takes 2 or more months for fistulas to develop before they can be used for dialysis. Grafts are usually ready to be used after a few weeks. Your child's catheter will be used while the fistula or graft develops.
- Needles will be used with every dialysis treatment. Your child needs to be able to hold still as staff places the needles. A numbing cream (called EMLA) can help reduce discomfort. Your child may put EMLA cream on the fistula or graft 1 hour before dialysis. Ask your child's doctor to order this if needed.
- The needles will be taped in your child's arm for the entire dialysis treatment. Your child will need to hold their arm still the whole time.
- Fistulas may last for your child's entire life. Grafts may last several years. Catheters may have to be replaced more often because of blood clots, infection or damage to the catheter.

Caring for my child's fistula or graft:

It's important to follow these guidelines when caring for your child's fistula or graft. This helps make sure the fistula or graft continues working for as long as possible.

Clean the site

- Wash the access site with antibacterial soap for at least 30 seconds every day and before dialysis treatments.
- You can also clean the needle sites and area around the fistula or graft.

Look, listen and feel

It's important to look, listen and feel 1 time every day. Your nurse will teach you how to do this.

- Look at the access site.
- Listen for a "whoosh, whoosh" sound with your stethoscope. This is called a bruit.
- Feel for a buzzing or humming sensation. This is called a thrill.

Avoid pressure on the access site

It's important to avoid any pressure on the access site. This helps prevent blood clotting.

- Avoid wearing elastic cuffs, jewelry, watches or tight clothing on the arm with the fistula or graft.
- Avoid activities that might tighten straps or handles around the fistula or graft, like carrying bags.
- Don't lie down or sleep on the arm with the fistula or graft for extended periods of time. This can prevent enough blood from getting to the arm.
- Don't lift heavy things with the access arm for 1 week after the procedure.

Medical procedures

- Don't let anyone take a blood pressure, draw blood, start an IV or place a tourniquet on the arm with the fistula or graft. The extremity with the fistula or graft should only be used for dialysis.

What to do in case of an emergency

Always keep an emergency kit with the following items:

- Gauze
- Gloves
- Tape

Bleeding of the fistula

- Hold pressure with a gloved hand and gauze while holding the extremity with the fistula above the level of your child's heart.
- **If the bleeding is excessive or doesn't stop within 30 minutes, please call 911 or go to the nearest emergency department.**

Loss of blood flow to the fistula

- If you can't feel the thrill or hear the bruit, please call the on-call nurse right away and **go to the nearest emergency department.**
- If your child has numbness, tingling, pain, coldness, or discoloration in the hand or foot on the access side, call the dialysis care team.

Infection

Call the on-call nurse right away if your child has any of the following signs of infection:

- Fever above 100.4 °F (38 °C)
- Redness, warmth, swelling, tenderness, bulging or drainage at the site.

Low blood pressure

If your child's blood pressure is low, it may cause the fistula or graft to clot or stop working.

- Check your child's blood pressure right away if they feel dizzy, faint or weak.
- Check for a thrill and bruit over your fistula or graft.

Call the dialysis nurse if your child's blood pressure is low or you have any concerns about your fistula or graft.

Lab Values, Diet and Nutrition

Lab Values

While on dialysis, your child needs labs tests to help watch their nutrition level, electrolytes, and how well their body is working. The table below describes the most common lab tests and why they are important.

Lab Test	Purpose
Sodium (Na++)	Sodium is an electrolyte important for contracting/relaxing muscles and maintaining fluid balance. High sodium may show dehydration, while low sodium can show too much fluid.
Potassium (K+)	Potassium is an electrolyte that helps your nerves work and muscles contract. High potassium is dangerous and can cause the heart to stop suddenly.
Calcium (Ca++)	Calcium is a mineral important in bone and heart health. Low calcium is often caused by high phosphorus. It may also be from not enough calcium in your diet or low vitamin D.
Phosphorus	Phosphorus is important in bone and heart health. High phosphorus is usually caused by phosphorus in the diet. High phosphorus can lead to low calcium and can cause bone disease if not corrected.
Intact Parathyroid Hormone (iPTH)	iPTH is a hormone important in bone and heart health. It is released when there is not enough calcium in the blood. It tells the body to remove calcium from the bones. A high iPTH shows a high risk of bone disease.
Hemoglobin (Hgb) and Hematocrit (Hct)	Hemoglobin measures how well blood can carry oxygen through the body. Hematocrit measures the percent of blood volume that is red blood cells. These values will determine if medicines are needed to help make red blood cells.
Creatinine and BUN	Waste products in the blood that are made when tissue is broken down and removed by the kidneys or by dialysis.

Diet and Nutrition

Good nutrition is very important for your child to grow and be healthy. The dietitian will go over your child's growth, lab test results and their medicines then recommend a diet that is right for your child. They will teach you about the recommended diet and help you make the diet work for your child.

Nutrition

Nutrients are compounds needed to grow and survive. Foods have many special nutrients. Carbohydrates, fats and proteins are 3 nutrients that give your child energy. Vitamins and minerals work with the carbohydrates, proteins and fats to keep your child healthy. Protein is also needed for many body tissues, including muscles. Children with kidney disease who are getting dialysis may need a diet with limited sodium, potassium, calcium, phosphorus and/or fluid.

Sodium

Sodium, also known as salt, is found naturally in many foods. Eating large amounts of salt can make the body hold onto fluid and increase blood pressure. The extra fluid in the body can cause swelling (edema) in the face, legs, and hands, and in severe cases swelling in the lungs (pulmonary edema). If fluid settles in the lungs, it can make it hard to breathe.

Some things you can do to limit sodium include:

- Limit the amount of salt used to make foods.
- Do not add salt from a saltshaker after food is made.
- Avoid high sodium foods like canned soups, "fast foods", pickles, olives, smoked and cured meats like ham, hotdogs, luncheon meats and boxed meals.
- Read labels and choose foods that have less than 140 mg sodium per serving.

Potassium

Potassium is found in many fruits and vegetables as well as nuts, seeds and chocolate. When the kidneys are not working, the potassium level in the body can become high. If this happens, electrical activity in the heart becomes irregular. This makes it hard for the heart to work well. If the potassium level gets too high, the heart can stop, causing death.

Avoiding the following foods can help lower potassium:

- High potassium fruits and vegetables like potatoes (including chips and fries), bananas, oranges and orange juice, tomatoes and tomato sauce/pasta, avocado and pumpkin
- Nuts, seeds and chocolate
- Salt substitutes that have potassium chloride

Phosphorus

Phosphorus is found in foods that have protein, like meat, fish, poultry, eggs and dairy (milk, cheese, yogurt pudding). It is also found in nuts, seeds, beans and cola type sodas. Your child will need to follow a diet that is lower in phosphorus to limit the amount of phosphorus that can get into their body. Your child may also need to take a medicine called a phosphorus binder to remove some of the phosphorus from the food so less gets into their blood.

Some things you can do to limit phosphorus include:

- Limit dairy foods to 1 serving per day (1/2 cup milk or 1-ounce hard cheese)
- Limit high phosphorous foods like beans, nuts, seeds, organ meats, whole grain bread and cereal
- Avoid all dark sodas and other sodas that have phosphoric acid
- Take phosphorous binder medicines as ordered by your child's doctor

Calcium

Calcium is found mainly in dairy foods, but it's also in other foods like almonds, calcium fortified cereals and juices and some canned fish. Like phosphorus, calcium is a mineral needed for healthy bones and good growth. Your child's calcium may come from both diet and medicines. The dietitian can help figure out how much calcium your child needs.

Protein

Protein is found in foods like meat, fish, poultry, eggs and dairy (milk, cheese, yogurt and pudding). It is also found in nuts, seeds and beans. Protein is needed to build, maintain and fix body tissues. When proteins are broken down in the body, they make a waste product called Blood Urea Nitrogen (BUN). It is important that your child gets enough protein to grow but if your child eats too much protein, it can increase their BUN level. The dietitian can teach you how much protein your child needs.

Energy

The body's first choice for energy is carbohydrates, so most of the calories in your child's diet should come from carbohydrate foods such as cereals, breads, pastas, rice, allowed vegetables, fruits and their juices, milk and other dairy foods and sugars. Fats are also a good source of energy. Some types of fats are healthier than others. If your child's weight is below the healthy range, the dietitian may recommend adding extra carbohydrates/sugars and fats to increase weight. If your child's weight is above the healthy range, the dietitian may recommend using less carbohydrates/sugars and fat to reach a healthy weight.

Vitamins

Many children with kidney disease have diet restrictions or a poor appetite that results in them not eating enough food. Without the right amount of food, they also don't get enough vitamins. Children treated with dialysis also lose some vitamins through the dialysis treatment. A multi-vitamin supplement (dialyvite) is often needed to replace the vitamins lost in dialysis.

Health Insurance

Health Insurance

Adjusting to your child's kidney disease and the need for dialysis can be challenging. Worrying about the cost of dialysis, medicines and other needed care can add even more stress.

Fortunately, there are often several health insurance options available to children who are on dialysis. It is not unusual for children to have 2 or more different sources of insurance. These can include:

- Employer issued group health insurance (such as United Healthcare, Cigna, Anthem BCBC, or Kaiser)
- Union health insurance plans
- Medicaid
- Medicare
- Charity programs

Please tell the social worker if your health insurance, address, phone number or employment status changes at any time. This can affect the billing for dialysis.

What is Medicare?

Medicare is a health insurance program paid for by the federal government that is most often used by senior citizens 65 and older.

People at **any age** with End Stage Renal Disease (kidney failure needing dialysis or a kidney transplant) are also eligible to apply for Medicare.

	What It Helps Cover	Cost
Medicare Part A	Treatment when your child is in the hospital (on an inpatient unit)	Cost may vary and usually includes a deductible for inpatient services.
Medicare Part B	When your child is not in the hospital, Part B helps cover the following: Dialysis Medicines given during dialysis Laboratory tests Clinic visits	Everyone must pay a monthly premium for Medicare Part B. This amount may be higher if you do not sign up for Part B when you first become eligible. ***If your child has Medicaid, then the premium will be paid by Medicaid.*

Signing up for Medicare

You can enroll your child in Medicare by going to your local Social Security office. Call 800-772-1213 and tell the representative you want to apply for Medicare because your child has End Stage Renal Disease. You need to have a CMS-2728 form, which the dialysis unit social worker can give to you.

For more information, visit www.medicare.gov.

Travel

If your family travels outside of the local area for more than 2 days, they may need to schedule "transient dialysis" at another dialysis facility. The availability of transient dialysis depends on the how many people the unit can treat. It's also important to check your health insurance for transient dialysis.

- Medicare will pay for the majority of costs associated with getting dialysis in a different state.
- Some employer and union health insurance plans will also cover dialysis in a different state.
- Colorado Medicaid will only pay for dialysis in the state of Colorado.

As you are planning travel, it is important to talk to the nurses and social worker about your plans at least 30 days before your scheduled trip. They will work together to contact local dialysis units.

Resources

Resources

Living with kidney disease can be stressful for both you and your child. Knowing and understanding the resources available can make living with kidney disease easier and more manageable.

Social work

Social workers are here to help you and your child adjust to living with kidney disease and dialysis. As the social worker gets to know your family's needs, they are able to help you and your child by connecting you with many resources. These may include:

- Coping with kidney disease
- Understanding your child's rights and responsibilities
- Education
- Insurance options
- Coping resources, including connections to counselors or other mental health specialists if needed
- Speaking on your family's behalf to the healthcare team

Education

While the Kidney Center staff will work hard to make sure your child is able to go to school regularly, they will miss at least a few hours of classes every week for their dialysis treatments. Your child should bring schoolwork with them and work on it during dialysis.

The social worker and learning specialist will work together to make sure your child's educational needs are met. If appropriate, they may:

- Talk to your child's individual school counselor to make sure their educational needs are met
- Help get home schooling resources
- Help get tutoring services
- Refer your child to specialized education programs such as Medical Day Treatment
- Help answer questions about IEP (individual education plan) and 504 (medical accommodation) plans

Family navigator

The family navigator can help you figure out some of the practical aspects of dialysis and connect you with resources. These may include:

- Financial assistance (housing, bills, food, etc.)
- Help with transportation
- Insurance (Medicaid and other healthcare programs: Medicaid Waivers and Buy In)
- Immigration
- Navigating hospital/medical systems
- Lodging referrals for hotel and Ronal McDonald House referrals

Other Treatment Options

Peritoneal Dialysis

Peritoneal dialysis: Removal of extra fluid and waste products from the blood by using the lining of the abdomen (peritoneum) as a filter.

How is it done?

Peritoneal dialysis is done at home, using the natural lining of your child's belly (the peritoneum) to filter blood in the body. A soft plastic tube (catheter) is placed in the abdominal space during surgery.

During treatment a sterile cleaning fluid is put into the belly through this tube. After the fluid is filtered, it leaves your child's body through the tube into a drain bag. A machine is used to do this while your child sleeps at night. You will be trained by a nurse to set up the machine and do treatments at home.

What are the benefits?

- This controls extra fluid more easily, which may reduce stress on the heart and blood vessels.
- Your child may be able to eat more and use fewer medicines.
- Your child can do more of their daily activities, and it is easier to work or travel.

Kidney Transplant

Kidney transplants are **not a cure** for kidney failure, but another way to treat it. This involves taking a healthy kidney from 1 person (the donor) and surgically grafting it into someone whose kidneys aren't working (the recipient). Once the surgery is done and the new kidney works as a healthy organ, your child will not need dialysis, a special diet or fluid restriction.

What are the 2 types of kidney transplantation?

Deceased donor

To get a deceased donor kidney (a kidney from a person who has died), your child must be placed on the national waiting list. There are several factors that determine how and when someone reaches the top of the list and gets a new organ. Wait time can vary and may be a few months to a few years depending on your child's individual situation.

Living donor

In some cases, you or another person may want to donate a kidney to your child. This is called living donation. In this process, 1 healthy kidney is taken from the donor and put into your child. It is possible for someone to donate a kidney because the human body only needs 1 kidney to work well.

Currently, Children's Hospital Colorado lets people between the ages of 18 and 50 donate a healthy kidney. The donors blood type must be compatible with the recipients and they must be in excellent physical health. If you want to find out if you are eligible to donate, please go to www.uchealthlivingdonor.org.

What type of kidney transplant is best for my child?

Choosing which type of transplant is best for your child is a personal decision that only you, your child and the rest of your family can make along with your care team. The Kidney Center staff are available to talk about your options and help answer any questions you may have. Whichever decision you make, the care team is here to support and help you along the way.

Steps to transplant

Once your child is ready to be evaluated for transplant, we will start the workup process. Below are the steps needed to make sure your child is a good candidate for transplant:

1. Pre-Evaluation: You and your child will meet with the Kidney Center team during your regular weekly and monthly visits. During these visits, we will examine your child, talk about their readiness for transplant and answer any questions.
2. Letter of Necessity: Your child's nephrologist will write this letter then send it to the insurance company(s) for financial approval.
3. Evaluation: Once the insurance company(s) gives financial approval, a member of the kidney transplant team will schedule an evaluation. This evaluation is done over 2 full days. It will include meeting the multidisciplinary transplant team:
    - Meeting with the surgeon (doctor doing the surgery)
    - Meeting with the anesthesiologist (doctor giving medicines that put your child to sleep during surgery)
    - Meeting with the transplant nephrologist and transplant coordinators
    - Meeting with the social worker and dietitian
    - Meeting with urology, psychology and/or any other specialist the transplant team thinks is needed
    - Medical screening. This includes getting a chest x-ray, EKG and multiple labs. All teens are tested for pregnancy, sexually transmitted diseases and drug use.
    - Dental screen

Once all the assessment information is gathered, the transplant team will take it to the transplant committee to discuss and determine if your child is a good candidate. If your child is deemed a good candidate for transplant, they will be placed on the list! Once placed on the list, it can still take several months to years to get a kidney transplant. The transplant team is always available for questions and to discuss where your child is in the transplant process.

Please note: The workup process for transplant may take several months and the information will be updated every year as long as your child is being considered or listed for transplant.

Author: Nephrology | Approved by Patient Education Committee | Valid through 2029

NEPH-868bwdqva-2026-03