



# Home Dialysis

**SANFORD**<sup>®</sup>  
HEALTH



# Table of Contents

Welcome .....	5
Kidney Functions .....	6
Acute and Chronic Kidney Disease.....	8
Treatment Options .....	11
Peritoneal Dialysis .....	13
Caring for Your PD Catheter .....	16
Home Hemodialysis.....	17
Home Hemodialysis Access .....	18
What to Expect at Monthly Dialysis Appointments .....	25
In-Center Hemodialysis.....	28
Which Dialysis is Best for Me?.....	29
Feeling Your Best .....	30
Medical Conditions Related to Dialysis and Kidney Disease .....	31
Infection Prevention .....	36
Medications.....	37
Nutrition and Fluids .....	44
Lab Tests and Values .....	50
Travel.....	54
Emergency Planning .....	56
Tobacco Use .....	60
Renal Network Bill of Rights and Who to call .....	65

Helpful Websites .....	70
Words to Know .....	72
Sanford Dialysis Locations.....	77

# Welcome to Sanford Dialysis

Our mission is: To provide **excellent end stage renal disease (ESRD) care** while promoting quality of life and independence to those we serve.

The Sanford Dialysis Vision is: **Empowering** lives through compassion, education, and innovation.

**Your dialysis contact phone number is:** \_\_\_\_\_

No two people respond the same way to dialysis. Over the next few weeks, you will learn many new things. It can feel like too much at times. The dialysis team will help you and your family learn what you need to know. Learning about ESRD and your treatment will make it easier for you to be involved in your care.

This book will help you and your family learn about treatment for end-stage renal disease (ESRD).

- Use it as a guide.
- Share it with your family or support persons.
- Bring it with you for learning sessions with your dialysis team.
- Write down your questions
  - Do not hesitate to ask questions.
  - All questions are important.

Please keep this handbook. It does not replace talking with your dialysis doctor or nurse about your care. It will provide more detail about your options.

Your comments, ideas, and concerns about your care are welcome. You may also talk with the dialysis manager or director by calling Sanford Home Dialysis at the number listed above.

# Home Dialysis

Home Dialysis is a treatment option that allows patients to have more flexibility with their schedule. There can also be less restrictions on food, diet, and fluid if followed correctly. There are currently two options for home dialysis: Peritoneal Dialysis and Home Hemodialysis.

## Kidney Functions

The kidneys have many important jobs that affect your entire body and keep you healthy.

- Most people are born with 2 kidneys.
- The kidneys are:
  - In your mid-back, tucked up under your ribs on each side of your spine
  - Shaped like a kidney bean
  - Slightly larger than your fist

## What Do the Kidneys Do?

Your kidneys are very important to your health. They have 5 main jobs:

- Make urine
- Filter blood to take out wastes
- Balance chemicals such as sodium and potassium (electrolytes) in your blood
- Help control blood pressure
- Help to make red blood cells

## What Causes Kidney Disease?

Several things can lead to kidney disease. Most kidney disease is from damage to tiny blood vessels in the kidney.

- When this happens:
  - The kidney does not get enough blood flow
  - Waste stays in the blood
  - Fluids and wastes can build up in the body
- Sometimes controlling an underlying health problem can slow progression from kidney disease to kidney failure.
- Some patients have more than one health problem that leads to kidney disease.
- When the kidneys stop working, it is called kidney failure.

## Common Causes of Kidney Disease

**Diabetes** is the leading cause of kidney disease.

- The body may not make enough insulin or may not use insulin the way it should. This causes the blood sugar (glucose) to be too high.
- High blood sugar affects tiny blood vessels in the kidneys slowing the blood flow to your kidneys. When this happens, the kidneys are not able to remove fluids or wastes from the blood.

**High Blood Pressure (Hypertension)** is the second leading cause of kidney disease.

- It causes the arteries to harden and decreases blood flow. This can damage the small arteries in the kidneys. When this happens, the kidneys are not able to remove fluids and wastes from the blood.
- High blood pressure can lead to a heart attack or stroke.
- Often, high blood pressure has few symptoms until it is in the advanced stages.

**Infection** anywhere in the body may cause the body to make toxins.

- These toxins can build up.
- They may damage the small blood vessels in the kidneys.
- Some medications used to treat infections cannot be used if you have kidney disease.

**Hereditary diseases** are passed down in families. An example is Polycystic Kidney Disease (PKD)

**Autoimmune disease** causes the body's immune system to attack itself. Some examples are:

- Berger's disease also known as IgA nephropathy
- Glomerulonephritis
- Lupus

**Obstruction** is a blockage

- In the urinary tract, a blockage:
  - May be caused by a kidney stone, cyst, blood clot, tumor, enlarged prostate, or inherited disease
  - Can prevent normal passing of urine
  - Increases pressure in the urinary system and can damage the kidneys
- In the blood vessels, a blockage:
  - May be caused by a blood clot
  - Can decrease blood flow to the kidneys
  - Does not allow the kidneys to remove fluids or wastes from the blood

**Drugs and Toxins** can be poisonous to the kidneys.

- Poisons build up in the body.
- The kidneys stop working when levels are too high.

Those poisons can include:

- Medications
- Chemicals
- Pesticides
- Street drugs

## Acute and Chronic Kidney Disease

There are 2 types of kidney disease. They are very different but may have similar treatments.

### Acute Renal Failure (ARF) or Acute Kidney Injury (AKI)

Both ARF and AKI mean the kidneys suddenly stop working. This condition is watched very closely in the hospital. Some causes of acute kidney injury can be:

- A severe injury or accident
- Infection
- Surgery
- Blood clot
- Burn
- Medications such as antibiotics, contrast dyes, and cancer drugs

Hemodialysis in a dialysis center may be used to help the kidneys get better. It may be possible to reverse an acute kidney injury and the kidneys may start working again. But sometimes acute kidney injury does not improve and becomes chronic renal failure.

### Chronic Kidney Disease (CKD)

CKD is usually a slow, gradual kidney shutdown over months or years.

- This is the more common type of kidney failure.
- Medications and lifestyle changes may slow down CKD.
- The kidneys will stop working if kidney disease is not treated and controlled.
- People with chronic kidney disease may not have any symptoms early in the disease. As kidney function slows down, symptoms become more noticeable. Symptoms may include:
  - Swelling in the hands or feet
  - Feeling tired
  - High blood pressure
  - Trouble breathing



## Chronic Kidney Disease Will Never Go Away

- Treatment will help you feel better.
- Treatment will not cure the disease.
- Dialysis or kidney transplant is needed when the kidneys stop working.

## Stages of Chronic Kidney Disease

Your kidney doctor (nephrologist) will use blood and urine tests to measure your Glomerular Filtration Rate (GFR). The GFR is the best test to measure how well your kidneys are cleaning your blood. The lower your GFR, the less your kidneys are working. Chronic Kidney Disease is measured in stages determined by your GFR.

**Normal kidney function:** GFR is between 90 and 120

- No kidney damage
- No protein in your urine

**Stage 1:** GFR is more than 90

- May have kidney damage
- May have protein in urine
- Often no symptoms of kidney damage

**Stage 2:** GRF is 60 to 90

- Some kidney damage
- Often no symptoms of kidney damage

**Stage 3:** GFR is 30 to 59

- When most new CKD is diagnosed
- Time to see a nephrologist.
- Symptoms of CKD are felt:
  - Begin to feel tired
  - Some swelling in hands or feet
  - Higher blood pressure readings
  - Some shortness of breath

**Stage 4:** GFR is 15 to 29

- Kidneys are working less
- Most patients feel more tired because:
  - Toxins start to build up
  - Not making enough red blood cells
- This is the time to start planning for treatment.
- Patients and family members are encouraged to attend CKD classes and treatment option classes.
- An access may be placed if peritoneal dialysis or hemodialysis is chosen.
  - For peritoneal dialysis a small tube called a peritoneal catheter is placed into your abdomen.
  - Most often for hemodialysis, an AV fistula is created by sewing a piece of a vein in your arm or leg into a nearby artery.

**Stage 5:** GFR is less than 15.

- Kidneys are barely working
- Start treatment
- The patient has symptoms:
  - Very tired
  - Decreased appetite
  - Sick to your stomach, queasy
  - Swelling in hands or feet

## Treatment of Chronic Kidney Disease

Your nephrologist will work with you to develop a treatment plan. The plan depends on the stage of your kidney disease. The goal is to slow down or limit kidney damage that may prevent kidney failure.

- The treatment may include medications to control high blood pressure or high blood sugar.
- You may talk to a dietitian to help you make the best food choices:
  - Before dialysis starts, limit how much protein you eat. This will reduce the amount of work your kidneys must do.
  - After dialysis starts, you will need to eat more protein.
- Your body may still make urine even if you have chronic kidney disease.
  - As kidney disease gets worse, you will make less urine.
  - Over time, you will stop making urine.

Your body will need dialysis or a transplant when your kidneys stop removing fluids and wastes.

**Note:** Not treating kidney disease will cause toxins to build up to dangerous levels that can lead to death. You have the option of treating kidney disease or not.

# Treatment Options

## Treatment Options for Chronic Kidney Disease (CKD)

CKD is a permanent condition. Treatment will:

- Help you feel better
- **Not** cure the disease
- **Not** make the kidneys start working again

You and your nephrologist will decide on the treatment option that is best for you. It is based on your:

- Needs
- Interests
- Abilities
- Medical problems

It is quite common for patients to change treatments as their life changes. Patients have 5 choices for their dialysis treatment:

- Peritoneal Dialysis
- Home Hemodialysis
- Hemodialysis
- Kidney Transplant
- No Dialysis

### Peritoneal Dialysis (PD)

Peritoneal dialysis uses the lining of the abdominal cavity to clean your blood. The membrane acts like a filter to remove the fluids and wastes from your body. This lining is called the peritoneal membrane. It holds organs like your intestines, liver, and stomach in place. One advantage of peritoneal dialysis is that you can do it at home. It allows your schedule to be more flexible.

## Home Hemodialysis (HHD)

The word **hemo** means blood and the word **dialysis** means to filter. Hemodialysis cleans your blood through a filter. To do these treatments at home, you must meet strict requirements. You must be able to do this on your own or with help from a family member or friend.

## Hemodialysis

Hemodialysis treatments are most often done in a center 3 times a week. The length of time depends on your condition. Hemodialysis uses the same access and special filter as home hemodialysis.

- Treatment time can be affected by a change in the doctor's orders or lab values.
- Treatments may be delayed if you have a problem earlier in the day.

The first concern is safety. You may be on a waiting list for a different dialysis time. Most patients are able to change times for future treatments.

## Kidney Transplant

A healthy kidney (from someone else) is placed in your body during surgery. The new kidney works in place of the diseased kidney. A transplant does not cure kidney disease. It is another treatment option.

- Donated kidneys can come from a living person or from someone who has just died.
- The transplanted kidney must match your blood and tissue type.
- A relative is often the best donor. Someone who is not related to you may also be a good match.

Your nephrologist and transplant center staff will meet with you to decide if kidney transplant is a good treatment choice for you. A series of tests to make sure you are healthy enough for the surgery will be done. This process can take many months.

- If you do not have a blood relative to donate a kidney you will be placed on a waiting list.
- Some people wait many months to years for a kidney match.

After the transplant, 2 things are very important.

- You **must** take medications to suppress your immune system.
- These drugs keep your body from destroying the transplanted kidney.
- Without medications to suppress your immune system, your body will fight or reject the kidney causing the kidney to stop working.
- You will need to be active in your own cares. This means working with the transplant team to monitor progress and treatments.
- You must keep all follow-up doctor and lab appointments.

Be sure to ask your doctor or dialysis nurse if you want to know more about kidney transplant.

## No Dialysis Treatment

All patients have the right to make decisions about their care. Your decisions will be respected. You may choose:

- Not to start dialysis
- To stop dialysis at any time
- To start dialysis again if you change your mind

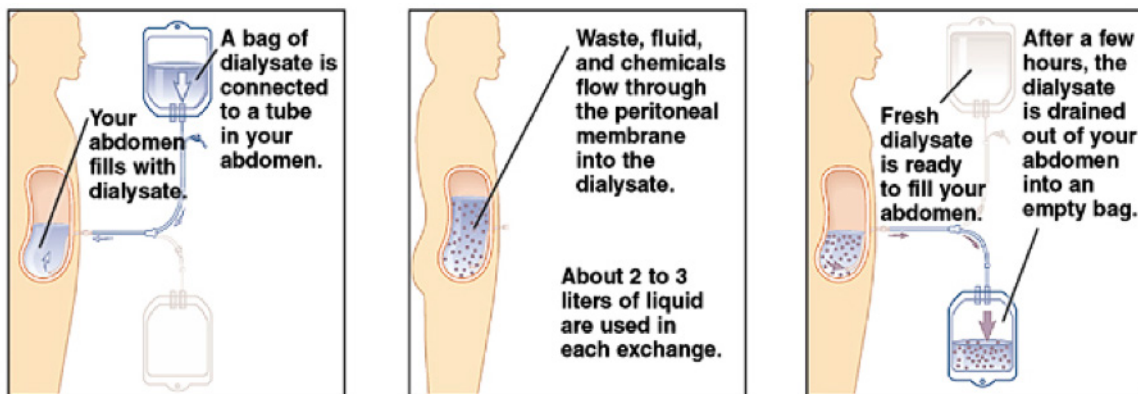
Before you stop dialysis, speak seriously with your family and doctor. Choosing no treatment or stopping dialysis will likely result in death within a few days to a few weeks.

If you choose not to have or continue dialysis treatment, ask your doctor or social worker to refer you to hospice or palliative care. Hospice will help you and your family with home care, comfort, as well as emotional and spiritual support.

## Peritoneal Dialysis (PD)

This treatment for kidney failure uses the body's own peritoneal membrane. This membrane:

- Lines the inside of the abdomen and holds your abdominal organs in place
- Creates a space that holds the dialysis fluid.
- Acts like a filter between the dialysate and your blood
- The dialysate removes the fluid and wastes from your blood through the membrane.
- Patients must have a special tube (catheter) in their abdomen to fill and drain the dialysate.



Copyright © 2020 The StayWell Company, LLC

## Peritoneal Dialysis Treatments

There are 2 ways to perform PD:

- Fluid exchanges can be done during the day (Continuous Ambulatory Peritoneal Dialysis)
- A PD Cycler can do the fluid exchange at night while you sleep. This allows you to get 8 to 10 hours of sleep each night.

### Continuous Ambulatory Peritoneal Dialysis (CAPD)

CAPD is done about 4 times every day at natural breaks in the day: morning, noon, evening, and bedtime. CAPD involves 3 steps:

1. **Drain** the old fluid from the abdomen:
  - Connect the catheter to tubing and a collection bag.
  - Drain the dialysate from the abdomen by gravity.
  - Takes about 20 minutes.
2. **Fill** the abdomen with new dialysate.
  - New dialysate goes into the abdominal cavity through the catheter.
  - This takes about 10 minutes.
  - Then disconnect the tubing from the catheter.
3. **Dwell**.
  - The dialysate sits in the abdominal cavity and absorbs fluid and wastes from the blood.
  - Drain the old dialysate and repeat the process.

### Continuous Cycling Peritoneal Dialysis (CCPD)

Some patients use a machine at night to do their PD. This allows you to continue most normal daytime activities. CCPD is done by a machine, usually at night. The machine drains, fills, and allows the fluid to dwell in your abdomen, while you sleep. Some patients may not need to have fluid in their abdomen during the day. Over time you may need to have fluid during the day or do CAPD during the day.



## Peritoneal Dialysis Access

You will need to have an access placed before training starts. The PD catheter is a soft plastic tube used to move dialysate in and out of your abdomen. The doctor places the catheter in an outpatient or day surgery department. It usually takes 2 to 3 weeks for the PD catheter to heal. During this time, your catheter will need to be flushed each week by a nurse at the dialysis home clinic to ensure your PD catheter is working the way it should. It is very important that your catheter stays covered, clean, and dry. Do not shower until your dialysis nurse tells you it is okay. Please call your home dialysis unit if your catheter dressing becomes loose, bloody, or soiled.



## What to Expect During Peritoneal Dialysis Training

You will be trained at your home dialysis unit Monday thru Friday. Training can take 1 to 2 weeks, 4 to 6 hours a day. You will meet with all members of your care team during training and be able to practice the steps needed to be successful on PD. Please bring your glucose meter and insulin to training. You will learn about:

- What the kidneys do
- How to safely do peritoneal dialysis
- Hand washing, keeping clean, and preventing infections
- Medication management
- Documenting on the flow sheet
- Fluid balance
- Diet – what you should and should not eat
- Ordering supplies
- Medical emergencies
- Traveling
- Communication
- Care of your PD catheter

During training you will receive information about a necklace or belt that can be used to hold the end of your PD catheter. These work well for keeping the end of your catheter contained when not in use.



PD Belt



PD Necklace

## End of Training

Training will continue until your PD nurse and you agree that you can safely do dialysis at home. You will be sent home with all the supplies needed to do PD (solutions, dressing supplies, hand sanitizer, masks, and other supplies). A PD nurse will come for a home visit at the end of your training.

## Caring for Your PD Catheter

It is very important to take care of your PD catheter to help prevent an infection. During training you will learn how to change your dressing. Change the catheter dressing as directed by your home dialysis nurse.

### Preventing Infection

Notify your PD clinic if you notice any of the following signs of an infection:

- Redness
- Drainage
- Pain
- Ability to gently press out drainage from around the catheter

Antibiotics can be used to treat these infections. It is very important to treat an infection immediately to help prevent it from becoming peritonitis (infection in the abdomen). The PD catheter may need to be removed if the infection does not respond well to antibiotics.

Peritonitis occurs when bacteria cause an infection of the peritoneal cavity. Signs that you may have peritonitis are:

- Cloudy fluid drains
- Abdominal pain
- Fever/chills

Most often, peritonitis happens after accidentally touching the dark blue end of the transfer set. This is called a “contamination”. It is **very** important to call your PD clinic and **not** use your dialysis catheter if you think you may have touched the dark blue end. Your clinic can help fix the catheter and prevent you from getting an infection. Peritonitis can be treated by adding antibiotics to the dialysis solution but it can also make you very sick. Sometimes people with peritonitis need to be in the hospital. The PD catheter may need to be removed if the infection does not go away.



## Dental Care and Procedures

Some procedures can increase your risk of getting a dialysis related infection. These infections can be prevented by taking an antibiotic before the procedure. Contact your PD clinic before the following procedures to see if antibiotics are needed:

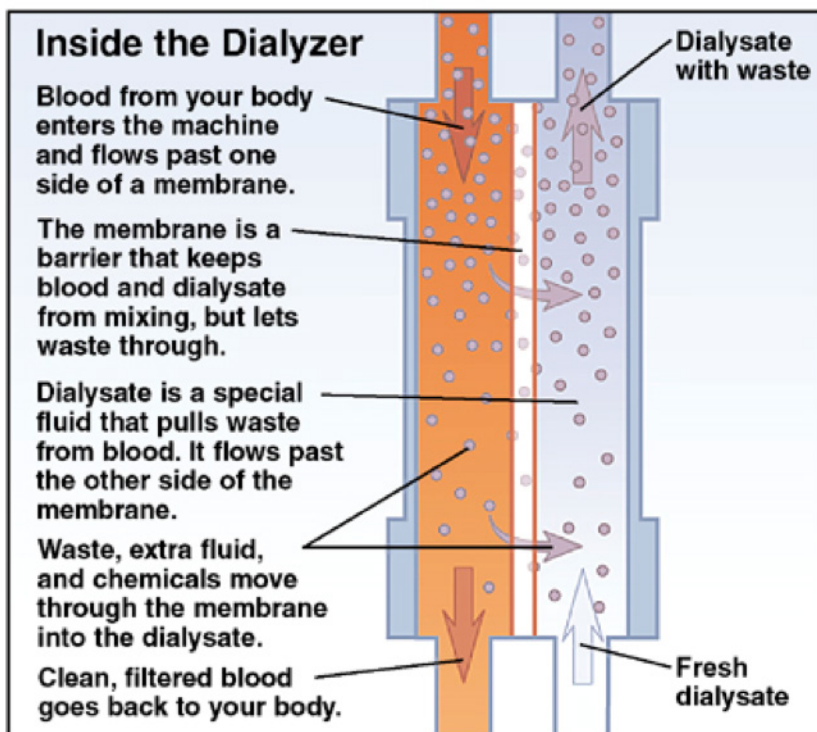
- Colonoscopy
- Endoscopy
- Dental cleaning or filling

**Tell your doctor or dialysis nurse if you have a dental appointment.**

## Home Hemodialysis

Hemodialysis is the process of removing fluids and wastes from the blood after the kidneys stop working.

- Blood is removed from your body and sent to the dialysis cyclor.
- Your blood then goes through a filter. It is cleaned and returned to you.
- This happens many times during the dialysis treatment.



Copyright © 2020 The StayWell Company, LLC

The blood is cleaned in an artificial kidney or special filter called a dialyzer. The dialyzer does 2 basic jobs that your kidneys no longer do. The dialyzer removes wastes and extra fluid from your blood. The fluid goes down the drain with the wastes.

## Monitors and Alarms

Monitors and alarms make sure your dialysis treatment is safe. In most cases, alarms are not dangerous. The home nurse will teach you how to correct them.

The monitors and alarms are checked before and during each treatment. An alarm may mean:

- There is a kink or blockage.
- The needle is out of the access.
- You moved your arm and the flow stopped.

## Air Detector

This monitor checks for air in the tubing as the blood goes back to you. The home nurse will teach you how to take the air out. If air is found:

- The machine will stop.
- You will remove the air.
- The alarm must be reset before the treatment can start again.

## Blood Pump

This pump controls how much blood goes through the bloodlines and dialyzer. The blood pump speed:

- Makes sure your blood goes through the dialyzer and is cleaned
- Is called the Blood Flow Rate (BFR)

## Home Hemodialysis Access

Dialysis access is needed to move your blood to the dialysis machine and return it to you. The Home nurse will teach you how to use and care for your access.

An access is generally placed surgically in your:

- Neck
- Chest
- Arm

There are 3 types of access for home hemodialysis:

- Fistula
- Graft
- Catheter

## Internal Home Hemodialysis Accesses

An internal access is required for home hemodialysis. Fistulas and Grafts are types of internal accesses. That means they are inside your body. The only time something is connected to the outside is during the treatment. A fistula is the first choice for long-term use.

**Your doctor may allow you to start home hemodialysis with an external access, but you will need to come back for further training when the internal access is healed.**

### Arterio-Venous Fistula

This fistula is made by surgically connecting an artery and a vein.

- A fistula is usually in the arm.
- It can be in the groin if the arm vessels will not work.
- It is ready to be used about 2 months after it is placed.

Fistulas are the best type of access for most people. Fistulas:

- Have fewer infections
- Have fewer problems with blood clots
- Allow more blood to be cleaned
- Can last for many years

### Fistula Exercises

Exercises make blood flow from the artery to the vein. Over time, this makes the vein wall grow bigger and stronger.

You will start exercising your arm with the fistula about one week after surgery. The home dialysis staff will show you how to do these exercises:

- Hold the squeeze ball in your hand with the new fistula.
- Press down with your other hand above the fistula. Make sure you are above, not on, the fistula.
- Open and close your hand to squeeze and hold the ball about 10 times.
- Do this 6 to 8 times each day.
- Sometimes a tourniquet is used to help the fistula get bigger. Be sure to use a tourniquet if you are told to do so.

### Arterio-Venous Graft

A graft is made by surgically joining an artery and vein with a special tube. The tube allows the nurses to access your blood for the dialysis treatment. A graft may be used when vessels are too small for a fistula.

- A graft is usually just under the skin in your arm.
- It can be used for hemodialysis a few weeks after it is placed.

## Caring for Your Fistula or Graft

You must learn how to take care of your access.

- Check your access every day for a pulse. This will watch for:
  - Blood flow problems
  - Signs of infection
- To feel for a pulse:
  - Put your fingers over the thumb side of your wrist.
  - Gently push down. You should feel a pulsing sensation.

**If you have a fistula**, you will need to feel for a thrill. To feel for a thrill:

- Put your fingers on the top of your access.
- You should feel a purr or vibration. This is called a thrill.

**If the pulse or thrill is not there,  
call your doctor or home hemodialysis department.**

Keep the area of your access clean to help lower the chance of infection.

- Wash your access arm with soap and warm water every day and before you start your treatment.
- Wear gloves when you hold your sites after the needles are taken out.
- Clean your hands before you leave your treatment area.
- Protect your dialysis access:
  - Be careful not to hit, bump, or cut your access arm.
  - Do **not** use a dressing that puts pressure on the access site.
  - Do **not** wrap anything tight around the access arm.
  - Do **not** wear tight clothing or jewelry around your access. That includes a watch or tight sleeves.
  - Do **not** sleep on your access arm.
  - Do **not** lift heavy objects with your fistula arm.
  - Do **not** let anyone use your access arm to:
    - Draw blood
    - Take blood pressures
    - Place an IV

Call your doctor or home dialysis department if:

- You do **not** feel a pulse or thrill in your fistula or graft.
- You have pain or numbness in your access arm.
- There is bleeding from your fistula or graft.
- Your access site:
  - Feels warmer or colder
  - Looks red
  - Is more swollen than normal

## Bleeding From Access

Your home nurse will teach you how to hold pressure on your vascular access to control bleeding. If you have bleeding from your vascular access:

- Immediately apply direct, firm pressure to the bleeding site.
- Cover the site with a dressing or clean cloth.
- If you can control the bleeding, apply pressure directly on the needle site for 15 to 30 minutes. Do not peek.
- If you cannot control the bleeding, immediately call 911 or your local Emergency Department.

**Tell your home dialysis staff about any bleeding.**

## External Access

A small flexible tube (catheter) is an external access. That means part of it is outside your skin. The catheter is often in a vein in the neck or chest.

- It may be used for a short time, like 1 to 2 months.
- A catheter may be used:
  - If someone needs to start dialysis right away
  - When an internal access is not ready to use
  - For longer periods when there are no other options for long-term access

There are 2 types of catheters: non-cuffed and tunneled cuffed.

- **Non-cuffed catheters** can be put in at the bedside, without going to surgery. They are used in for short periods of time and in emergencies.
- **Tunneled cuffed catheters** are placed in surgery or x-ray. They are used when access is needed for a short time.

## Preventing Access Infection

Infections are common in home hemodialysis patients. Stopping the spread of infection is very important.

- Infections are the second leading cause of death in dialysis patients.
- Infections can become very serious in a short time.
- The most common infections are due to a central venous catheter.

Cleaning your hands is the easiest and most important thing you can do to prevent infections. Use hand sanitizer or soap and water to clean your hands.

Other things you can do to help prevent infection are:

- Washing your access arm before dialysis
- Washing the dialysis machine and table in between treatments
- Wearing gloves and masks when advised
- Keeping your catheter dressing dry

Tell the dialysis staff if you injure yourself or have any signs of infection including:

- Pain
- Redness
- Drainage
- Swelling
- Fever
- Cough with thick sputum
- General weakness

## Caring for Your Catheter

Catheters are the leading cause of infection in dialysis patients.

How to care for your catheter:

- Your catheter must stay clean and dry to help prevent infection.
- You may take baths or tape a plastic wrap over the dressing area before taking a shower.
- Some catheters need a dressing or bandage.
- Do **not** get the dressing or tube site wet.
- Do **not** go swimming or use a hot tub.
- Do **not** take the dressing off if you have one. The hemodialysis staff will change the dressing.
- Do **not** remove the caps.
- Do **not** kink or bend the catheter.
- Make sure the catheter clamps are **always** closed.

## What to Expect During Home Hemodialysis Training

The home nurse will set up a time with you to talk about home dialysis and see if it is right for you. A home visit before training may be needed.

Once you are approved for home dialysis, the home nurse will plan a start date with you and those who are going to help you.

Training is done at the home dialysis unit Monday through Friday. Training can take 4 to 8 weeks, 4 to 6 hours a day.

You will learn:

- What the kidneys do
- Hand washing and keeping clean
- How to prevent infections
- How to manage your medications
- How to document on the flow sheet
- How to manage your diet
- How to collect lab samples
- About ordering supplies
- What do to for medical emergencies
- Tips for traveling
- Communication hints
- Fluid management
- How to do home hemodialysis safely
- How to care for your access

## Using the Bathroom During Training

Urinals and bedpans are available for use during dialysis. If needed, you may be able to use a bedside commode or bathroom for a bowel movement.

Remember:

- Do not use laxatives before coming to training.
- Eating a large meal before dialysis or eating during dialysis may cause your bowels to move.
- Low blood pressure may start the urge for your bowels to move.
- If you need to have a bowel movement during your dialysis treatment:
  - It is important to maintain your personal dignity and safety.
  - Staff must make sure your vital signs are stable before you get up.
  - Blood will be returned to you before you can before you get up. This takes time.
  - If your treatment time is interrupted, there may be more clotting in the dialyzer.

## Guidelines for Eating and Drinking During Home Hemodialysis Training

- **Limit** how much you drink to one cup (8 ounces) during each home hemodialysis treatment.
- You cannot eat or drink during home hemodialysis “on” and “off” times.
- Only small portions or finger foods are allowed.
- Food cannot be refrigerated or heated on the unit.
- Microwave popcorn is not allowed.
- Food cannot be delivered by a restaurant.
- If you often have low blood pressure, limit your intake of liquids and calories during your treatment.
- If you are diabetic and take insulin, bring a small snack.
- Eat a snack within 1 hour of coming in for dialysis training if you are not able to eat during your treatment.

Low blood sugars will be treated with 15 grams of carbohydrate, such as:

- Glucosegel
- Glucose tab
- Nutrition supplement

Dietitians are available to talk to you about your nutrition questions and needs.

## Comfort Measures During Training

During training you will sit in a recliner and have a dialysis treatment. The staff can help you get comfortable.

It is common to feel chilled or cold during dialysis. Your body temperature often cools down when blood is outside the body and exposed to the dialysis solution. Bring a blanket and pillow with you to use during your treatment. The dialysis unit does not supply magazines or books. You are welcome to bring reading material from home.

## Use of Cell Phones and Other Electronic Equipment During Training

Cell phones and other electronic equipment may be used during your dialysis treatment. **It is not allowed during your “on” or “off” times.**

Laptop computers, iPods, and personal DVD players may be used while you are in the home dialysis unit at the discretion of the home staff.



## Visitor Guidelines

Visitors are welcome during your training. We ask that visitors follow these rules:

- Wait in the lobby until patients are settled.
- Limit visitors to 1 or 2 at a time.
- Keep voices low to not disturb others.
- Shirts and shoes must be worn in the dialysis unit.
- Do not bring small children to visit during dialysis treatments if possible.
  - If a child visits, an adult other than the patient must be with the child at all times.
  - Children should not play, crawl, or lay on the floor.
- Visitors cannot eat or drink in the patient care area.

## What to Expect at Monthly Clinic Visits

Monthly visits are completed each month at your home unit and can last up to 2 hours. You will have time to talk with the nurse, physician, social worker, and dietitian.

### Telehealth

Telehealth (video visits) are another way for you to check in with your dialysis team. To have video visits, you must be stable and not receiving an iron product. Ask your home nurse for more information to see if this is right for you.

## Who You Will See at Monthly Dialysis Appointments

Many staff members will be involved with your care. The home staff is made up of:

### Registered Nurses (RN)

- Review your care and treatment plan
- Provide training, education and support
- Schedule monthly visits with the team and Nephrologist
- Answer questions for you and your family

### Patient Care Technicians

- Greet and settle you in your appointment room
- Schedule appointments
- Help you with dialysis supplies
- Help you reach the nurse

## Social Worker

- Help you with your living situation or financial needs
- Refer you to community agencies that help with home care, meals, and other needs
- Make referrals to financial resources
- Help you fill out Medicare forms and answer questions
- Help with transportation issues
- Help with travel plans, such as, if you need to have dialysis elsewhere for a period of time
- Provide counseling and support to help you:
  - Cope with stress
  - Handle concerns
  - Solve problems related to kidney failure and chronic disease

Chronic Kidney Disease (CKD) can cause major changes in your life. These changes may affect your daily routines. This can affect your:

- Emotions
- Friends and family
- Fun activities
- Financial status

Talks with the social worker are private. The social worker may share information with other members of the health care team if you agree.

You can reach the social worker by calling the dialysis department. You can also ask to talk to the social worker when you come to the clinic.

Feel free to talk to a social worker about:

- Anxiety or depression
- Family-related stress
- Changes in housing
- Information on employment or education programs
- Dialysis at another facility when traveling
- Community resources such as home health and meals-on-wheels.
- End-of-life issues such as information about or help with Advance Care Planning. This may include a Power of Attorney for Health Care or an Advance Directive.

## Renal Dietitian

- Review your nutritional needs
- Work closely with your doctor and dialysis team
- Follow your monthly lab results
- Teach you how to get the best nutrition to keep you healthy

## Nephrologist

- Responsible for your overall care
- Monitor your physical health and general well-being
- Directs your care based on your needs

## Dialysis Pharmacist

- Monitor your medications
- Monitor your labs
- May adjust the dose of medications used to treat and prevent complications of kidney disease

## Your Plan of Care and Care Conferences

Your dialysis service has a leadership team. Let the nursing staff know if you want to speak to someone in charge. Your health care team meets each month to review your care. They talk about any concerns that you or they may have. The dialysis team looks at your:

- Lab test results
- Diet
- Social needs
- Physical changes

## When to Call Your Doctor or Home Dialysis Staff:

If your catheter site shows signs of infection:

- Feels tender
- Looks red
- Has drainage
- If you have any questions or concerns

## Dental Care

There are many bacteria in the mouth. You may need antibiotics before routine dental work or cleaning.

**Tell your doctor or dialysis nurse about any dental appointments you have.**

# In-Center Hemodialysis

Hemodialysis in a center is usually done 2 to 4 times a week for 2 to 5 hours each time. During your treatment, you can watch TV, read, sleep, or whatever quiet activity will help you pass the time.

Most patients feel cold during their treatment. This is because some of the blood is outside your body. You may bring a blanket to keep you warm.

Sometimes people do not feel good during hemodialysis. The staff can help you feel better. It is important that you tell the staff right away if you have:

- Bleeding or drainage from the access site
- Redness or tenderness of the access site
- Chest pain
- Cramps
- Dizziness
- Edema (swelling)
- High or low blood pressure
- Muscle weakness
- Short of breath
- Nausea (feel sick to your stomach)



# Which Dialysis is Best for Me?

There are many things to consider when choosing which type of dialysis is your best option.

	Peritoneal Dialysis	Home Hemodialysis	In-Center Hemodialysis
Flexible Schedule	X	X	
Set Schedule			X
Completed At Home	X	X	
Must Travel to Center for Treatment			X
Able to enjoy more high potassium foods (potatoes, tomatoes, oranges, bananas)	X	X	
Potassium foods are restricted			X
Limited Fluid Intake			X
Less Restrictive Fluid Intake	X	X	
Portable therapy - can take when traveling	X	X	
Not portable - must find unit for dialysis			X
Can Shower	X	X (if arm access)	X (if arm access)
Requires training	X	X	
No needles	X		
Requires needles for treatment		X	X
Completed Every Day	X		
Space for Supplies	X	X	
Can be completed while sleeping	X	X (Must have partner)	
Completed 3 times a week			X
Completed 4 to 6 times a week		X	
Easier on the body	X	X	
May feel tired after treatment			X
Control your own care	X	X	
Patients report a higher quality of life	X	X	

## Concerns

If you have a complaint or concern about your care at dialysis, you can talk to a:

- Social worker
- Clinical manager or department director
- Sanford Health patient representative

You can also contact outside agencies for concerns about your care:

- Renal Network
- State Department of Health
- State Office of Ombudsman

Learn more and find other resources for help in the following pages.

## Feeling Your Best

### Activity

Exercise regularly for 30 minutes at least 3 times each week. This may include:

- Walking
- Treadmill use
- Cleaning
- Climbing stairs

Benefits will include lighter mood, improved appetite, weight and glucose control, and less chance of complications. Blood pressure and other factors may cause your activity to be restricted.

### Intimacy

Dialysis and kidney failure can affect sexual function and how you feel. You may want to experience the comfort of being close, or you might lack desire for intimacy.

Talking to your partner will help both of you to cope. Begin slowly and give yourself time. Try hugging, kissing, or touching at first. Speak to your doctor if you have problems with vaginal dryness or getting an erection. There may be products or medicines to help.

If you want to become pregnant or avoid a pregnancy, talk to your nephrologist.

# Medical Conditions Related to Dialysis and Kidney Disease

## Possible Medical Problems

Let your hemodialysis staff know how you are feeling. You could be at risk for medical problems because your kidneys do not work. Some of these may be life-threatening. Do **not** ignore signs that there may be a serious problem.

Be sure to tell the dialysis staff if you feel:

- Pain in your chest or arm
- Short of breath
- Dizzy or lightheaded
- Anxious or nervous

Some problems are due to your kidney disease; others may be complications of dialysis.

## Anemia

This happens when you do not have enough red blood cells. It is sometimes called low blood.

Hemoglobin

- A blood test to check for anemia
- Blood is also checked for iron levels
- Red blood cells carry oxygen to the body. When there are not enough red blood cells, you may:
  - Feel tired or weak
  - Feel short of breath
  - Have low blood pressure

Causes of anemia

- The most common cause of anemia is that diseased kidneys do not make enough erythropoietin. This hormone helps the body make red blood cells. Erythropoietin needs iron to work.
- Blood loss
- Not enough iron in the body

Treatment of anemia

- Medications called Aranesp or Epogen, a man-made form of erythropoietin, given during your dialysis treatment
- Iron supplements given during your dialysis treatment
- Blood transfusion to get more red blood cells

## Bone Disease

Healthy kidneys help keep bones strong. When the kidneys do not work well, bones become weak and brittle.

## Falls

You are at more risk of falling due to dialysis and kidney disease. Be aware some medicines may cause you to be unsteady. There are things you can do to make it less likely you will fall:

- Always rise slowly.
- Avoid throw rugs and hazards in your home that may lead to falls.
- Consider using devices to make you safer such as canes, walkers, or safety bars.
- Ask for help when you do not feel steady.

## Congestive Heart Failure (CHF), Heart Inflammation, Abnormal Heart Rhythms

Heart problems can be a result of kidney disease or other medical problems. The body can have too much fluid which causes added stress on the heart.

## Drinking Too Much Fluid

The extra fluid collects in your body tissues and blood vessels. This can cause swelling and fluid around the heart and lungs.

- Your heart has to work harder to move the fluid through your body.
- Your blood pressure goes up because your heart is working harder.

## Volume Overload

When the kidneys do not remove enough water, you have too much fluid for your heart to pump. This may lead to:

- Extra fluid in your tissues which is seen as swelling (edema) of your hands, ankles, feet or face.
- Extra fluid in your lungs which can cause shortness of breath or chest pain.
- Volume overload which can cause your blood pressure to go up.

Dialysis is the only treatment for volume overload. It is important to prevent volume overload and limit your fluid intake as you are instructed. Dialysis can remove some of the extra fluid but may not remove all of it.

The goal with dialysis is to get you to your dry weight. Dry weight is what you weigh when all the extra fluid is removed.

- Your doctor will decide your dry weight.
- Dry weight is used to figure out how much fluid needs to be removed at dialysis.



## Cramps

Muscle spasms or charley horse of the hands, arms, feet, legs, or stomach can occur. Cramping can occur at any time. Applying pressure or rubbing the affected area may help. Inform your home staff if cramping continues or gets worse.

## Low Blood Pressure (Hypotension)

Low blood pressure is less likely to occur at home on treatment but can still occur. It can be caused by:

- Removing too much fluid
- Not taking blood pressure medicines correctly

If your blood pressure is \_\_\_\_\_, you can do things that will help make your blood pressure more stable:

- Home hemodialysis – change the cyclers settings and give saline.
- Peritoneal dialysis – change to a lower percent dextrose. Drink water.
- Eat salty foods like chips, pretzels, or popcorn.

If your blood pressure does not come up or you do not feel good, end the treatment and call your nurse for further guidance.

Signs of low blood pressure are:

- Nausea and vomiting
- Sweating
- Sudden, warm feeling
- Yawning
- Feeling anxious or suddenly nervous
- Feeling dizzy, lightheaded or faint

If any of these happen, tell the home staff immediately. If symptoms are severe, call your doctor or go to your local Emergency Department.

## High Blood Pressure (Hypertension)

High blood pressure is a serious health concern for some dialysis patients. You may have no symptoms, feel not well, or have a headache.

High blood pressure can cause serious damage to your body such as:

- Heart failure
- Heart attack
- Stroke
- Aneurysm (a weakened area in a blood vessel wall)
- More damage to tiny blood vessels in the kidneys

Kidney failure can also cause high blood pressure. The effects of high blood pressure can last for the rest of your life.

## Hepatitis

Hepatitis is a serious liver infection spread by a virus through the blood. Dialysis patients have a high risk of getting a hepatitis virus due to risk of blood contact in the dialysis department.

There are several types of hepatitis. Two types are more common in dialysis patients, hepatitis B and C.

### Hepatitis B

This virus can cause liver damage or death. All patients are checked for Hepatitis B when starting dialysis and then once each year.

Hepatitis B vaccinations are highly recommended for dialysis patients.

- Vaccinations stop the spread of this virus
- A series of shots is given
- The shots will be given in the dialysis department

Signs and symptoms:

- In the early stages, there may not be any symptoms.
- In the late stage, signs and symptoms are:
  - Light, clay colored stools
  - Orange to yellow-colored skin
  - Whites of eyes look yellow
  - Dark, tea-colored urine
  - Pain in the liver area (right side of the abdomen)

### Hepatitis C

This virus is spread by contact with infected blood.

- Commonly spread by shared needles or illegal drugs
- A major cause of liver cirrhosis
- No vaccine at this time

## Itching (Pruritus)

Some patients have severe itching. This may be due to dry or irritated skin.

Skin irritation can be caused by:

- Decreased sweating
- A buildup of phosphorous and toxins in the skin or blood

Things that may help:

- Medications to help you feel more comfortable
- Phosphate binders to help lower phosphorous levels to normal
- Mild soaps or creamy lotions

## Neuropathy

Numbness or tingling in your hands or feet can be a side effect of kidney failure. This can be permanent due to nerve ending damage. Medications may give some relief.

## Restless Leg Syndrome (Jumpy Legs)

Restless Leg Syndrome is a dull, aching pain in your legs with no known cause. It can happen during rest, sleep, or hemodialysis. Talk to your doctor or dialysis staff if this happens to you.

### Treatment

- Moving your legs often
- Exercise like walking or biking
- Medications



# Infection Prevention

## Hand Washing – A Healthy Habit

**Washing your hands is the single most important way to help fight the spread of infections.**

Hands pick up germs when we touch other people or surfaces like door handles, faucets and animals. Washing hands with soap and water removes viruses and bacteria that we cannot see with the naked eye.

### When Should I Wash My Hands?

Wash your hands as often as you can, especially:

- After using the bathroom
- Before touching or preparing food
- After petting or touching animals
- After sneezing or coughing
- When your hands are visibly dirty

### How Should I Wash My Hands?

Washing your hands the right way will take away 99% of the germs. Follow these steps:

1. Wet your hands with clean, warm water.
2. Apply soap.
3. Rub your hands together for at least 20 seconds. (Be sure to rub all over your hands. Do not forget between your fingers, the back of your hands, your thumbs and under your fingernails.)
4. Rinse your hands with clean, warm water.
5. Use a clean cloth or paper towel to dry your hands.
6. If your hands are dry, use a lotion on your clean hands. (Use your own bottle of lotion. Throw away the bottle when empty. Do not refill small lotion bottles.)

### What About the Gels or Foams?

Alcohol-based hand gel or foam is a good choice if soap and water are not available.

- Alcohol-based hand cleaners are available at most stores.
- Be sure to use enough. Usually, a nickel to quarter sized amount is needed.
- Rub all over your hands until they are dry. This should take about 20 seconds.
- Use soap and water if you can see that your hands are dirty.

## Cover Your Cough

Many things like the common cold and flu spread through droplets in the air. Other more serious diseases like SARS and tuberculosis are spread the same way.

- Cover your nose and mouth with a tissue when you sneeze or cough.
- Covering your cough reduces the germs that go out into the air.
- Be sure to throw the tissue away in the wastebasket.
- Wash your hands or use an alcohol-based hand cleaner.

## What Else Can I Do to Stop Infections?

- Clean your hands often with soap and water or alcohol-based cleaners.
- Take a bath or shower every day.
- Learn the signs and symptoms of infection. Tell your doctor or dialysis nurse if you have:
  - Fever
  - Chills
  - Pain
  - Redness
  - Swelling
  - Drainage from a surgical wound or catheter site
- Keep your dialysis dressings clean and dry. If they become loose, know how to care for your site.
- Know when to call your doctor or home dialysis center.
- Remind doctors and nurses to wash their hands or use an alcohol-based hand cleaner.
- Keep your immunizations up to date, including Hepatitis B and Pneumovax.
- Have a flu shot **every** year.

## Medications

Many medications can be used for people with Chronic Kidney Disease. What is right for you may not be right for another person.

- Take your medications as instructed.
- Some medications must be closely monitored.
- Some medications will not work if they are not taken correctly.

Do **not** take any medications without talking to your nephrologist and/or dialysis pharmacist first. This includes medications and herbal supplements that you can buy without a prescription.

- Medications can build up to toxic levels in your body because your kidneys are not working.
- They may react with each other and cause serious problems.
- Kidney disease changes how your body uses and breaks down medications.
- Your nephrologist will order the right medications and dosage for you.

## Anticoagulants

These are sometimes called blood thinners. They can prevent blood from clotting.

- Tell your doctors and other providers if you are using one of these medications before you have any treatment or procedure.
- Sometimes these medications are given to treat other medical conditions.

## Heparin

**Home hemodialysis:** Heparin can be given before your treatment so your blood does not clot in the dialyzer. Heparin stays in your body 4 to 6 hours after dialysis.

**Peritoneal dialysis:** You may be instructed to inject heparin into the peritoneal dialysis solution to help prevent fibrin from clogging the peritoneal dialysis catheter. Fibrin is a buildup of protein and is not harmful.

## Things to Know If You Are Using an Anticoagulant:

A minor fall, cut, or other injury can cause serious bleeding.

Be careful using sharp objects so you do not cut yourself.

If you hurt yourself and you are bleeding, hold firm pressure over the bleeding area with a clean dressing or cloth.

**If you cannot stop the bleeding, call for help or go to the local emergency department. Do not drive yourself.**

## Call Your Doctor If You Have:

- Frequent bruising
- Bloody nose
- Bleeding longer than 30 minutes from your needle sites
- Blood in your urine
- Black, tarry stools
- Foul-smelling stools

## Anemia Medications

### Erythropoietin

Healthy kidneys make the hormone erythropoietin.

Dialysis patients receive a man-made form of erythropoietin. It helps your body make red blood cells to increase your hemoglobin level, and prevent anemia.

Erythropoietin can be given as a shot under the skin or into your vein through the dialysis machine.

Erythropoietin has different names depending on what company makes it:

- EPO
- Aranesp
- Darbepoetin
- Epogen
- Procrit

It is important to keep your hemoglobin at a safe level.

- The dose of erythropoietin is based on your hemoglobin level.
- Erythropoietin should not be given if your hemoglobin is more than 12.

Tell the doctor or dialysis nurse if you have:

- Chest pain
- Trouble breathing
- Coolness, paleness, or weakness in one arm or leg

### Iron

This helps your body make hemoglobin. If you do not have enough iron in your body, erythropoietin will not work.

- Blood tests check your iron levels.
- Hemodialysis patients may get iron supplements in the vein during dialysis treatments.
- Peritoneal or home hemodialysis patients may take iron pills.
- Home patients may need iron supplements given in the vein at the dialysis center.

Iron has different names depending on what company makes it. Iron may be called:

- Ferrlecit
- Venofer
- Niferex
- Nulecit
- Ferrous Gluconate
- Ferrous Sulfate

## Bone Medications

### Activated Vitamin D

This medication helps the body absorb calcium from food and keeps the bones from losing calcium. It is usually given in the vein during hemodialysis. Activated Vitamin D may be called:

- Calcitriol
- Calcijex
- Hectorol
- Zemplar
- Rocaltrol

Peritoneal dialysis or home hemodialysis patients may take a Vitamin D pill.

### Phosphate Binders

This medication attaches to phosphorus in food before it can be absorbed in the body. Phosphate leaves the body when you have a bowel movement (poop).

Phosphate binders need to be taken with **all** meals and snacks.

Too much phosphorous in your diet will increase your phosphorous level. A high phosphorous level lowers your calcium level. Low calcium can make your bones weak and more likely to break.

High phosphorus causes calcium to deposit in the kidney, heart, eyes, blood vessels, lungs, brain, joints, and skin. This is called calcification. Some phosphate binders are:

- Phoslo (calcium acetate)
- Fosrenol (lanthanum carbonate)
- Renvela (sevelamar carbonate)
- Velphro (sucroferric oxyhydroxide)
- Auryxia (ferric citrate)

## Vitamins

Check with your doctor before starting any vitamin or supplement. Your doctor may order a special multivitamin for people with kidney disease.





## Antibiotics

Antibiotics are medications that fight infections. They can be given in the vein, intraperitoneal, and or by pill.

Peritoneal dialysis patients may need to inject antibiotics into their dialysis solution if they get an infection called peritonitis. The home nurse will teach you how to do this.

Tell every doctor that you are a dialysis patient. Dialysis patients:

- Cannot take some antibiotics because their kidneys do not work
- May need a lower dose of an antibiotic

## Blood Pressure Medications

Many different kinds of pills are used to control blood pressure. Most people take more than one.

- Blood pressure pills can make your blood pressure go too low before, during, or after dialysis.
- Blood pressure pills are usually taken after dialysis.
- Ask your doctor when you should take them. Your doctor may want you to take your blood pressure pills before dialysis if your blood pressure is normally very high.

You may feel dizzy or lightheaded if your blood pressure is too low. Midodrine (Proamatine) may be given for low blood pressure during home dialysis treatments. This medication makes the blood vessels get narrow and smaller which:

- Makes the blood pressure go up
- Allows for better fluid removal during dialysis
- Is usually taken 30 minutes before home hemodialysis and again in the middle of the treatment

## Kayexalate

This medication is used to treat a high potassium level. High potassium can be life-threatening. Kayexalate removes potassium from the body when you have a bowel movement (poop).

Do not take Kayexalate:

- Unless your doctor or dialysis nurse tells you to
- At the same time as your take antacids or laxatives

## Anti-Diarrhea Medications

These medications are taken as needed for frequent loose stools. Examples are loperamide and Imodium-AD.

## Constipation

Constipation is common in dialysis patients due to diet and fluid limits. Stools may be hard, dry and hard to push out; or stools may not be complete or happen very often.

It is best not to become constipated while on peritoneal dialysis.

Constipation can affect the flow of the dialysate in and out of the peritoneal dialysis catheter.

Long term constipation can lead to an infection called peritonitis. Peritoneal dialysis patients should have a bowel movement every day. Some ways to help prevent constipation are:

- Eat regular meals.
- Increase your physical activity.
- Stool softeners make it easier for stool to move through the body.
- Laxatives make the bowels move.
- Common medications to help with constipation include:
  - Colace
  - Miralax
  - Lactulose
  - Senna

Things you need to know:

- Powder laxatives need to be mixed with liquids. This liquid must be included in your fluid limits.
- Many laxatives and stool softeners have aluminum or magnesium and should not be used. They can cause serious problems for people with kidney disease.

Do **not** take:

- Milk of Magnesia
- Gaviscon
- Maalox
- Magnesium Citrate
- Fleets or other enemas

**For the best options, check with your doctor, dietitian, or dialysis nurse before taking over-the-counter laxatives or stool softeners.**

## Over-the-Counter Medications

Check with your doctor before taking any medication you can buy without a prescription. Some over-the-counter medicines and herbal supplements are dangerous when you have kidney disease.

### Analgesics and Pain Relievers

These are used to treat pain, fever and inflammation.

- Do **not** take aspirin, ibuprofen (Advil or Motrin) or naproxen (Aleve) unless prescribed by your doctor. These can cause bleeding in the stomach and damage your kidneys.
- Use acetaminophen (Tylenol) for minor aches, pains or headaches. Ask your doctor how much to take.
- Narcotics are used for severe pain.
  - Use with caution
  - May cause breathing problems or seizures in high doses

### Cold Medicines

Over-the-counter cold medicines often contain decongestants. This will help to clear a stuffy nose.

- They can raise your blood pressure to very high levels. Ask your doctor or pharmacist which ones are best for you to take.

### Natural or Herbal Remedies and Nutritional Supplements

Many natural or herbal products and nutritional supplements are used to treat health problems. Some of these products:

- May be harmful to people with kidney disease
- Could interact with medications you are taking now
- Are not well studied in dialysis patients. It is not known if they are safe or they will hurt those with kidney disease.

Talk with your doctor, dialysis pharmacist, nurse, or dietitian before taking any natural or herbal products or nutritional supplements.

**If you have any questions or concerns about your medications, contact your doctor, dialysis pharmacist or dialysis staff.**

# Nutrition and Fluids

Nutrition is an important part of your dialysis treatment.

People with kidney disease have special dietary needs.

- What you eat will affect your health and how you feel.
- You will need to limit what you drink.
- A dietitian will:
  - Review your nutrition needs
  - Teach you about your new diet
  - Help you learn the best choices to eat and drink
  - Consider your own likes and dislikes when helping you make food and drink choices

**Remember:** Only you can control what you take in.

People who do home dialysis may be able to have more foods such as those containing potassium.

## What You Need to Do

Most dialysis patients need to:

- Eat more protein
- Eat less:
  - Potassium
  - Sodium (salt)
  - Phosphorus
- Drink less fluid
- Control your blood sugar if you have diabetes

## Why Do I Need Protein?

Your body and tissues (like bones, muscles, hair, and skin) need protein to heal and grow.

Protein helps the body:

- Fight infections
- Heal wounds
- Balance fluid

People who do not get enough protein:

- Have less energy
- Heal slower
- Have more infections
- Are in the hospital more
- Have a higher death rate

Some protein is lost during every dialysis treatment. It is important to replace what is lost by eating protein at every meal 3 times each day.

If you are interested in taking a nutritional supplement, talk with your dietitian first. Some supplements are dangerous for people on dialysis.

Good protein sources are:

- Beef
- Poultry
- Pork
- Fish
- Eggs

## Why Should I Limit Potassium?

Potassium is a mineral found in many foods. The body needs potassium to help muscles and nerves work. Because the kidneys do not work, potassium builds up in the blood.

- High potassium levels may cause weakness, tingling, or numbness.
- Dialysis will take some of the potassium out of your blood.
- Limiting potassium in the food you eat will help keep your potassium at a safe level between dialysis treatments.

Some high potassium foods are:

- Oranges and orange juice
- Bananas
- Tomato and tomato products
- Potatoes
- Milk
- Baked beans
- Prunes and prune juice
- Low sodium foods with added potassium

**For the best options, check with your doctor, dietitian, or dialysis nurse before taking over-the-counter laxatives or stool softeners.**

The dietitian will teach you about foods containing potassium. Together you will work these foods into your diet plan.

## Why Should I Limit Sodium (Salt)?

Sodium has an important role in fluid balance in your body.

Too much sodium may cause:

- Thirst
- Shortness of breath
- Swelling (edema) in your hands and feet
- High blood pressure
- Your heart to work harder (This could lead to heart failure.)

Salt is found in table salt, processed foods, and restaurant foods.

Tips to help limit your sodium intake:

- Take the salt shaker off the table.
- Check labels for sodium additives and amounts.
- Choose foods that have 200 milligrams of sodium per snack and less than 600 milligrams of sodium per meal.
- Avoid salty foods and snacks such as:
  - TV dinners
  - Chips
  - Pretzels
  - Luncheon meats
  - Bacon
  - Pickles
  - Canned soups
  - Canned vegetables
- Try using herbs and different spices for added flavor such as garlic or onion. Herb blends such as Mrs. Dash are safe to use.
- Do **not** use salt substitutes. Salt substitutes are high in potassium.



## Why Should I Limit Phosphorus?

Phosphorus is a mineral found in many foods. A high phosphorus level in your blood can cause serious problems.

Healthy kidneys remove phosphorus from the blood and help absorb calcium from food. Phosphorus and calcium depend on a balance to work

When kidneys do not work right, phosphorus builds up in the blood. This upsets the balance between phosphorus and calcium. When phosphorus levels are too high in your blood, calcium is pulled from your bones.

Two things can happen when calcium is pulled from your bones:

- Your bones get weak and are more likely to break.
- Calcium can travel through your body.

Extra calcium can build up where it does not belong like in your heart, arteries, and skin.

This is called calcification. Calcification can cause:

- Itchy skin
- Red eyes
- Painful joints
- Painful, open skin wounds called calciphylaxis

To control phosphorus, you need to:

- Limit foods that are high in phosphorus:
  - Milk
  - Cheese
  - Ice cream
  - Nuts
  - Peanut butter
  - Dark colored sodas
  - Chocolate
  - Processed foods
  - Luncheon meats
- Take a phosphate binder when you eat
- Come to your dialysis treatments

Your dietitian will discuss ways to help keep your phosphorus at a safe level.

## Diabetes Control

Diabetes is the most common cause of kidney disease. If you have diabetes, you need to:

- Check your blood sugar to prevent problems.
- Eat a small snack that includes carbohydrate and protein before dialysis.
- Have a doctor or diabetes educator manage your diabetes.
- A dietitian will help you manage your food needs.

## Fluid Balance

### Why Should I Limit My Fluids?

Healthy kidneys remove extra fluid from the body. In kidney failure, the kidneys do not remove extra fluid.

- The home dialysis nurse will teach you when and how to weigh yourself.
  - Peritoneal dialysis – this will help you decide which color dextrose to use.
  - Home hemodialysis – this will help you set your cyclor to remove the correct amount of fluid.

Your nephrologist will determine your dry weight. Dry weight is your weight without extra fluid.

The weight gained between dialysis treatments is called fluid weight gain.

### Why is This Important?

- The home dialysis staff uses your weight and dry weight to figure out how much fluid to remove for home hemodialysis.
- The goal is to get you back to your dry weight after dialysis.

As an example, when you come to dialysis, your weight is 73 kg.

- Your dry weight is 70 kg.
- You have 3 kg fluid weight gain between treatments.
- You will set the dialysis machine to remove 3 kg of fluid weight during your treatment.

When you have more fluid weight gain between dialysis treatments, more fluid must be removed. It is important to keep your fluid weight gain to less than 4% of your dry weight. Your nephrologist or dietitian can help you figure out how much fluid you should drink based on your dry weight.



## What Happens If I Have Too Much Fluid?

Too much fluid can harm your body. It may cause:

- Swelling (edema) in your eyes, face, hands, legs, feet, and/or abdomen
- High blood pressure
- Tiredness
- Shortness of breath because extra fluid shifts to your lungs
- Headaches
- Nausea
- Drop in your blood pressure
- Cramping

If you gain too much fluid, your treatment may be more difficult. The more you gain, the harder it is on your body to remove the extra fluid. It may take some time after your treatment before you will feel better and want to resume your normal activities.

## What Counts as Fluids?

- Any liquid you drink
- Anything that melts to a liquid at room temperature including:
  - Water
  - Coffee
  - Soda
  - Milk
  - Ice
  - Ice cream
  - Jello
  - Pudding
  - Soup

## How Much Fluid Can I Have?

Your fluid limit is 32 to 48 ounces (1 to 1.5 Liters) daily. Your dietitian or nephrologist will tell you how much you should drink each day. This will be based on the amount of urine you make.

- Measuring fluids will help you stay within your fluid limit.
- The dietitian and dialysis staff will give advice on how you can stay within your fluid limit.

# Lab Tests and Values

Blood tests help measure and evaluate how well your dialysis treatments are cleaning your blood.

**Normal ranges can vary by clinic.**

- Blood tests are generally done on a routine schedule before your hemodialysis treatment.
- The results can be used to make changes to your diet or medications. The dialysis staff and dietitian will review your lab test results with you.

## Potassium

Potassium is important for your heart and muscles to work the way they should:

- This mineral is found in many foods.
- Healthy kidneys can get rid of extra potassium.
- In kidney failure, potassium builds up in the blood. Dialysis patients usually have high levels of potassium.
- Dialysis treatments will help take potassium out of your blood.
- High or low potassium levels effect the way you feel.

Signs your potassium may be too high include:

- Upset stomach
- Cramps
- Diarrhea
- Tingling in your fingers and toes
- Poor muscle function such as wobbly legs

## Calcium

Calcium is a mineral found in many foods. It is common in dairy products. Healthy kidneys help your body absorb the calcium from the foods you eat. Calcium is important for:

- Teeth formation
- Bone growth
- Blood clotting
- Muscles

In kidney failure:

- Your body does not absorb calcium from the food you eat.
- The calcium level in your blood will be low.
- Calcium can be pulled from the bones.
- Bones will become weak and break easily.

Do **not** eat foods that are high in calcium because they are usually high in phosphorous, too.

Low calcium levels can cause:

- Muscle twitching
- Seizures
- Cramps
- Hair loss

High calcium levels can cause:

- Loss of appetite
- Bone pain
- Confusion

Your nephrologist can prescribe a calcium supplement to keep your calcium level in a normal range.

## Phosphorus

This mineral is found in many foods. It is needed for strong muscles and digesting food.

- Phosphorus and calcium work together to make bones and teeth hard.
- Phosphorous and calcium must be kept in balance with each other.

Most dialysis patients need to take a phosphate binder and limit the amount of phosphorous they eat. This prevents the phosphorous from getting too high.

High and low phosphorous levels can cause:

- Bone pain
- Bone weakness and breaking

Low phosphorous levels can cause:

- Tiredness
- Weakness
- Irregular heartbeat

**If your blood phosphorous level gets too high,  
it acts like a magnet and pulls calcium from your bones.  
That makes your bones weak and more likely to break.**

## Sodium

This is a mineral found in salt and many foods. Increased sodium in your diet makes you thirsty. You will want to drink more fluids.

Too much fluid and sodium can cause:

- Swelling
- High blood pressure
- Shortness of breath
- Fluid buildup in your lungs
- Your heart to work harder

Sodium is added as a preservative in many processed and packaged foods. The dietitian will help you learn how to avoid foods high in sodium or salt.

## Creatinine

Dialysis patients have higher creatinine levels that can vary from 10 to 20 mg/dL. People who are very active or have more muscles have a higher creatinine level.

Creatinine is a waste product formed from muscle breakdown and normal muscle function. It:

- Measures kidney function
- Goes up as kidney function goes down
- Checks how well your dialysis treatments remove wastes from your blood

## Blood Urea Nitrogen (BUN)

This is the amount of urea in your blood. Urea is a waste product made when the protein in food breaks down. Comparing the BUN levels before and after your treatment measures how well your dialysis treatment cleaned your blood. Too much urea in the blood can make you feel sick. You may have:

- Nausea
- Vomiting
- Bad taste in your mouth
- Tiredness
- Trouble sleeping

## Hemoglobin

The normal range of hemoglobin is different for men and women:

- 14 to 16 grams/100 mL for women
- 15 to 18 grams/100 mL for men

The goal for dialysis patients is 10 to 10.9 grams/100 mL.

Hemoglobin (Hgb) is found in red blood cells. Low hemoglobin is called anemia. Hemoglobin carries oxygen to all parts of the body. If you do not have enough red blood cells you may be:

- Tired
- Cold
- Pale
- Low on energy
- Short of breath
- Having chest pain

Dialysis patients generally have low hemoglobin for several reasons:

- People with kidney disease do not make as many red blood cells.
- Dialysis patients bleed more.
- Medications that slow blood clotting may cause bleeding during or after dialysis.
- The buildup of waste products in the blood harms red blood cells and they do not live as long.
- Some red blood cells break during every dialysis treatment because of the mechanical operation of the dialysis machine.

Most dialysis patients get an artificial form of erythropoietin to help their bone marrow make more red blood cells. Hemoglobin levels determine the dose of erythropoietin needed.

It is important that the hemoglobin levels do not get too high.

There is a high risk of a heart attack or stroke in dialysis patients who have a normal or high hemoglobin.

## Iron Studies

Iron studies are blood tests to check iron levels in your body. Iron is:

- A mineral found in food and vitamins
- Needed to make red blood cells
- Needed for erythropoietin therapy to work

If your iron studies are low, you do not have enough iron to make more red blood cells. You may need to take iron pills or get an iron infusion during your monthly clinic visit.

## Serum Iron

This test measures the amount of iron in your blood.

## Ferritin

This test tells how much iron is stored in your body. Ferritin is needed to make red blood cells. It is a protein that stores iron in the liver.

## Transferrin Saturation (TSAT)

This test measures a protein called transferrin. It shows how much iron is available to make red blood cells.

## Total Iron Binding Capacity (TIBC)

This test measures the total amount of transferrin that can hold more iron.

## Dialysis Adequacy

Each month blood tests are done to see if you are getting enough dialysis. This test is called Adequacy. The test confirms that your blood is cleaned well. It will let your doctor know if:

- You are getting enough dialysis
- The machine settings need to change
- You need more or less time on the machine

## Travel

It is very important that you discuss your travel plans with your travel coordinator; this may be a Social Worker or home dialysis nurse. You need to do this as soon as you begin planning a trip. If you choose to:

- Bring your cyclor and dialyze yourself
  - If you are gone more than 4 days, the supply vendor will send supplies to your destination.
  - If you are gone less than 4 days all the supplies are your responsibility to bring to your destination.
- Not bring your cyclor and to dialyze in an out-patient facility at an accepting dialysis unit, staff will try to help you make arrangements. There is no guarantee that this can be arranged.

Some outpatient facilities require 6 to 8 weeks' notice. There are many required steps to locate and plan care.

- You may need prior authorization from your insurance company.
- Facilities need copies of medical records.
- Some facilities require lab work within the last 30 days.
- Some facilities **may require payment** at the time of treatment.

## What You Need to Know

If you are gone for more than 30 days, you will be transferred to another home dialysis unit that is closer until you return and can be re-admitted.

## Your Role in Patient Safety

Safety starts with each one of us. You can:

- Learn about kidney disease.
- Tell the home staff about any changes such as:
  - New medications
  - Recent injuries
  - Falls
  - Hospital admissions
  - New phone number or address
- Keep copies of your medical information available and up to date.
- Complete your dialysis treatments as prescribed.
- Wear a medical alert bracelet or necklace.
- Know your diet and fluid limits.
- Know your medications.
- Wash your hands often.
- Wash your access site before dialysis.
- Keep your access visible at all times during dialysis.
- Be aware of possible bad weather and take precautions.
- Know what to do if you miss a dialysis treatment.
- Read the emergency information in this book.
- Have a stock of emergency food and supplies.
- Know your emergency diet.
- Use common sense.
- Attend care plan meetings with the dialysis team.
- Ask questions.

# Emergency Planning

An emergency can happen at any time. Sometimes, there is no warning. This can be a natural disaster such as a:

- Blizzard
- Tornado
- Flood
- Earthquake
- Fire
- Electrical power blackout

Some emergencies affect a community and some affect the dialysis center.

Emergencies can occur at any day, time, or place. Emergency plans must be in place. The goal is to be ready.

## Preparing for an Emergency

The most important thing is to plan for an emergency. Make sure you have enough supplies for weather or power outage emergencies.

- Make an emergency supply kit.
  - Keep your kit with you at all times.
  - Make sure the information and supplies are up to date.
  - Keep at least 7 days' worth of treatment supplies.
  - Put these things in plastic zipper bags inside a plastic container:
    - List of your allergies
    - List of all the medicines that you take
    - 5 to 7 day supply of your medicines (Replace this supply at least once each year.)
    - Name and phone number for your doctor and dialysis center
    - Copy of your insurance card
  - If you are diabetic, keep a 5 to 7 day supply of your medicines and supplies:
    - Insulin (Keep it cool but do not freeze it. It is best to keep it refrigerated but it will keep at room temperature for up to 1 month.)
    - Syringes
    - Your glucometer, lancets, alcohol wipes, test strips and spare batteries
    - Treatment for low blood sugar readings



- Make an evacuation plan.
  - Plan to leave your home if local authorities tell you to leave.
    - If you go to a shelter, tell the person in charge that you are on dialysis.
- Wear a medical alert necklace or bracelet.
  - Include your medical problems
  - Ask your social worker if you need help
- Know what diet to follow if you miss your dialysis treatment.
  - Keep a supply of canned foods and a can opener
- Other things to think about:
  - Battery-operated radio with new batteries
  - Flashlights with new batteries
  - Extra batteries
  - First aid kit
  - Fire extinguisher
  - Give the dialysis center another phone number for you and an emergency contact.

## Winter Weather

- If bad weather is forecast, make sure you have food, medication, and treatment supplies.
- Do not leave home if no travel is advised.
- If you travel, bring your medications and extra supplies with you.
- Take your cell phone, if you have one.
- Keep extra warm clothes and blankets in your car in case you get stranded.
- Know the emergency services in your area.

## Flood

- Stay out of low-lying areas where it is likely to flood.
- Move to higher ground.
- Do not drive through flooded areas or cross water that may be more than knee deep.
- Remember the water supply may be contaminated.

## Loss of Power or Water

Each dialysis center has a back-up plan in case of power failure or water contamination.

## Medical Emergency

Dialysis staff have current CPR training. All staff have training every year on the use of emergency medical equipment.

## Emergency Disconnect

You must know how to remove yourself from the home hemodialysis machine. This is called emergency disconnect. You would do this **only** if you are in **immediate** danger or if you need to leave your home. A fire or tornado is an example of this type of emergency.

Hopefully, you will never have to do this. But, it is important to be prepared just in case. The home staff will review this with you often. Again, the goal is to be prepared but never have to use emergency plans.

### Emergency Disconnect Procedure:

There are a total of 4 clamps on the tubing:

- Close the 2 clamps closest to your access.
- Close the 2 clamps on the tubing that goes to the dialysis machine.
- The machine will alarm when the clamps are closed. Ignore the alarm.
- Twist the connections apart between your access and the bloodlines.
- If all lines have been clamped, there should be no bleeding.
- Do **not** take the needles out of your arm.
- If you have a partner ask them to help you disconnect.
- If you are by yourself, follow the directions your home dialysis staff have reviewed with you.
- Remain calm.

### After an Emergency

- Make sure your surroundings are safe.
- Stay home unless you are hurt or authorities tell you to leave.
- Listen to the TV or radio for community information.
- Call your dialysis center and let them know what has happened.
- Follow your emergency diet.
- If you are in a shelter, let them know you are a dialysis patient.

### An Emergency at the Home Dialysis Center

The dialysis center has policies and procedures to be prepared for an emergency.

## Fire

- The dialysis center has regular fire drills.
- The fire alarms are tested periodically to make sure they are working.
- The local fire department is notified when the fire alarm goes off. They will arrive within a few minutes.

## Tornado

All of the dialysis centers receive emergency weather notices from local authorities.

- If severe weather is close, you will be told what to do.
- We cannot force you to stay at the dialysis center if you choose to leave.
- It is much safer in the building than in your vehicle.

## Missing a Home Hemodialysis Treatment

An emergency situation may cause you to miss your dialysis treatment. If this happens:

- Call your home dialysis center to notify your home staff as soon as possible. Do not wait to contact your home dialysis staff.
- Your diet is very important. You must:
  - Cut back on what you drink to half of your normal fluid limit or less than 2 cups.
  - Avoid salt and salty foods as these can make you thirsty.
  - Avoid high potassium foods such as:
    - Potatoes
    - Tomatoes
    - Oranges
    - Bananas
    - Dried fruit
  - Talk with your dietitian if you have questions about certain foods.

Patients who miss treatments or do not get their full treatment time have:

- More hospital admissions
- More infections
- More bleeding
- A poor appetite
- Feel more tired and weak
- A higher chance of death

# Tobacco Use

Studies show that most tobacco users really want to quit. Most people do not know **how** to quit. This section talks about:

Tobacco and how it affects:

- Kidney disease
- Diabetes
- High blood pressure
- Kidney transplants
- How to quit smoking

## Tobacco and Kidney Disease

Heart disease is the leading cause of death in kidney patients. Tobacco use can cause heart disease. Kidney failure and dialysis can also increase heart disease. The combination can be deadly.

Stopping the use of tobacco is one of the most important things you can do for your health.

All tobacco products have nicotine. Nicotine is very addictive. This makes quitting tobacco use one of the most difficult things to do.

What does nicotine from tobacco do to the body? It:

- Increases blood pressure and heart rate
- Decreases blood flow to the kidneys and other organs
- Damages the tiny blood vessels in the kidney and other organs
- Speeds up the loss of kidney function

## Smoking and Diabetes

- Diabetes is the leading cause of kidney disease.
- People who smoke and have diabetes have a very high risk for kidney disease.
- Both smoking and diabetes decrease blood flow to the kidneys. This means the blood does not get cleaned as well.

## Smoking and High Blood Pressure

High blood pressure is the second leading cause of kidney disease. If you have high blood pressure, smoking will cause your blood pressure to increase.

- High blood pressure damages the tiny blood vessels in the kidney.
- Smoking interferes with high blood pressure medications.
- Smoking increases the risk of heart attack and strokes in people with high blood pressure. The heart has to work harder to move blood through the body which can lead to heart failure.

## Smoking and Kidney Transplant

Patients who smoke after a kidney transplant have a higher risk of organ failure and heart problems. Some transplant centers will not accept patients who smoke.

### Benefits of Not Smoking

Even if you have smoked for years, you can improve your health if you stop smoking. When you stop using tobacco, it helps your:

- Heart
- Lungs
- Blood vessels
- Kidneys

When you stop smoking it lowers your risk of:

- Heart attack
- Stroke
- Cancer
- Lung diseases

### It is Not Easy

Many people have to try several times before they are able to stay tobacco free. Why is it so hard to quit?

- Nicotine creates a pleasure and reward system in the brain. Human beings really like this! That is part of addiction.
- Tobacco products have other chemicals commonly called tar.
  - Tar is bad for your body.
  - The combination of tar and nicotine makes smoking dangerous.

### How to Stop Using Tobacco

There are medications and products to help. A word of caution: Some of these **cannot** be used with kidney disease. Talk to your doctor before you use any product to help you stop smoking.

- Think about using nicotine replacements. They are available over-the-counter at many stores.
  - They do not have tar so they do not harm you like cigarettes.
  - You slowly stop using nicotine so you do not go through nicotine withdrawal feeling miserable.
- Check with your doctor about what may work for you. Your health insurance may pay for some products to help you stop smoking.

Attempts to quit tobacco do not always work on the first try. Motivation (desire) helps a lot. Try again if you are not successful.

## Who Can Help

Support is available through toll-free phone numbers and online websites all along your journey. For more information, contact the smoking quit line for your state. They will:

- Help you create your own plan to quit smoking
- Offer phone-based or web-based support
- Not judge or preach
- Have many other resources to help you quit

## For More Information

Smokefree.gov/talk-to-an-expert  
(800) QUITNOW / (800) 784-8669

National Cancer Institute Smoking Quitline:  
(877) 44U-QUIT / (877) 448-7848

### State Quitlines:

Iowa: [www.quitline.iowa.org](http://www.quitline.iowa.org)  
(800) QUIT NOW / (800) 784-8669

Minnesota: [www.quitplan.com](http://www.quitplan.com)  
(888) 354-PLAN / (888) 354-7526

Nebraska: [www.quitnow.ne.gov](http://www.quitnow.ne.gov)  
(800) QUIT NOW / (800) 784-8669

North Dakota: [www.ndhealth.gov/ndquits](http://www.ndhealth.gov/ndquits)  
(800) QUIT NOW / (800) 784-8669

South Dakota: [www.sdquitline.com](http://www.sdquitline.com)  
(866) SD-QUITS / (866) 737-8487



# Midwest Kidney Network (Renal Network 11)

The Midwest Kidney Network is a non-profit organization supporting people with kidney disease. This group serves the following states:

- Michigan
- Minnesota
- North Dakota
- South Dakota
- Wisconsin

## Admission

A patient at Sanford Dialysis must:

- Have a diagnosis of acute or chronic kidney disease
- Need dialysis treatments
- Be treated by a nephrologist
- Be age 16 or older
  - Patients under age 16 are considered on a case by case basis

The dialysis department must be able to meet your needs. You will sign consents for treatment and other forms as needed before dialysis begins.

## Discharge

You may be discharged from dialysis if you:

- Ask to move to another facility
- Receive a kidney transplant
- Do not follow the policies and procedures of Sanford Dialysis

A doctor may stop dialysis if:

- You regain kidney function
- Dialysis can no longer be done for medical reasons
- You and your family choose to stop dialysis
  - You and/or family must meet with the doctor to talk about your choice.

## Involuntary Discharge

When a patient is discharged against their will, it is called an **involuntary discharge**. This may happen if you:

- Affect the ability of the department to function
- Are disruptive or abusive toward other patients or staff

A good faith effort will be made to work with each patient. The dialysis center staff will record in the medical record:

- Assessments
- Ongoing problems
- Efforts to resolve the problems

In most cases, the dialysis center will give the patient a written, 30-day advance notice of discharge. If there is an urgent threat to the health or safety of others, little or no notice may be given. The patient will be given choices for treatment by other doctors and dialysis departments.

## Transfer

You may change to a different facility for any reason.

- Sanford will give your medical records to the accepting facility.
- You will be discharged from Sanford.





# Renal Network 11 Bill of Rights

## **Patients have a right to:**

Respect, dignity, and recognition of their individuality and personal needs, and sensitivity to his or her psychological needs and ability to cope with ESRD.

Receive all information in a way that they can understand.

Privacy and confidentiality in all aspects of treatment and in personal medical records, including the right to view and receive a copy of their medical record (a nominal charge may be assessed).

Be informed about and participate, if desired, in all aspects of their care, and be informed of the right to refuse treatment, to discontinue treatment, and to refuse to participate in experimental research.

Be informed about their right to execute advance directives, and the facility's policy regarding advance directives.

Be informed about all treatment modalities and settings, including, but not limited to transplantation, home dialysis modalities (both peritoneal and hemodialysis), and in-facility hemodialysis.

The patient has the right to receive resource information for dialysis modalities not offered by the facility, including information about alternative scheduling options for working patients.

Be informed of facility policies regarding patient care, including, but not limited to, isolation of patients.

Be informed of facility policies regarding the reuse of dialysis supplies, including hemodialyzers.

Be informed by the physician, nurse practitioner, or physician's assistant treating the patient for ESRD of their own medical status as documented in the medical record, unless the medical record contains a documented contraindication.

Be informed of services available in the facility and charges for services not covered by Medicare.

Receive the necessary services outlined in the Patient Plan of Care.

Be informed of the rules and expectations of the facility regarding patient conduct and responsibilities.

Be informed of the facility's internal grievance process.

Be informed of external grievance mechanisms and processes, including how to contact the ESRD Network and the State Survey Agency.

Be informed of their right to file internal grievances or external grievances or both without reprisal or denial of services; and be informed that they may file internal or external grievances, personally, anonymously, or through a representative of the patient's own choosing.

Be informed of the facility's policies for transfer, routine or involuntary discharge, and discontinuation of services to patients.

The right to equal consideration of treatment without regard to age, sex, race, religion, or ethnic origin.

Receive written 30-day notice in advance of an involuntary discharge after the facility follows the specific involuntary discharge procedure in the Conditions for Coverage, except in the case of immediate threats to the health and safety of others, when an abbreviated discharge procedure may be followed.

## Patient Responsibilities

In order to make your treatment effective and improve the quality of your life, you and your family should take some specific responsibilities in the day-to-day management of your care. To improve your care:

- Learn all you can about your disease, its treatment, treatment options, and your rights and responsibilities as a renal patient.
- Recognize what an emergency is and what actions must be taken in emergency situations.
- Provide a complete and accurate medical history to the professional team supervising your care.
- Let a member of your professional team know if you do not understand information about your care and treatment.
- Tell a member of your professional care team if there is a sudden change in your condition.
- Obtain and take the medications prescribed for you or discuss with the professional care team why you are unable to do so.

Follow your diet or request further instructions if you do not understand or are unable to follow your diet.

Make every effort to arrive for your scheduled dialysis treatments on time and inform the dialysis unit if you are unable to come.

Stay on dialysis for the prescribed length of your treatment run.

Consider the needs of other patients whom you encounter and understand that the professional team has a responsibility for all of the patients under their care.

Tell a member of your professional care team if you are diagnosed with a communicable disease.

Inform a member of your professional care team if you need to miss regularly scheduled dialysis treatment(s) for vacation or any other reason.

Adapted from the Conditions for Coverage for End Stage Renal Disease Facilities, Centers for Medicare and Medicaid Services

Final Rule published April 15, 2008, Effective date October 14, 2008 Approved,

Network 11 Consumer Committee 01/15/2009 Approved, Network 11 Executive Committee

## If You Have a Concern or Complaint

You have the right to voice concerns or complaints. These are taken very seriously.

## What You Should Do:

Write out your concern.

- Be very specific about dates, events, and persons involved.
- Include all facts about the concern.
- Include what has been done to resolve the issue.
- Make copies of all written information.
- Ask to talk with the Social Worker, Dialysis Clinical Manager, or the Dialysis Director.
- A staff member will meet with you to talk about the issue.
- You may have a family member or another person come with you.
- Bring copies of the written report.
- The goal is to make a plan of action and reach a solution.
- You can talk to the patient representative.

If you want to bypass this process or you cannot solve the issue, you may call other agencies to help you:

Renal Network of the Upper Midwest 1360  
Energy Park Drive, Suite 200  
St. Paul, MN 55108  
(651) 644-9877 / (800) 973-3773

If you live in **Minnesota**:

- Minnesota Department of Health  
651-201-5000  
888-345-0823
- Office of Ombudsman for Older Minnesotans  
(800) 657-3591
- If you are on Medicare:  
Stratus Health  
2901 Metro Drive Suite 400  
Bloomington, MN 52425  
(952) 854-3306

If you live in **North Dakota:**

- North Dakota Department of Health  
600 East Boulevard Avenue  
Bismarck, ND 58505-0200  
(701) 328-2352
- Office of Ombudsman for Older North Dakotans  
(800) 451-8693
- If you are on Medicare: ND Health Care Review  
800 31st Avenue SW  
Minot, ND 58701  
(701) 852-4231

If you live in **South Dakota:**

- South Dakota Department of Health  
600 East Capital Avenue  
Pierre, SD 57501-2536  
(605) 773-3361 / (800) 738-3361
- Office of Ombudsman for Older South Dakotans  
(605) 773-3656
- If you are on Medicare:  
South Dakota Foundation for Medicare  
2600 West 49th Street, Suite 300  
Sioux Falls, SD 57105  
(705) 336-3505 / (800) 658-2285

## **Heartland Kidney Network (Renal Network 12)**

Heartland Kidney Network is a non-profit corporation under contract with the Centers for Medicare and Medicaid Services (CMS) to oversee the End Stage Renal Disease Program in Kansas, Missouri, Nebraska, and Iowa. **A poster will be present in these locations.** There are 17 other Networks with the same purpose across the United States.

# Who Do I Call If I Have Questions?

There are many resources to call if you have questions about your care. The place to start is your home dialysis department.

## What If I Have Questions About My Bill?

Call (800) 437-4010 and ask for the Patient Accounts Office.

They will be able to answer questions about billing. If this is about a dialysis bill, ask to talk with the person who does dialysis billing.

## Public Notice This Notice is Required by the Joint Commission

The Joint Commission may conduct an unannounced accreditation survey of this organization, Sanford Health, at any time. The purpose of the survey will be to evaluate Sanford's continuous compliance with nationally established Joint Commission standards. The survey results will be used to determine whether, and the conditions under which, accreditation should be awarded to Sanford Health and its organizational entities.

The Joint Commission standards deal with organizational quality of care issues and the safety of the environment in which care is provided. If an individual has any concerns about patient care and safety at Sanford Health that have not been addressed, he or she is encouraged to contact the

### **Sanford patient representative:**

- Bemidji area: (218) 333-6459
- Bismarck area: (701) 323-1050
- Fargo area: (701) 234-5876
- Sioux Falls area: (605) 333-6546

If concerns cannot be resolved through the patient representative, you are encouraged to contact the Joint Commission:

Office of Quality Monitoring The Joint Commission  
One Renaissance Boulevard  
Oakbrook Terrace, IL 60181  
E-mail: [patientsafetyreport@jointcommission.org](mailto:patientsafetyreport@jointcommission.org)  
Phone: (800) 994-6610  
Fax: (630) 792-5005

# Helpful Websites

Many websites have dialysis information. Here are some websites that may be helpful to you.

These resources are for your own use and do not replace medical care. Be sure to ask your care team any questions you have.

## Sanford Health

[www.sanfordhealth.org](http://www.sanfordhealth.org)

Click on the **Patients & Visitors** tab at the top of the page. Click on **Search the Health Library**. You can search for many topics using the search box. Or just click on the letter **D** (for dialysis) or the letter **K** (for kidney). Scroll down to the topics you want.

## My Sanford Chart

[www.sanfordhealth.org](http://www.sanfordhealth.org)

## Kidney School

[www.kidneyschool.org](http://www.kidneyschool.org)

Kidney School is a great website for patients, families, and professionals. There are short learning modules that can be read online or downloaded and printed. The modules are available in an audio format, too. The site is easy to use and the information is easy to understand. Some information is available in Spanish.

## National Kidney Foundation (NKF)

[www.kidney.org/](http://www.kidney.org/)

The NKF is a national organization. They work to prevent kidney disease and improve the health of people with kidney disease. There are many patient education resources available and easy to find. Start at the **Kidney Disease** or **Patients** tab at the top of the page. Look at the Kidney Kitchen tab to find good recipes. NKF has a lot of professional information including regulations and standards. Some information is available in Spanish.

## Life Options

[www.lifeoptions.org/](http://www.lifeoptions.org/)

Life Options is a program that helps people live a long time with kidney disease. There are many patient education resources available. Free material includes audio and video presentations. Many things can be downloaded and printed. It has a glossary that is easy to understand.

## Fistula First

<https://esrdncc.org/en/fistula-first-catheter-last/>

Fistula First works to increase the use of fistulas and improve the care of dialysis patients. There is a lot of free patient information that is easy to download and print. There are also links to other resources and professional information.

## **National Kidney Disease Education Program**

[www.nkdep.nih.gov](http://www.nkdep.nih.gov)

This site is part of the United States Department of Health and Human Services. It has many education resources and information on living with kidney disease. Free brochures can be ordered or downloaded. Information is also available in Spanish.

## **Dialysis Facility Compare**

<http://www.medicare.gov/Dialysis/Include/DataSection/Questions/SearchCriteria.asp?version=default&browsers=IE%7C7%7CWinXP&language=English&defaultstatus=0&pagelist=Home>

This site lets you compare dialysis centers. It is based on quality indicators reported to Medicare. It tells what services each unit offers. There is also patient information on kidney disease.

## **Dialysis Finder**

[www.dialysisfinder.com](http://www.dialysisfinder.com)

Use this website to find dialysis centers anywhere in the United States. This site would be useful if you are planning to travel.

## **Kidney Community Emergency Response Coalition (KCER)**

<http://www.kcercoalition.com/>

This site is dedicated to emergency planning. It has resources on how to prepare for and respond to an emergency. Information is easy to read and download. This is a good site for everyone to look at. It includes phone numbers for national kidney agencies.

## **Renal Network 11**

<http://www.esrdnet11.org/>

Renal Network 11 is one of 18 federal networks that monitor dialysis quality and transplants. It has many facts for dialysis centers within the network. Renal Network 11 will also help with patient complaints and concerns.

## **Renal Network 12 Heartland Kidney Network**

<http://heartlandkidney.org/>

Heartland Kidney Network is a non-profit corporation under contract with the Centers for Medicare and Medicaid Services (CMS) to oversee the End Stage Renal Disease Program in Kansas, Missouri, Nebraska, and Iowa. There are 17 other Networks with the same purpose across the United States.

## Words to Know

<b>Access</b>	See vascular access.
<b>Acute Kidney Injury (AKI) or Acute Renal Failure (ARF)</b>	Both terms mean a sudden loss of kidney function. This may be caused by an injury, surgery, medication or other reasons. Sometimes kidney function will come back after treatment. Sometimes it does not.
<b>Anemia</b>	A condition where the body does not have enough red blood cells to carry oxygen. Sometimes it is called low blood. Patients with kidney disease often have anemia because they do not make erythropoietin.
<b>Aneurysm</b>	A weakened area in a blood vessel that stretches.
<b>Antibiotics</b>	Medications that kill bacteria and fight infection.
<b>Anticoagulant</b>	Medications that prevent the blood from clotting in the dialyzer. They are sometimes called blood thinners.
<b>Arterio-Venous Graft (AVG)</b>	See graft.
<b>Arterio-Venous Fistula (AVF)</b>	See fistula.
<b>Artery / Arteries</b>	A blood vessel that carries blood from the heart to the body.
<b>Artificial Kidney</b>	See dialyzer.
<b>Binders</b>	See phosphate binders.
<b>Blood Flow Rate (BFR)</b>	How fast the blood goes through the dialyzer per minute.
<b>Blood Pump</b>	Part of the dialysis machine that moves the blood through the dialyzer and back to you.
<b>Blood Urea Nitrogen (BUN)</b>	A blood test that tells how much urea is in the blood. This measures how well the kidney is working. See urea.
<b>Bruit</b>	A swish sound heard when listening with a stethoscope over a fistula or graft.
<b>Calcification</b>	Calcium deposited in the skin and blood vessels due to too much phosphorous in the blood stream.



<b>Calciophylaxis</b>	Painful open skin wounds caused by high phosphorous levels in the blood.
<b>Calcium</b>	A mineral found in many foods. People with kidney disease cannot absorb calcium from the food they eat. As a result, the body may take calcium from the bones making them weak.
<b>Catheter</b>	A small tube outside the skin used for short-term vascular access. It is usually placed in the neck or chest.
<b>Chronic Kidney Disease (CKD)</b>	A slow, progressive, permanent loss of kidney function over months or years. It is also called chronic renal failure.
<b>Creatinine</b>	A waste product the body makes from muscle breakdown. It is a measure of tell how well the kidneys are working.
<b>Diabetes Mellitus</b>	A disease that causes high blood sugar levels. High blood sugar levels damage the tiny blood vessels in the kidney.
<b>Dialysate</b>	A special solution used in the dialysis machine to take out the wastes and extra fluid in the blood. It is sometimes called the bath.
<b>Dialysis</b>	A process to take wastes or fluids out of the blood through a filter. See also hemodialysis and peritoneal dialysis.
<b>Dialyzer</b>	A special filter used to take wastes and extra fluids from the blood. This is also called an artificial kidney.
<b>Dietitian</b>	A member of the dialysis team who is an expert in nutrition.
<b>Dry Weight or Ideal Dry Weight</b>	Body weight without extra fluid.
<b>Edema</b>	Swelling of the body caused by too much fluid.
<b>Erythropoietin</b>	A hormone healthy kidneys make that tells the body to make red blood cells. Not enough red blood cells causes anemia.
<b>End Stage Renal Disease (ESRD)</b>	Damage to the kidneys that does not go away.
<b>Exit Site</b>	The place where a catheter leaves the body.
<b>Fistula</b>	A type of vascular access made by surgically joining an artery to a vein. This is also called Arterio-Venous Fistula (AVF).

<b>Fluid Overload</b>	Too much fluid in the body. It causes shortness of breath, swelling, and high blood pressure.
<b>Glomerular Filtration Rate (GFR)</b>	A test that measures kidney function.
<b>Graft</b>	A type of vascular access made by surgically joining an artery and vein with a special tube. This is also called Arterio-Venous Graft (AVG).
<b>Healthcare Directive</b>	A legal, written document. It may include a Living Will and/or Power of Attorney for Healthcare. A Living Will tells a patient's doctor and family their wishes for healthcare if the patient is not able to do so. A Power of Attorney for Healthcare names a person to make healthcare decisions if the patient is not able to do so. A copy is kept with the patient's medical record. It can be changed at any time. It may also be called an Advance Directive.
<b>Hemodialysis</b>	The use of a machine and dialyzer to take wastes and extra fluid out of the blood.
<b>Hemoglobin</b>	Part of the red blood cell that carries oxygen in the body.
<b>Heparin</b>	A medication used during hemodialysis to prevent blood from clotting. See anticoagulant.
<b>Hepatitis</b>	A liver infection spread by a virus in the blood.
<b>Home Hemodialysis</b>	The patient and a helper do hemodialysis treatments in their home 5 to 6 times each week.
<b>Hypertension</b>	High blood pressure.
<b>Hypotension</b>	Low blood pressure.
<b>Immunosuppressant</b>	A medication used after a kidney transplant to prevent the body from rejecting the new kidney.
<b>Insulin</b>	A medication used to treat diabetes and lower blood sugar.
<b>Kidney</b>	A bean shaped organ that takes wastes and extra fluid out of the body.
<b>Kidney Transplant</b>	Surgical placement of a donor kidney into a person with kidney disease.

<b>Living Will</b>	See Healthcare Directive.
<b>Nephrology</b>	The study of diseases of the kidney.
<b>Nephrologist</b>	A doctor who specializes in kidney disease.
<b>Nurse Practitioner (NP)</b>	A registered nurse with advanced education and clinical training who works with the dialysis team to provide your care.
<b>Obstruction</b>	A blockage.
<b>Peritoneal Dialysis</b>	Uses the peritoneal membrane in the abdomen to remove wastes and extra fluid from the body.
<b>Peritoneal Membrane</b>	The inside lining of the abdomen.
<b>Pharmacist</b>	A member of the dialysis team who specializes in medications.
<b>Phosphate Binder</b>	A medication taken with food that helps the body get rid of the phosphorous in foods. They are also called binders.
<b>Phosphorous</b>	A mineral found in many foods. Too much phosphorous can make bones weak.
<b>Physician Assistant (PA)</b>	A member of the dialysis team with advanced medical training who works directly with the doctors to provide your care.
<b>Potassium</b>	A mineral found in many foods important for nerves and muscles. Too much potassium can make your heart stop.
<b>Renal</b>	Related to the kidney.
<b>Restless Leg Syndrome</b>	A dull, achy, or jumpy feeling in the legs that can happen during dialysis or at rest.
<b>Semi-Permeable Membrane</b>	A special filter that lets only certain things through it. The dialyzer uses this to filter wastes and extra fluids out of the blood.
<b>Social Worker</b>	A member of the dialysis team who provides support related to treatment and lifestyle changes due to kidney disease. They also offer resources or referrals for community services.

<b>Sodium</b>	A mineral in many foods important for fluid balance in the body. Too much sodium makes the body hold on to fluid. This can increase blood pressure and make dialysis harder.
<b>Target Weight Loss</b>	The goal amount of fluid to remove during dialysis. It is found by subtracting your dry weight from your weight at the start of dialysis.
<b>Thrill</b>	A vibration felt when lightly pressing down over a fistula or graft.
<b>Toxins</b>	Another term for waste products that build up in the body.
<b>Transmembrane Pressure</b>	The difference in pressure inside the dialyzer that causes the movement of wastes and extra fluids from the blood to the dialysate.
<b>Transplant</b>	Movement from one location to another.
<b>Urea</b>	A waste product the body makes from muscle breakdown and digestion of food. It is measured by the BUN.
<b>Vascular Access</b>	A way to move blood from the body to the dialyzer and then return it to the body. There are 3 types: fistula, graft, and catheter. This is also called access.
<b>Vein</b>	A blood vessel that carries blood from the body to the heart.
<b>Volume overload</b>	See fluid overload.

## Sanford Dialysis Locations

### **Bismarck, ND**

209 N 7th Street  
Bismarck, ND 58501  
Hemodialysis and Home Dialysis  
(701) 323-2800

### **Fort Yates, ND**

10 N River Road, Box J  
Fort Yates, ND 58538  
Hemodialysis (701) 854-7553

### **Jamestown, ND**

300 Second Avenue NE  
Jamestown, ND 58401  
Hemodialysis and Home Dialysis  
(701) 952-4872

### **Sioux Falls, SD**

1305 W 18th Street  
Sioux Falls, SD 57117  
Hemodialysis (605) 333-6350  
Home dialysis (605) 333-7443

### **Madison, SD**

323 10th Street SW  
Madison, SD 57042  
Hemodialysis (605) 256-8870

### **Chamberlain, SD**

300 S Byron Blvd  
Chamberlain, SD 57325  
Hemodialysis (605) 734-7273

### **Hospers, IA**

112 Sunrise Drive  
Hospers, IA 51238  
Hemodialysis (712) 752-8330

### **Worthington, MN**

1018 6th Avenue  
Worthington, MN 56187  
Hemodialysis (507) 372-3279

### **Canby, MN**

112 St Olaf Avenue S  
Canby, MN 56220  
Hemodialysis (507) 223-7277 ext. 162

### **Fargo, ND**

2801 University Drive S  
Fargo, North Dakota 58103  
Hemodialysis (701) 234-8400  
Home dialysis (701) 234-8410,  
Toll Free (888) 749-3447

### **Bemidji, MN**

1300 Anne Street NW  
Bemidji, MN 56601  
Hemodialysis (218) 333-5460  
Home dialysis office (218) 333-6370

### **Detroit Lakes, MN**

1234 Washington Avenue  
Detroit Lakes, MN 56501  
Hemodialysis (218) 846-2200  
Home dialysis office (218) 846-2200

### **Morris, MN**

Stevens Community Medical Center  
400 E 1st Street  
Morris, MN 56278  
(320) 589-2832

### **Red Lake, MN**

Indian Health Services Hospital  
23990 State Highway 1 East  
Red Lake, MN 56671  
(218) 679-3117  
Located in Indian Health Services (IHS)  
Hospital in Red Lake, MN  
*Only Native American patients per IHS regulations*

### **Thief River Falls, MN**

120 Labree Avenue S  
Thief River Falls, MN 56701  
Hemodialysis (218) 683-4246  
Home dialysis (218) 683-4248





