

A guide for families of children on hemodialysis



Information from the Pediatric Nephrology Team

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Introduction

At McMaster Children's Hospital, your child will be cared for by a team of health care providers. You and your child are an important part of this team. Together, we will identify your child's needs and design a plan of care to meet those needs.

The health care team will give you information and support. We believe that you need to know as much as possible about your child's illness so that you will be able to take part in all stages of his or her care.

We welcome your questions.

This book can help you learn:



- about kidney disease and how you can help your child manage symptoms
- about hemodialysis treatments and how to care for the hemodialysis catheter
- the medications and tests your child may need
- your role on the health care team
- how to help your child through dialysis treatments
- how health care providers can help your child
- where you can get more information
- when to call for help

Use the blank pages at the end of the booklet to write down your notes and questions about your child's condition and progress. The chart will help you schedule medications.

What do the kidneys do?

Kidneys have important work to do, including:

- ✓ making urine, which removes waste from the body
- ✓ balancing the fluid and electrolytes in the body
- ✓ helping to control the level of acid in the blood
- ✓ helping to control blood pressure
- ✓ making hormones

When kidneys are working well, they help to balance things in the body.

What happens when kidneys fail?

When kidneys are not working well, things get out of balance and symptoms start to appear. For a while, diet changes and medication can help the body stay in balance.

As kidney disease slowly worsens, diet and medication can no longer keep the balance. Dialysis or a kidney transplant become necessary.

What symptoms are possible while on dialysis?

Your child's kidneys are not working well. He or she needs dialysis to keep things balanced. Your child may already have symptoms of kidney disease. Other symptoms may appear after dialysis has started.

The charts on the next few pages describe:

- symptoms of kidney disease
- what you can do to help your child
- what the health care team will do to help

The doctor we refer to in the chart is the Pediatric Nephrologist. This is the doctor that cares for your child's kidney disease.

Symptom: No appetite

Cause	Effect	What parents and family can do	What the health care team will do
 When kidneys fail the build up of waste in the body causes nausea and may cause changes in the way things taste. Frequent nausea causes lack of appetite. Anemia can also cause a poor appetite. 	 Your child's appetite may decrease over time. Some children get to the point where they refuse to eat anything. You may find that your child vomits in the mornings and/or at other times. 	 Gentle encouragement is important. Do not get angry with your child if he/she refuses to eat. Make meal times as pleasant as possible. Your child may eat more during the day if you offer many small meals, rather than 3 large meals. Always have healthy snacks available for when your child is willing to eat. Make sure your child receives all medications or supplements as prescribed. 	 The dietician will check your child and offer suggestions. You may have to supplement your child's diet with a liquid formula. The doctor will prescribe iron supplements, vitamins and medications to boost your child's red blood cells. It may be necessary to place a tube into your child's stomach to give the liquid formula. Your doctor will discuss this with you if it becomes necessary.

Symptom: Slow growth

	Cause	Effect	V	Vhat parents and family can do	V	What the health care team will do
•	When kidneys fail the body does not respond well to growth hormone. Growth hormone may be given by injection.	Your child will not grow as quickly as other children and over time may stop growing.	•	Give growth hormone as prescribed by the doctor. Make sure your child takes medication (usually TUMS) to prevent the build up of phosphate in the blood.	•	Growth hormone will be prescribed. This medication must be given as an injection every day. Your doctor will prescribe a phosphate binder, usually TUMS.
•	High levels of phosphate in the blood can affect growth.				•	Monthly blood tests will monitor levels of phosphate and PTH.
•	Other hormonal imbalances in particular parathyroid hormone (PTH).					

Symptom: High blood pressure

	Cause	Effect	What parents and family can do	What the health care team will do
•	When the kidney fails, it may release too much of the hormone that raises blood pressure.	 Your child blood pressure gets too high. Signs of high blood pressure include headaches, shortness of breath, chest pain or problems with vision such as spots, floaters, blurred or wavy vision. 	 Give blood pressure medications prescribed by the doctor. Tell your doctor if your child has signs of high blood pressure. 	The doctor will prescribe medication to lower blood pressure.
•	When there is too much fluid and less urine being made, blood pressure rises.	With too much fluid and less urine, everything your child drinks stays in the body, causing high blood pressure.	 Keep track of how much fluid your child drinks. Limit fluids if the doctor asks you to. 	 During dialysis the nurse will try to take off enough fluid to help reduce the blood pressure. Your child may need longer or more frequent dialysis treatments.
•	When there is too much salt, the body retains water, which raises blood pressure.	If your child eats too much salt, blood pressure rises.	If needed, limit the amount of salt your child eats.	 The doctor and dietician will discuss how much salt your child should have. The dietician will teach you how to lower the salt in your child's diet.

Symptom: Puffiness

Cause	Effect	What parents and family can do	What the health care team will do
• When the body cannot get rid of extra fluid it goes into the tissues causing puffiness (called edema).	• Puffiness can show up almost anywhere. Your child's face, tummy, legs or feet may be puffy.	 Keep track of how much fluid your child drinks. Limit fluids if the doctor asks you to. 	 During dialysis the nurse will try to take off enough fluid to help reduce the blood pressure. Your child may need longer or more frequent dialysis treatments.
• Too much salt.	• If your child has too much salt water will stay in the body even if your child is passing urine.	If needed, limit the amount of salt your child eats.	 The doctor and dietician will discuss how much salt your child should have. The dietician will teach you how to lower the salt in your child's diet.

Symptom: Itchy skin

Cause	Effect	What parents and family can do	What the health care team will do
 Waste products (toxins) build up and try to exit through the skin. Too much phosphate. 	Your child's skin becomes itchy.	 Make sure your child gets to all dialysis treatments. Make sure your child takes medication to prevent the build up of phosphate in the blood. Creams and lotions sometimes help. 	Monthly blood tests help the doctor decide if the dialysis treatment needs to be adjusted.

Symptom: Headaches

	Cause	Effect	What parents and family can do	What the health care team will do
•	Can be caused by high blood pressure. Some medications can cause headaches. Fluid shifts during dialysis treatments.	Your child may develop headaches from one or more causes.	 Make sure your child takes all blood pressure medications prescribed by the doctor. Discuss possible causes with your doctor. 	 The doctor may prescribe acetaminophen (Tylenol®) to relieve headaches. Depending on the cause, the doctor may change blood pressure medications or dialysis treatments.

Symptom: Less urine

	Cause	Effect	Wł	hat parents and family can do	\	What the health care team will do
•	With hemodialysis, some of the blood is diverted into the machine to be filtered. This reduces blood supply to the kidneys. As a result, less urine is made.	 Over many months, you may have noticed a gradual drop in your child's urine ouput. Once dialysis has started, the urine output may drop more quickly. 		Know that this is expected to happen on hemodialysis. Reassure your child.	۰	As urine output lowers the dialysis treatments may have to be a bit longer.

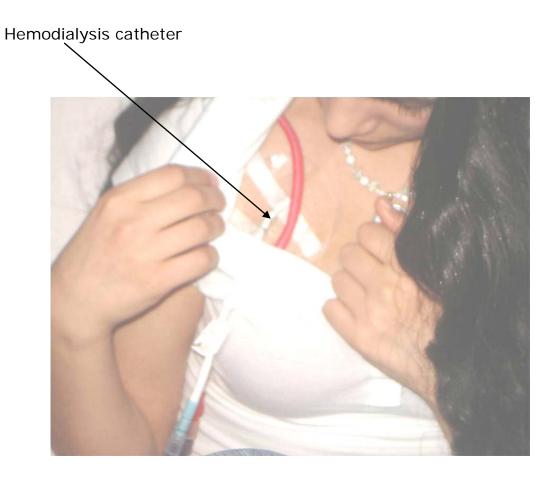
Symptom: Feeling very tired (fatigue)

Cause	Effect	What parents and family can do	What the health care team will do
 The build up of toxins in the body can cause fatigue. Anemia. Dialysis treatments. Excessive fluid. 	 After a dialysis treatment your child may feel "washed out" and may need a nap. He or she should feel better a couple of hours after treatments. You may find your child becomes more tired as you approach time for the next dialysis treatment, especially on weekends. 	 Allow for extra naps or rest periods. Explain to your child's teacher that there may be times when he/she is very tired. Give the medication prescribed to treat anemia, if needed. 	 The doctor will adjust dialysis treatments as necessary. If your child has anemia, the doctor will prescribe iron supplements, vitamins, and medications to boost your child's red blood cells.

What is hemodialysis?

Hemodialysis is a treatment that removes waste and water from the blood when the kidneys can no longer do this. This helps to keep the balance of fluid and electrolytes in the body. Other imbalances caused by kidney failure can be helped by medications and diet.

The treatment is done through a **hemodialysis catheter**. This is a plastic tube that is put into a blood vessel. It has two openings or 'arms' called lumens that can be used to access the blood. This type of catheter is also called a central line. It is permanent and requires special care.



How do we begin?

When the healthcare team determines that it is time to begin hemodialysis, your child will be referred to a surgeon. Your child will need an operation to put in the hemodialysis catheter.

Before surgery, your child will have a pre-op appointment.

- During this visit, you and your child will meet a pre-op nurse and a Child Life Specialist. They will help you and your child prepare for the surgery.
- You will also meet the Anesthesiologist. This is the doctor who will give your child an anesthetic so that he/she will be asleep and feel no pain during the surgery.
- Your child will have blood tests.
- The nurse will tell you when your child must stop eating and drinking before the surgery, and when to come to the hospital.

On the day of surgery, you can stay with your child until it is time for him/her to go into the operating room. Then, you can go to the waiting room. The surgeon may visit you there to give you an update after the surgery. As soon as possible, a nurse will take you to the recovery room to be with your child.

When your child is awake, he or she will go to the children's ward. How long your child stays in the hospital will depend on his/her health and when hemodialysis is to start.

Depending on your child's condition:

- Treatment may begin right away. Your child will stay in the hospital for several days to have dialysis treatments each day.
- Your child may go home after the hemodialysis catheter is put in and return for dialysis treatments at a later date.

How often will my child need hemodialysis? How long is a treatment?

Your child's first hemodialysis treatments will be short, lasting 1 to 2 hours for several days in a row. Once things are going well, the treatment schedule will slowly change over to longer treatments less often.

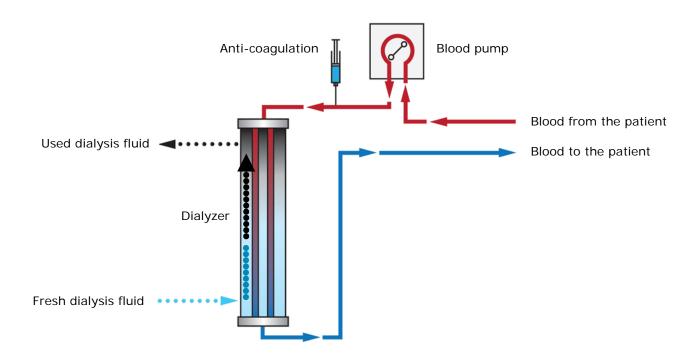
Most hemodialysis patients receive treatment 3 days a week, lasting 3 to 4 hours. The hemodialysis nurse and the doctor will discuss your child's schedule with you.

Each child's kidney disease and treatment is unique.



How does hemodialysis work?

During treatment the hemodialysis catheter is connected to special tubing which allows the hemodialysis machine to take the blood from the body. The blood passes through a filter or artificial kidney, which removes fluid and waste. Then the blood is returned to the body.



Who does hemodialysis?

A specially trained nurse will do the hemodialysis and closely monitor your child. The nurse talks with the doctor often about the treatments.

How do we take care of the hemodialysis catheter?

Keep the catheter dressing clean and dry.

- The hemodialysis nurse will give you pouches to cover the end of the catheter. A clean one will be put on after each treatment. Please take the used ones home to wash them. Bring them back to the nurse.
- If the pouch gets wet, dirty or falls off at home, put on a clean pouch.
- Make sure the catheter site (where it goes in) is clean. The hemodialysis nurse will change the dressing each week and as needed during visits.
- Keep a dressing kit at home, just in case you need to change your dressing in between treatments. The hemodialysis nurse will teach you how to change the dressing.
- Your child cannot shower or swim. You must not wet the catheter site or catheter dressing. Moisture can cause infection. Taking a bath is safe if you make sure the catheter and catheter dressing stay dry.
- If you or your child has a cold or infection, wear a mask every time the catheter is opened and when the dressing is being changed.

Protect the catheter

- **Air must not enter the catheter.** Never remove the cap on the end of the catheter.
- **Keep the catheter caps and clamps tightly closed** when not being used for dialysis.
- Only your hemodialysis nurses should use the dialysis catheter.

When to call for help

- If the area around the catheter looks red or is painful call the dialysis team right away.
- Ask the team about other warning signs that need immediate medical help.

By taking good care of your child's hemodialysis catheter, it will last longer and you will prevent problems such as infection.

What happens if there is an infection?

You can help to prevent infection by follow your catheter care instructions, exactly as you were taught.

Call the doctor or hemodialysis nurse right away if you notice any of these signs of a catheter infection:

- your child has a fever or chills
- there is drainage, redness or tenderness at the catheter exit site
- your child feels weak or unwell

Treatment depends on the type of infection and how bad it is. Your child may need:

- an ointment
- antibiotics
- a solution containing an antibiotic can be used to 'lock off' the catheter between treatments
- the hemodialysis catheter replaced.

What happens when my child's catheter is not working well?

At times your child's catheter may not work properly. This could be because a clot has formed in the catheter or at the end of the catheter. If this happens, there will be more alarms than usual during the hemodialysis treatment.

The hemodialysis nurse will put a medication called alteplase (Cathflo®) into the line to break up the clot. The doctor may increase the medication that is used to prevent clotting during the treatment, or may decide that the catheter needs to be replaced.

What happens during a dialysis treatment?

It is important that your child wears the same clothes during dialysis. Your child may choose a "dialysis outfit" or put on hospital pajamas when you arrive at the dialysis unit. Your child is weighed to determine the amount of fluid to be taken from the body, so the weight of the clothes must always be the same.

After the nurse weighs and checks your child (including vital signs), your child will sit in the dialysis chair. The nurse will program the machine and then hook the catheter up to the machine. During the treatment, the nurse will closely monitor your child and the machine.

You will hear many loud beeps during the set up and treatment. The hemodialysis machine has many safety features that beep to alert the nurse of what is happening.

For your child's safety, he or she should sit fairly still in the dialysis chair during the treatment. The hemodialysis lines attached to your child's hemodialysis catheter will be secured to the chair.

Your child will not be allowed to eat during dialysis. Your child may have a drink, if the hemodialysis nurse determines this will not affect treatment.

Your child can stay busy and happy during the treatment, by choosing activities including TV, video games, crafts, colouring and board games. Volunteers may also help entertain your child, or your child may choose to sleep during dialysis.

When can my child leave the hospital after a treatment?

After the treatment, the nurse disconnects the lines from your child's catheter. The nurse will check your child's weight and vital signs again. If everything is well you may take your child home. Occasionally, you may have to wait for your child to be seen by the doctor.

Will the treatments always be the same?

Most of the time the treatments will be the same. Treatments may be longer if your child has a lot of extra fluid to remove. The doctor will visit during each treatment and adjust the treatment if needed. Most often, changes to treatment are made during a monthly review. The changes are usually small and do not often affect the length or frequency of the treatments.

How long will my child be on hemodialysis?

If your child's kidneys fail due to a short-term (acute) illness, hemodialysis is only needed until your child's kidneys get better.

If your child has long-lasting (chronic) kidney disease, hemodialysis will continue until he or she receives a kidney transplant. Your child will need several appointments and tests to prepare for a transplant. This is called a 'work-up'. We will adjust your child's dialysis schedule for these appointments.

- If the transplant is from a deceased donor, the work up takes several months. When the work up is done, the wait begins for a kidney to become available. We cannot predict how long you will have to wait.
- If the transplant is from a living donor, the work up takes six months or more. Then, the hospital will give you a date for the transplant.

What is my role on the health care team?

You and your family are important members of the health care team. You know your child best. We encourage you to take part in your child's care, and to tell the rest of the team if you have concerns or see changes in your child's condition.

Your love, attention, support and encouragement will help your child during treatment.

As part of the healthcare team your family also has some responsibilities.

Being on time for appointments

It is very important to arrive at the unit on time.

- If you are too early, you will need to wait while the hemodialysis nurse finishes another patient's treatment or sets up the machine.
- If you are late it may affect several treatments throughout the day.

If you are going to be more than 15 minutes late for treatment please call the unit and let the hemodialysis nurse know.

Calling in for emergencies or bad weather

If an emergency or bad weather prevents you from coming to hemodialysis, let the hemodialysis nurse know as soon as possible. The pediatric nephrologist will determine when your child's next treatment will be, and if you need to do give your child any medications while you wait for the next treatment.

Avoiding scented products

Many staff and patients have allergies and asthma. They can have very serious reactions to perfume and other scents. Do not wear any perfume, cologne or any scented products when coming to dialysis.

Preventing infections

To prevent the spread of germs, you must wash your hands whenever you enter or leave the unit. Hand rub (sanitizer) dispensers are located inside and outside the unit. You and your child should wash your hands often. Tell the hemodialysis nurse if you or your child have a cold, sore throat or feel ill.

Helping your child through dialysis treatments

- Read to your child.
- Play his or her favorite music.
- Talk to your child about their treatments and other aspects of his or her illness.
- Save some favorite activities to do during hemodialysis treatments.
- Bring in some favorite movies or video games for your child to play during dialysis.



Staying close by

If you wish, you may leave the room during treatment, but please stay in the building. We may have to call you back for your child or if the treatment ends early.

Make sure you return in time to pick up your child after treatment. Another patient may be coming in to have dialysis on the same machine.

If you must occasionally leave the building, remain close by and tell the hemodialysis nurse how to reach you.

Being mindful of safety

Occasionally, you may be asked to wait outside the unit if another patient is being put on or taken off dialysis. Too many people in the room at these crucial times may affect the safety of the treatment by distracting the nurse or increasing the risk of infection.

When you are with your child during dialysis, you may ask questions at any time **except** for when the nurse is starting or ending a hemodialysis treatment.

Limiting visitors during treatment

One parent or visitor may stay beside the chair, to play or do quiet activities with your child during treatment.

Please be respectful of other patients' privacy and belongings.

Notifying your child's school

If your child is in school, you need to tell the school staff your child's dialysis schedule. It can be helpful to provide them with information about the hemodialysis catheter and its care. The team would be happy to help you with this if you wish.

What medications does my child need?

If your child has had kidney disease for a long time, he/she is probably already taking many medications.

- Some of them will change when hemodialysis begins.
- Some will no longer be needed.
- Some injections can be given through the dialysis tube. This means fewer needles for your child.

Your child's medications will be reviewed every month. The hemodialysis nurse or the doctor will discuss any changes with you.

You are responsible for:

- Making sure that your child gets the correct dose of medication at the correct time.
- Refilling your prescriptions before they run out, so your child will not miss any doses.

The nurses, doctors and pharmacists will discuss each of your child's medications and advise you about timing.

- Some of the medications interact and have to be given at different times.
- Some will have to be given either before or after hemodialysis to make sure they get absorbed.

The chart at the end of this booklet will help you schedule medication times.

Common medications for dialysis patients

You can expect that your child will have to take most of these medications.

Medication	Reason for taking
Calcitriol	A special form of Vitamin D that helps with the calcium balance in the body.
	 Can be given by mouth or while your child is on dialysis.
Replavite	• Some vitamins are washed out by dialysis, this vitamin replaces them
	Must be given by mouth
	 On dialysis days, must be given after dialysis or it will be "washed out" by dialysis
TUMS	Binds with phosphate in your child's stomach so it will not be absorbed by the body
Iron	To help prevent and treat anemia.
	Can be given while on dialysis or by mouth.
Aranesp	Helps the body make red blood cells which carry the iron.
	Will be given while your child is on dialysis.
Vitamin D	Important for many functions in the body.

What blood tests does my child need?

Your child will need many blood tests. The results help the team know:

- how well the dialysis is working.
- how the rest of your child's treatment is working.
- whether your child is getting enough medication.
- if your child needs diet restrictions.

Most blood tests are taken from the hemodialysis catheter, so your child will need fewer needles.

- Some blood tests are done each Monday, at the beginning of treatment.
- Once a month more blood test are done to see how well your child's dialysis treatment is working.
- If blood samples are needed during treatment they can be taken directly from the hemodialysis catheter.

The chart lists common blood tests and what you can do to help keep them within the desired range.

Test	Desired range	How to keep results in desired range
Potassium	3.5 - 5.0	 Monitor your child's potassium intake carefully, be aware of hidden sources of potassium.
Phosphate	1.2 - 1.8	Make sure your child takes a phosphate binder usually in the form of TUMS with meals.
Hemoglobin	115 - 120	• If your child is taking oral iron supplements ensure that it is taken at the correct time, away from taking TUMS as they interfere with the absorption of iron.

Your child will have other blood tests too. The team will help you learn about the tests and what the results mean for your child. Please ask us questions at any time.

How do health care providers help my child?

The chart lists the members of our hemodialysis team and how they can help your child. You may already know some team members from the pediatric nephrology clinic. We want you to have a positive experience with hemodialysis and we will help you overcome any issues that may come up.

Team Member	How they help your child
Pediatric Nephrologist Name:	A doctor who specializes in the care of children with kidney disease.
	• Visits your child during each treatment.
	 Reviews your child's care and treatment each month and as needed.
	Answers questions about kidney disease.
Pediatric Hemodialysis Nurse Names:	A registered nurse with specialized training in caring for children on hemodialysis.
	 Provides nursing care and coordinates hemodialysis treatment.
	• Coordinates appointments with dialysis treatments.
	 Answers questions about hemodialysis and kidney disease.
Pediatric Nephrology Clinic Nurse	A registered nurse specializing in the care of children with chronic kidney disease.
Names:	 Coordinates special blood work and appointments with other facilities while working towards kidney transplant.
	 Coordinates these appointments with the hemodialysis nurse.
	Make sure all tests and appointments for transplant work up is complete.

Team Member	How they help your child	
Clinical Dietitian Name:	 Assesses your child's dietary needs and restrictions. Helps plan a diet for your child that limits the amount of fluid, and meets other restrictions. Answers dietary questions about kidney disease. 	
Social Worker Name:	 Provides emotional support and counseling. Helps your family deal with changes in routine. Gives practical help with finances, legal issues or community referrals. 	
Pharmacist Name:	 Expert regarding medications. Coordinate special doses and special medications for patient's with kidney disease. Checks for possible drug interactions. 	
Pharmacy Technician Name:	Helps to meet your child's medication needs.Helps to manage supplies and solve issues.	
Child Life Specialist Name:	 Helps your child express his or her concerns. Explains tests and procedures in a way your child can understand. Helps your child and family learn to adjust and cope with the changes in routine, provides support. Provides play and learning activities. Helps your child understand, cope and prepare for a kidney transplant. 	
Volunteers	Trained volunteers can talk, play games and do activities with your child to make treatment time more enjoyable and seem shorter.	

How do we work together?

The health care providers will work with you to identify:

- your child's medical and emotional needs.
- the goals for care during treatment.

Each visit, health care providers and family members share information and work together to help your child reach his or her goals. The health care team providers communicate with each other in person, or through your child's health record. They welcome your thoughts, suggestions and questions.

Occasionally a team meeting may be arranged where you can:

- talk with health care providers.
- provide information about your child and family.
- take part in setting goals and planning for your child's transplant.
- ask questions and get information.
- discuss your concerns.

Where can I get more information?

You can find a lot of information about kidney disease, hemodialysis treatment and kidney transplant on the internet. If you do not have a home computer, you can access the internet from the computer in the Ronald McDonald Room on the 3rd floor of the hospital or at your local public library.

Some reliable internet sites are:

www.kidneyhealth.ca www.kidney.ca

Please discuss the information you find on the internet with your child's health care team. Make sure it is accurate, complete, and relevant to your child's needs.

When should I call for help?

Call for help if:

- there is redness, swelling, drainage or pain at the catheter site.
- your child has a fever above 38° C (100° F).
- there are concerns about your child's blood pressure.

On treatment days: call the hemodialysis nurse.

On non-treatment days (during business hours): call the nephrology nurse.

During evenings and weekends: call the hospital and have the pediatric nephrologist on call paged.

For any severe or urgent concerns not related to kidney disease take your child to the nearest emergency room.

They will contact the pediatric nephrologist if necessary.

Contact numbers			
Hemodialysis Unit	905-521-2100, ext. 73888		
Hemodialysis nurses pager	905-521-5030, ask for pager 1280		
Nephrology nurse	905-521-2100, ext. 73855		
After hours and emergencies	905-521-5030, ask for the pediatric nephrologist on call		

Save your questions about your child's medication or hemodialysis schedule for treatment days, when you can talk with the hemodialysis nurse.

Word list

Here are definitions of some words you might hear in the dialysis room.

Word	Definition
Hemodialysis	Hemodialysis is a treatment that removes waste and water from the blood when your kidneys can no longer do this.
Dry weight	This is the weight we would expect your child to be if he/she had no extra fluid on his/her body.
Ultrafiltration	The amount of fluid removed during a hemodialysis treatment.
Nephrology	The branch of medicine concerned with the study and treatment of diseases of the kidneys.
Hemodialysis Catheter	A special catheter or tube that is placed in the body to allow access to the patient's blood in order for dialysis to take place.

Questions and notes	

My child's medications

Medication Name	Reason for taking	Dose	Timing	What to watch for

