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The Purpose and Benefit of a Booklet
Now that you are on dialysis, there are some things in your healthcare that are going to be different. We hope this booklet helps answer a lot of these questions for you and your family.

Getting Started
You are now a patient at a dialysis clinic. This clinic will now keep your chart and medical records. You are still a patient of ours, but we will take care of you at the clinic instead of the office. You will no longer come to the office for visits; we will see you in the clinic.

If you have a question, you should call the dialysis clinic first. If they cannot help you, they will direct you to call the office. There is always a doctor on call, so you can still call the office if the clinic is closed and your issue cannot wait until the clinic opens.

You may not see the same doctor you have been seeing in the office. Each clinic has a doctor that covers it; you will see the doctor that goes to your clinic. The doctor will make rounds once a month. There is also a Nurse Practitioner or Physicians Assistant at every clinic that will round once a week on the other weeks.

It is YOUR Responsibility to go to your treatments three times a week. If you are absent from treatment when the doctor makes rounds, they will not be back for another month. You need to check you medicines every week so that you can notify the Nurse Practitioner or Physicians Assistant that you need a refill while they are there. You are seen every week; there should be no reason for refills to be called in after hours.
Your Dialysis Team
Your dialysis team consists of:
Nephrologist
Nurse Practitioner/Physicians Assistant
Social Worker
Dietician
Dialysis Nurse
Dialysis Technician
YOU
Everyone plays a part in your care. We all the same goal: To keep you healthy and feeling well.

What to Expect During Treatments
When you get to the clinic for your first treatment, you will first complete your paperwork. There are several things you will have to sign. After your paperwork is done, you will go to the treatment area.

You will get on the scale. You will be weighed before and after every dialysis treatment, this tells the staff how much fluid you need to have removed and how much you took off during your treatment. Your weight will be in kilograms, not pounds (one kilogram = 1 Liter of fluid).

You can multiply your weight in kilograms by 2.2 to get your weight in pounds.

Next, you will go to your machine. You will have a recliner to sit in and a TV to watch. You will stand at your recliner and get a standing blood pressure. Then, you will sit down and get a sitting blood pressure. A nurse will listen to your heart and lungs before and after every treatment. They will ask you how have you felt since your last
treatment. This is VERY important. We need to know if you had any cramping, shortness of breath, coughing, weakness, nausea/vomiting, swelling or other issues since your last treatment. This helps them know if we are taking off the right amount of fluid. We also need to know if you have seen any other doctors or had any tests done since your last treatment.

You will get settled in your recliner. If you have a catheter, they will remove the old dressing and clean the catheter, your dialysis lines will be connected to it. You will be asked to wear a mask while they access your catheter. Your blood will come out of one lumen of the catheter, run through the machine and the filter and go back in to your catheter through the other lumen.

If you have a graft or a fistula, you will be asked to wash your access when you come in with soap and water at the sink. They will then clean your arm again before they put you on the machine. This is very important to prevent infections. The nurse or tech will put two needles in your graft or fistula. If you have a graft, they may ask you which side takes out. This tells them which side to connect the red lines to. There is a cream available that you can put on your access before you come to treatment to help numb it. Some clinics also have a spray that they use before they put the needles in to help numb it.

It will take at least 3-4 hours to clean your blood properly. The machine will take your blood pressure every thirty minutes.

The dialysis machine may beep or buzz. It has alarms to protect your safety and alert the care team. The machine will beep if:

- A needle comes loose.
- Your blood pressure changes a lot.
- You bend or kink the blood tubing.

If an alarm goes off, a nurse or technician will check the machine.
During your dialysis treatment, **you** can take an active role in monitoring your care:

Tell your care team if you have pain or feel funny. Keep your access in clear sight of your care team. Never cover it up! If a needle came out, you could lose a lot of blood very quickly. Learn to check your machine. As you learn more about it, you can double-check the settings yourself. In time, you can learn where to check your fluid goal, treatment time, and blood pump speed.

When you are finished, your blood will be given back to you. If you have a catheter, the catheter will be flushed and taped up. If you have a graft or fistula, you will have to hold your needle sites. You should try to hold them yourself if you can. They have clamps available, but holding them yourself is better for your access. You should hold them one site at a time. It is not good for your access to hold both of them at the same time. It may take 5-15 minutes or longer for each needle site to stop bleeding. After your sites have stopped bleeding or your catheter is wrapped up, you will stand for a standing blood pressure. The nurse will listen to your heart and lungs, and you will weigh yourself again.

Nurses and patient care technicians will watch you during your treatment. If you start to feel strange or sick, **alert** them right away. Don’t worry about “bothering” staff—if you don’t say anything, they won’t be able to help you feel better.

**Low blood pressure:** During your treatment, your blood pressure may go up or down due to the movement and removal of fluid from your body. Blood pressure can drop when too much fluid is removed, when it is removed too fast, or as a side effect of some drugs. You will know right away if your blood pressure has dropped too low, because you may feel:

- Faint
- Dizzy
- Sweaty
Nauseous

Severe, painful muscle cramps

If your blood pressure drops, your team will teach you to drink something salty or add some saline (sterile saltwater solution) into your bloodlines to ease the symptoms. If you feel faint shortly after your treatment, don’t try to drive. Stay in the waiting room and alert the staff. They may have you drink a bit more or lie down for a few minutes until you feel better.

**Broken blood cells:** If there is a kink or twist in the bloodlines, the pressure of the blood pump can cause the blood cells to break. If you feel any pain in your chest, back, or stomach during a hemodialysis treatment, or you see that the blood in your tubing or dialyzer is a lighter (cherry kool-aid) color than usual, call the care team right away. These are symptoms that can give them a clue that your blood cells are breaking.

**Access clotting:** A graft or fistula that clots off won’t allow blood flow for dialysis. You’ll learn how to feel the thrill, or rushing sensation of blood through your access. If the thrill stops or the bruit sound changes, call your care team right away.

**After Dialysis Treatment**

Most people have some form of transportation to and from dialysis. You should not drive yourself to dialysis until you know how it is going to affect you. Some people feel weak and tired after treatment; you should NEVER DRIVE if you don’t feel well. If transportation is a problem, please talk to your social worker.

If you have a graft or fistula that starts to bleed after you leave the clinic, hold pressure to the sites just like you did at the end of your treatment. If you cannot get it to stop after 10-15 minutes, or you cannot control it while you are holding it, call 911 and get to the nearest emergency room. **NEVER JUST SIT AND WATCH IT BLEED...YOU NEED TO HOLD PRESSURE TO IT.**
It is normal to go home and lay down for a nap. It will take your body about 2-3 hours to “re-balance” after your treatment. You should avoid having routine blood work drawn for other doctors immediately after dialysis. You lab work will be abnormal until your body is re-balanced.

**Your Primary Care Doctor**

It is important that you keep a Primary Care Provider (Family Doctor) to take care of your other health needs. They will still manage your diabetes, your cholesterol, and your other health problems. We will focus on your dialysis needs. You still need to have blood drawn for your other doctors when they ask. We draw only dialysis lab work in the dialysis clinic. The clinic is not a lab and cannot draw labs for other doctors. The lab work we routinely draw include a complete blood count (CBC), chemistry panel (potassium, calcium, phosphorous, etc.), dialysis adequacy (how clean your blood is getting), parathyroid hormone levels (NOT to be confused with THYROID) and Hepatitis antibody levels (to monitor your protection from Hepatitis B). We can draw other labs for problems we are addressing, but cannot draw routine labs for your other doctors.

**Medicines**

Your dialysis nurse will ask you to bring in your medicines every month to review. **THIS IS VERY IMPORTANT.** We will make decisions based on your medication list and it MUST BE CORRECT in order to provide you the safest and best care. Please bring your medicine BOTTLES in when you are asked. This allows us to verify that our list is correct every month.

**Social Workers**

Every dialysis clinic has a social worker. The social worker is available if you have any insurance questions, family/life concerns, financial issues with medications or healthcare, issues with the dialysis clinic, travel arrangements and many other things.
PLEASE talk to the social worker BEFORE you make any changes to your insurance. You now have a MAJOR PRE-EXISTING CONDITION that will be very difficult to cover if your insurance is not appropriate. Unfortunately, many insurance carriers may try to lead you to taking on their plan because it is cheaper. Your social worker is there for YOU not the insurance company, so talk to them before you make any changes to make sure you will still be getting the coverage you need. If you have a “private” or employer based insurance, PLEASE talk to the social worker before letting this lapse. This will often times provide your medication coverage and co-payments that Medicare does not cover. It is usually cheaper to keep that coverage than to pay for those expenses. The social worker has resources available to assist with those premium payments. The social worker is there to help identify resources that can help you live with a chronic condition as well as identify resources for family/life issues.

You can still travel when you are on dialysis, you just need to plan ahead. Talk to your social worker as soon as you

What to Bring to Treatments
You should bring your own blanket, a small pillow if you want one, headphones for the TV. You may want to bring a book or something to occupy your time while you are on the machine. Some people bring laptop computers, needlepoint, or books on tape. You may also want to pack a small snack in case you need something to eat when you are finished. We don’t like you to eat on the machine because it can make you get sick or make your blood pressure drop. It is ok to eat a light breakfast before you come for treatment.
**Labwork**

Every month, you will have a series of tests to check the levels of certain substances in your blood. These tests help your doctor see how you’re doing and decide your dialysis prescription. They are used to decide which medications or diet changes may be needed. They may also suggest when more testing is needed to pinpoint problems.

The **URR** or **Kt/V** test checks how well your dialysis is working and tells your doctor how your treatments are working. They look at how much extra urea is removed from your blood during treatment. Although urea is just one waste product your body produces, how well it is removed is a clue to how well other wastes are removed.

A **hemoglobin** test measures the amount of red blood cells. A lowered blood count can mean anemia, which makes you feel tired and weak.

**Calcium** and **phosphorus** tests check levels so that you can keep them in a safe balance to make sure your bones stay healthy.

An **albumin** test shows how much protein you have in your diet. If you don’t have enough protein, you will become malnourished, and your body will steal protein out of your muscles.
Access Options & Care

Hemodialysis access is the way you reach your blood for the procedure. To allow blood to flow from you to the dialyzer and back, you need a large blood vessel with good blood flow. To create a vessel that is large enough, an access to your blood is created with outpatient surgery, usually in your arm or leg.

Choosing your access is a decision that you and your doctor will make early in your treatment. It will take several weeks to a few months for your access to heal or “mature” and be ready to use for dialysis.

Fistula

A fistula is a surgical connection of one of your own arteries to a vein under the skin of your arm. It’s the most natural access because it’s made with your own blood vessels. Most people can have a fistula. However, if your veins are too small or too weak for a fistula, there are other options.
Pros

- Less chance of infection than other types of access
- Less chance of clots forming than other types of access
- Usually works for many years—sometimes decades
- Usually needs fewer “tune-ups” (revisions) to repair
- Can use the Buttonhole Technique for needles

Cons

- Can be seen on your forearm
- May take time to develop

Graft

A graft is a surgical insertion of a special tube that connects to a vein and an artery and is used like a fistula. If you have small blood vessels that won’t develop into a fistula, a graft may be a good option for you.

Pros

- Does not have to “mature” like a fistula, so it can be used with a few weeks after surgery
- Permanent access option if a fistula won’t work

Cons

- Has a higher risk of clotting than a fistula has
- Has a higher risk of infection than a fistula has
- Doesn’t last as long as a fistula (a few years at most)
- Need “tune-ups” (revisions) in the hospital one or more times a year
- Can be seen on your forearm
**Central Venous Catheter**

A catheter is a long plastic tube, shaped like a “Y”. A doctor places it under the skin of your chest, into your neck (see picture). The “stem” of the Y is in your heart. The two ends of the Y come out through the skin of your chest. For dialysis, the machine tubing connects to each end of the Y. The Y catheter can be placed and used the same day, and is primarily used when a patient needs emergency dialysis and no other access is available. Long-term use of a central venous catheter is discouraged because of potential complications that can occur.

**Pros**

- Once the catheter is placed, no needle contact for the patient
- Can be used right away for hemodialysis

**Cons**

- There is a very high risk of clotting
- There is a very high risk of life-threatening blood infections
- May cause narrowing of the vein in which it is placed, which makes future permanent access on that side of the body less likely
- Catheters may need to be changed often
- Blood flow rates are lower, so longer treatment times might be necessary
- You can’t get the catheter wet, so swimming is off-limits and showers may not be possible
**Dietary Guidelines for Adults Starting on Hemodialysis**

Use this brochure as a guide until your dietitian prepares a personalized meal plan for you. You will need to:

- Eat more high protein foods.
- Eat less high salt, high potassium, and high phosphorus foods.
- Learn how much fluid you can safely drink (including coffee, tea, and water).

**Salt & Sodium**

- Use less salt and eat fewer salty foods: this may help to control blood pressure and reduce weight gains between dialysis sessions.
- Use herbs, spices, and low-salt flavor enhancers in place of salt.
- Avoid salt substitutes made with potassium.

**Meat/Protein**

People on dialysis need to eat more protein. Protein can help maintain blood protein levels and improve health. Eat a high protein food (meat, fish, poultry, fresh pork, or eggs) at every meal, or about **8-10 ounces of high protein foods everyday.**

3 ounce = the size of a deck of cards, a medium pork chop, a ¼ pound hamburger patty, ½ chicken breast, a medium fish fillet.

1 ounce = 1 egg or ¼-cup egg substitute, ¼-cup tuna, ¼-cup ricotta cheese, 1 slice of low sodium lunchmeat.

**Note**: Even though peanut butter, nuts, seeds, dried beans, peas, and lentils have protein, these foods are generally not recommended because they are high in both potassium and phosphorus.
Grains/Cereals/Bread

Unless you need to limit your calorie intake for weight loss and/or manage carbohydrate intake for blood sugar control, you may eat, as you desire from this food group. Grains, cereals, and breads are a good source of calories. Most people need 6 -11 servings from this group each day.

Avoid “whole grain” and “high fiber” foods (like whole wheat bread, bran cereal and brown rice) to help you limit your intake of phosphorus. By limiting dairy–based foods you protect your bones and blood vessels.

Milk/Yogurt/Cheese

Limit your intake of milk, yogurt, and cheese to ½-cup milk or ½-cup yogurt or 1-ounce cheese per day. Most dairy foods are very high in phosphorus.

*The phosphorus content is the same for all types of milk – skim, low fat, and whole! If you do eat any high-phosphorus foods, take a phosphate binder with that meal.*

Dairy foods “low” in phosphorus:

- Butter and tub margarine
- Cream cheese
- Heavy cream
- Ricotta cheese
- Brie cheese
- Non-dairy whipped topping
- Sherbet

*If you have or are at risk for heart disease, some of the high fat foods listed above may not be good choices for you.*
Certain brands of non-dairy creams and “milk” (such as rice milk) are low in phosphorus and potassium. *Ask your dietitian for details.*

**Fruit/Juice**

All fruits have *some* potassium, but certain fruits have more than others and should be limited or totally avoided. Limiting potassium protects your heart.

**Limit or avoid:**

<table>
<thead>
<tr>
<th>Oranges and orange juice</th>
<th>Raisins and dried fruit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kiwis</td>
<td>Bananas</td>
</tr>
<tr>
<td>Nectarines</td>
<td>Melons (cantaloupe and honeydew)</td>
</tr>
<tr>
<td>Prunes and prune juice</td>
<td></td>
</tr>
</tbody>
</table>

**Always AVOID star fruit (carambola).**

**Vegetables/Salads**

All vegetables have *some* potassium, but certain vegetables have more than others and should be limited or totally avoided. Limiting potassium intake protects your heart.
Kidney Transplant

A kidney transplant is not a cure. It is a treatment option that requires lifelong commitments (taking medications and being followed by a kidney specialist).

A transplant is thought of as the “gold standard” because it is the treatment that comes closest to “normal” kidney function. It is a major surgical procedure that places a healthy kidney from another person into your lower abdomen. It is possible to have a kidney transplant without going on dialysis.

A kidney transplant is not for everyone. Several factors determine if a transplant is an option for you, including general health, emotional health, and health insurance/financial resources.

Peritoneal Dialysis

Another type of dialysis that is done from home is called peritoneal dialysis or PD for short. This uses blood vessels in your belly to filter your blood. This kind of dialysis is done every day. Most people use a machine at night to filter their blood while they sleep. It is called a cycler. Not everyone can do peritoneal dialysis. If you have had a lot of surgery in your belly you may have too much scar tissue to do PD. You also have to have room at home for all of your supplies.
Conclusion

Dialysis is a new lifestyle with a lot of different things than what you may use to. We hope this information answers a lot of questions for you. Please talk to us about any other questions you may have. We want dialysis to help you feel better and improve your life.
Dialysis Clinic______________________________

Social Worker______________________________

Dietician______________________________

Phone Number______________________________

Nephrologist______________________________

______________________________ NP/PA

Phone Number (843) 767-9312

Surgeon______________________________

Phone Number______________________________

Primary Care Doctor______________________________

Phone Number______________________________

Pharmacy______________________________

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