

CARE FOR YOUR DIALYSIS

A PATIENT'S GUIDE



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The Care for Kidneys Foundation is a non-profit charitable organization dedicated to improving the health and quality of life of patients living with kidney disease and those at risk of developing kidney disease. If you found this material helpful, please consider donating to this cause, so we can continue to provide material like this to patients with hypertension and kidney disease in the future.

For more information on the Care for Kidneys Foundation and ways in which you can support the foundation please visit <u>http://www.careforkidneys.org</u>

Sincerely,

KADR

Dr. A. Kadri Director, Care for Kidneys Foundation

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If you are reading this book, your nephrologist (kidney specialist) has told you that you need dialysis. You may already be on dialysis or may be starting soon. Chances are that you have had chronic kidney disease for some time now that has progressed to the point where your kidneys are unable work well enough to keep you healthy. You may be experiencing symptoms at this point and your nephrologist has told you that it is time to consider starting dialysis. If this is the case, dialysis may be long term unless you are eligible for a kidney transplant (more on this later). If your kidney disease has been present for a long time prior to starting dialysis, it is a good idea to make sure your dialysis therapy is optimized to keep you healthy for the long term.

There is also a small chance you are starting dialysis because you have developed acute kidney injury. This means your kidneys were normal previously and have failed in a very short time. If this is the case dialysis may only be temporary for you. However, if enough damage has been done to your kidneys it also could be long term. In most cases you will have discussed this with your physician prior to needing dialysis. You will be starting either on peritoneal dialysis, or hemodialysis (either in a dialysis unit or at home).

If you are starting dialysis urgently than there may not have been enough planning done in the past to allow you to start on peritoneal dialysis or home hemodialysis. Do not worry though. If you are interested in either of these options, you should let your nephrologist know as soon as possible. Once you are feeling better you can be transitioned to one of these methods. They will allow you to have more independence and more control over your schedule.

Regardless of which type of dialysis you are starting on, your nephrologist is happy to discuss changing methods if your first selection does not work for you. If you have given it a good try and you are not feeling it will work long term please speak to your nephrologist. It is important to remember that peritoneal dialysis and home hemodialysis allow you to have the most freedom in your schedule and remain the most independent. There are two major ways in which dialysis can be done:

- 1) Intermittent Hemodialysis or Home hemodialysis
- 2) Peritoneal Dialysis

These will be discussed in more detail later. The major difference between the two is that hemodialysis involves using a machine to help clean your blood, while peritoneal dialysis uses your own body to clean your blood **in a different way** than your kidneys.

No matter which type of dialysis you choose with your doctor, they all require creating "access" to your body. This access is then used to clean the blood through various mechanisms.

For Intermittent hemodialysis and home hemodialysis there are 3 types of access which can be used (discussed in detail later).

- 1) AV Fistula 2) AV Graft
- 3) Central Venous Catheter

For peritoneal dialysis, a peritoneal dialysis catheter is used to access your body through your abdomen.

Your access will need to be created before you can begin dialysis treatments.

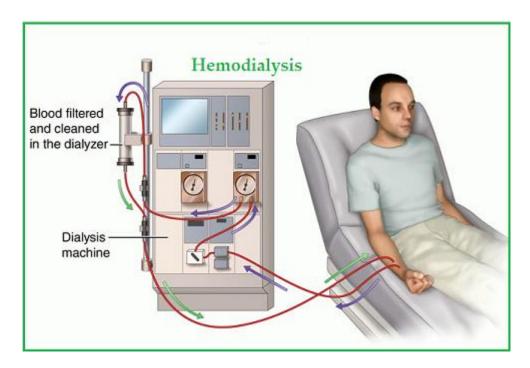
With all of the options it is hard to decide which type of dialysis is right for you. Peritoneal and home dialysis can be performed by yourself or a loved one at home, which lets you maintain your independence. In addition because they are performed at home you have more control over your schedule and more freedom.

You may notice a significant increase in your quality of life by choosing one of these two methods. You will have more freedom over your schedule, more independence, spend less time travelling and be able to perform treatments up to 7 days a week.

If you do not feel you can perform dialysis at home, please talk to your doctor as there is often much help available to make dialysis at home possible. You will never know until you ask!

If you are unable to do dialysis at home even after evaluation and supports you can always do hemodialysis at a dialysis unit approximately 3 times a week. You will have to travel there and may have less control over your schedule. Hemodialysis is a type of dialysis where a machine takes over the job of your kidneys and filters and cleanses your blood artificially.

The machine pumps your blood from the body, runs it through a semipermeable membrane, which acts as a filter and returns it to your body cleaner than before. While doing hemodialysis toxins and waste products are removed from your blood. At the same time potassium, salt and acid levels are regulated. Lastly excess water is removed from your blood so that you do not develop edema. It is important to note that you are not getting new blood, or losing blood during this process. All blood is your own, and is returned to you, the machine simply cleans it. Hemodialysis can be performed in a dialysis unit or at home.



Dialysis Unit

If you have dialysis at a unit, you will need to arrange travel to and from the center. If this is not possible a social worker may be able to help with arranging third party transportation through available community resources.

At the dialysis unit nurses and doctors will be able to monitor you closely. Nurses will also hook you up to the machine before your treatment, monitor you during the treatment and unhook you after.

If you have dialysis in a unit you will usually have treatments 3 times per week. Each treatment is usually about 4 hours long.

Home Hemodialysis

Home hemodialysis is where you perform dialysis through the use of a machine at home instead of at a dialysis unit. If you have dialysis at home, you will have to learn how to use the machine and hook yourself up to it. You will need to undergo training to do this. Training usually takes 6 weeks to complete, but may sometimes take slightly longer.

A machine is brought to your home and after modifications to your water and electrical supply (if needed), you perform dialysis 3-7 times per week for a set number of hours each time. How often and for how long will be decided with your physician. Since there are no nurses available, you are responsible for hooking yourself up to and unhooking yourself from the machine. You are also responsible for setting up, operating and caring for your machine.

Home hemodialysis offers a lot of freedom for your own schedule but requires a large amount of independence and responsibility, as well as very intense training in the beginning. You will dialyze at a training site 3 times per week and when you are able to perform dialysis adequately by yourself you will start at home. Once you get the hang of it though, it can be as easy as riding a bike!

Although we encourage most people to consider a home based therapy, home hemodialysis is not realistic for everyone. You must undergo extensive training and be reasonably self-sufficient to be successful. Don't underestimate yourself and talk to your doctor about your suitability for a home therapy!

Peritoneal dialysis, involves using your own body to clean your blood in a way that is different from your kidneys.

A membrane inside your abdomen called the peritoneal membrane acts like a filter which is used to clean the blood in your body.

Peritoneal dialysis requires the placement of a peritoneal dialysis catheter (PD catheter), which is used to infuse clean fluid into your abdomen around the membrane. This fluid then removes toxins and excess water from your blood through the membrane. The fluid is then drained out through the catheter. The drained fluid can be disposed of in the toilet. This catheter comes out of the abdomen and is hidden under your shirt.

Peritoneal dialysis requires training, and requires you to be independent, or have someone at home to help you. It may not be possible if you have had many previous abdominal surgeries or serious medical problems. If you are interested in peritoneal dialysis talk to your physician about it. There are two main types of peritoneal dialysis. They are:

1) Continuous Ambulatory Peritoneal Dialysis (CAPD)

2) Automated Peritoneal Dialysis (APD)

The main difference between the two is that APD involves using a machine to perform the dialysis while you sleep. On the other hand in CAPD, you are responsible for performing the dialysis yourself multiple times throughout the day.

APD may be done while sleeping, while CAPD requires you to perform "exchanges" (more on this later) throughout the day.

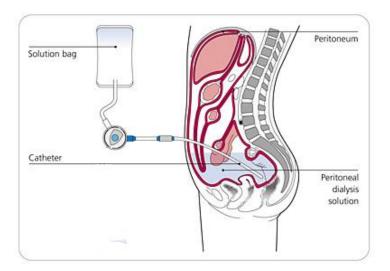
Continuous Ambulatory Peritoneal Dialysis (CAPD)

In CAPD you will instill clean fluid (Dialysate) through your catheter into your abdominal cavity. This will stay in there for a set duration of time (usually about 4 hours). You will start this when you first wake up in the morning.

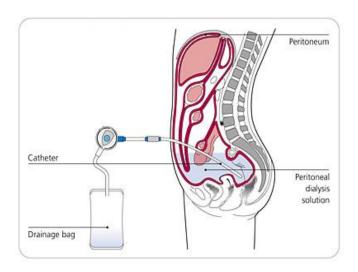
After several hours, this fluid will become filled with toxins and excess water from your body and will have to be drained. At this time you will drain the fluid through your catheter and put fresh dialysate fluid back in. This process is repeated 3-4 times during the day. One full exchange will take you 15-20 minutes to perform.

At night you will repeat this prior to going to bed and then leave that fluid in overnight and begin again in the morning. You will receive extensive training on all of this before beginning at home by yourself.

To fill your abdomen with clean solution, you will hook the dialysate bag up to your catheter and let it drain into your abdominal cavity under gravity until the bag is empty.



To drain fill your abdomen of dirty fluid, you will hook the collection bag up to your catheter and let it drain out of your abdominal cavity to gravity until drainage stops.



Automated Peritoneal Dialysis (APD)

In APD, you will hook your catheter up to a machine at night before you sleep. This machine will perform the "exchanges" for you throughout the night over a set period of time. The size and number of exchanges that occur will be decided by your physician. You are responsible for setting up the machine each night, hooking yourself up and unhooking yourself in the morning.

This treatment is done every night but offers you more freedom during the day. Sometimes if you need it the machine will fill your abdomen for the last cycle in the morning before you disconnect yourself. You will then carry that fluid around for most or all of the day and drain it in the afternoon or evening before starting again.

Before beginning with your machine at home, you will receive training on how to use the machine, hook yourself up and unhook yourself. You will be taught in a supervised setting until you are comfortable. There are four main types of access. AV Fistulas, AV grafts and central venous catheters are used for hemodialysis. A peritoneal dialysis catheter is used for peritoneal dialysis.

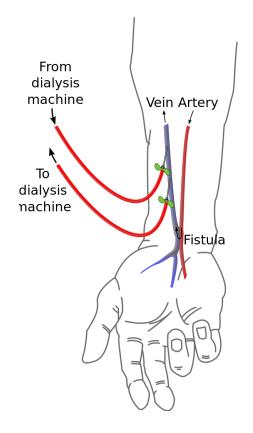
Depending on the type of dialysis you have selected with your nephrologist, you will have one of these. If you are having any issues with your access, please let your dialysis team know immediately. If you are starting dialysis urgently, you will likely be starting on hemodialysis with a central venous catheter. This type of access has the highest rate of complications and you should talk to your nephrologist about switching to a different type of access as soon as possible for hemodialysis. If you are interested in peritoneal dialysis you should talk to your nephrologist about switching to a peritoneal dialysis catheter.

The three types of access for hemodialysis are outlined below:

AV Fistula

This is the preferred type of access for hemodialysis. It is less likely to have infections and complications compared to catheters. It requires you to undergo a minor surgical procedure to create a direct connection between your artery and vein. It is usually done in the lower arm. This type of access is located under your skin. During dialysis two needles are used to connect the fistula to the machine. Blood is removed from your body through one needle, and returned to your body through the other.

An AV fistula is usually created many weeks to months before it is used for dialysis. This is to allow time for the area to heal and for the fistula to "mature" so that needles can be inserted into it. It is important to keep the veins in your arms healthy so that they can be used to create a fistula when needed. Try whenever possible to avoid having blood drawn from an arm where fistula is being planned and if needed try to use only small hand veins for blood work.

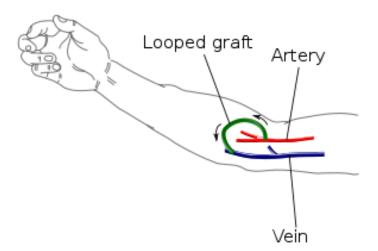


AV Graft

Your veins may not be suitable for creating a fistula. This can happen when the veins in your arm are very small or become damaged. This may be due to repeated blood draws from a particular vein or various other reasons. In this case your doctor may suggest an AV graft for dialysis access. For this a surgeon will use a flexible synthetic tube to create a path between an artery and a vein in your arm.

The graft will remain under the skin and is used in a similar way to the fistula described above. The biggest difference is that the two needles which are put into the access for dialysis are inserted into the synthetic tube and not your vein.

Grafts can be used as quickly as two weeks after they are created. However they do have higher rates of complications than fistulas including narrowing of your blood vessels and infections.



Caring For Your Fistula or Graft

Regardless of whether you have a Fistula or Graft for access, it is important you care for them in a similar way.

This is done to prevent complications. Complications can still occur even if you are careful but they are much less frequent.

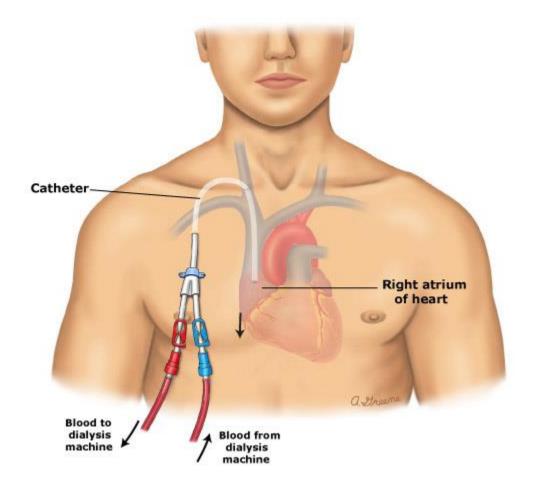
- 1) Wash your area of access with soap and warm water each day, and always before dialysis.
- 2) Do no scratch the area.
- 3) Check the area daily for signs of infection including redness and warmth.
- Check the area for blood flow daily. There should be a vibration over the area. If this is absent or changes notify your dialysis unit.
- 5) Take care not to injure the arm where the access is located. Avoid tight clothing, heavy lifting or sleeping on the arm.
- 6) Do not allow anyone to take blood from or measure blood pressure on the arm containing your access.

Central Venous Catheter

This is the third, and least preferred method of access for hemodialysis. It is the most likely to encounter serious complications such as infections that could cause you to become quite ill. If you are starting dialysis urgently, you will likely use this. It is only temporary though in many cases and you should talk to your nephrologist as soon as possible about switching if you have one of these.

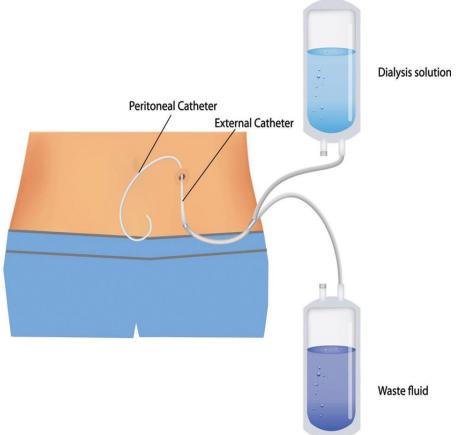
It is a thin flexible tube that is placed into a large vein in your neck and travels down to your heart. The tube exits your skin and has two ports, which are used to connect you to the dialysis machine. One port removes blood from your body while the other port returns blood. It is important that only dialysis healthcare professionals use these ports. This type of access can be used immediately and is usually used when dialysis must be started urgently and no fistula or graft is present. It should only be used temporarily and if you need one you should be transitioned to a graft or fistula as soon as possible. Sometimes it is used permanently if a fistula or graft is not possible or if you run into problems maintaining a fistula or graft.

Catheters have the highest risk of infection and complications of all three types of access.



Peritoneal Dialysis Catheter

A peritoneal dialysis catheter is placed through a minor procedure in the lower abdomen to allow fluid to be exchanged in and out of the abdominal cavity to allow for cleansing of your blood and removal of fluid and waste products. Once in place, the catheter can usually be used within 2-4 weeks of insertion. In caring for your catheter is important that you avoid constipation. You may require medications for this. Avoiding infection of the catheter and abdominal fluid is very important for any peritoneal dialysis patient. Regular hand washing prior to doing exchanges and proper exchange technique as well as exit site care will be important in maintaining your peritoneal dialysis catheter.



The majority of patients tolerate hemodialysis very well.

Since hemodialysis removes excess electrolytes (sodium and potassium), waste and water from your blood, the most common side effect is low blood pressure. Symptoms that you may experience due to the removal of electrolytes, waste and water include, lightheadedness, muscle cramps, abdominal cramps, nausea and vomiting. This does not happen often once you are on routine dialysis but is more likely to occur when you are starting and your team is trying to remove the correct amount of fluid from your body.

You may experience a fever during dialysis. This may be a sign of infection, sometimes related to your access, particularly if you have a central venous catheter. Other times it is not related to infection. If you feel feverish you should let your dialysis team know so further investigations can be done.

You are much more likely to experience side effects during your dialysis if your fluids gains between dialysis sessions are above the recommended amount. This will make you more likely to drop your blood pressure, experience cramping and pain on dialysis and feel weak and tired after dialysis.

With peritoneal dialysis, symptoms are not common but may occasionally include abdominal distention, back discomfort or getting full fast after a meal. Now that you are on dialysis you may require additional medications. Regardless of the type of dialysis you are on, you will probably require these medications. You may also already be on some of these medications.

Diuretics

These are medications which are used to get rid of excess salt and water from your body. If you still make urine while you are on dialysis your doctor my prescribe this to help maintain your urine output and help eliminate extra fluid from your body. This will require you to have less fluid removed during your treatments leading to less side effects. A commonly used diuretic is furosemide (Lasix).

Erythropoietin Injections

Because your kidneys no longer make the hormone erythropoietin, your bone marrow may not make enough hemoglobin. For this reason your doctor may prescribe you erythropoietin injections to help increase your hemoglobin to adequate levels. When you are on hemodialysis this medication is given through the intravenous lines with your treatments and most often no injection is needed. If you are on peritoneal dialysis this will be given through weekly injections just under the skin. The dose will be titrated to make sure your hemoglobin levels are adequate.

Activated Vitamin D

From our last book, you know that vitamin D goes through many steps before it becomes the active form. Your kidneys are responsible for the last step in this activation. You may have already been on activated vitamin D before dialysis but if you were not you may need it now that you are. This medication will usually be given orally and helps maintain your calcium balance and keep your bones healthy.

Phosphate Binders

When you are on dialysis your kidneys lose their ability to get rid of phosphate. Phosphate levels can build up in the body and lead to problems with your calcium levels and bone disease. To help lower phosphate levels your doctor may prescribe you pills (usually calcium pills) to take with your meals. Calcium will bind the phosphate in your food and prevent it from being absorbed into your body.

Anti-Nausea Medication

Sometimes you will develop nausea or vomiting on dialysis. Your nephrologist may prescribe you medication to have during your treatments which helps with this. A medication commonly used for this is gravol.

Anti-Histamines

Rarely you may experience itchy skin on dialysis. If this happens you may be given a medication to help with the itch. A common medication used for this is Benadryl.

Even though dialysis is a good treatment, it is not as good as having working kidneys. For that reason you have to watch what you eat and how much fluid you drink.

Normally the food you eat is broken down in your stomach and transported to your cells. These nutrients are then used by your cells and waste products formed by using them are put back into your blood. Before being on dialysis your kidneys would have helped to get rid of these toxins. Now that you are on dialysis, the dialysis treatment removes waste from your body. Between sessions waste and toxins can build up and make you sick. You can reduce the chances of this by watching what you eat. As part of your care, it is important to meet with a dietician to discuss this further but this guide will go over the following basic areas:

- 1) Calories
- 2) Fluid intake
- 3) Potassium
- 4) Sodium
- 5) Phosphorus
- 6) Protein
- 7) Vitamins and Minerals

Calories

It is important for you to meet with a dietician to understand your calorie needs. Some people on dialysis need to gain weight, some people need to lose it. Depending on your situation you may need to eat more or less calories than you currently are. That being said, eating the right type of calories are important. Patients on dialysis are at increased risk for cardiovascular disease, and for that reason a balanced diet that does not contain too many fatty foods is needed.

You will work with your doctor and dietician to meet your caloric needs and goals, as well as get suggestions on ways to keep your diet "interesting" at the same time.

Fluid Intake

When you start dialysis you may still make urine. As time goes on however, the amount of urine you make will likely decrease. Because of this the amount of fluid your body can get rid of between dialysis will also decrease.

Most of the excess fluid you gain will be taken off during dialysis, but because there can be problems with blood pressure on dialysis the amount of fluid that can be removed may be limited.

While on dialysis treatments your healthcare professionals may talk to you about your "dry weight". This is your weight after all excess fluid has been removed from your body with dialysis. Every litre of fluid you drink will increase your weight by 1 kg. This is how your doctor can determine how much fluid you have gained in between dialysis sessions.

If you drink 2L of fluid between dialysis sessions your weight will increase by 2kg. For most people the maximum amount of fluid that can be removed in a 4 hour dialysis is 4L. Therefore it is important that you ensure you do not gain more than 4 Kg of weight between dialysis sessions. It puts a strain on your body and especially your heart to have 4 L of fluid removed every dialysis. For that reason you should limit your weight gain between dialysis to 2-2.5 kg. You can accomplish this by:

- 1) Reducing the amount of sodium you eat (chips, pretzels, salted nuts etc).
- 2) Drinking smaller portions, or sucking on several ice chips instead of drinking a glass of water.
- 3) Weighing yourself everyday to see how you are progressing between dialysis sessions.

It is also important to realize many foods contain water and can cause fluid gain outside of drinking liquids. Talk with your dietician to get a better idea of how much fluid you are gaining from the foods you eat in your diet.

Potassium

Potassium is found in many foods, and is eliminated from the body by your kidneys. Now that you are on dialysis, the potassium you eat will build up in your blood. High levels of potassium can lead to abnormal heart rhythms and even death.

Dialysis will remove potassium from your body but this is limited so it is important you limit the amount of potassium you take in between dialysis sessions.

Many foods are high in potassium. These include bananas, peaches, potatoes, tomatoes, oranges, berries and dry fruit. If you do eat any of these try to limit yourself to smaller portion sizes. Preparing foods

such as potatoes by soaking and boiling them can also reduce the potassium levels.

It is important to speak to your dietician to get a full sense of which foods you eat in your diet contain high levels of potassium. Your dietician can also give you a better idea of how much potassium you should take in between sessions.

Sodium

Sodium is found in salt, and other foods. Most canned preparations including soups, prepackaged meals, deli meats and frozen dinners contain large amounts of sodium.

Large amounts of sodium will cause your brain to make you thirsty. This will result in you drinking large amounts of fluid. This not only makes fluid removal on dialysis difficult, but can lead to complications such as high blood pressure. This can place strain on your heart and cause it to fail in the long term.

The best way to avoid sodium is to eat fresh foods that require preparation and to avoid adding salt.

It is extremely important you do not use salt substitutes that contain potassium, as high levels of potassium can lead to abnormal heart rhythms and death.

Your dietician will be able to help you with tips on preparing foods with low sodium content.

Phosphorus

This is a mineral found in a large number of foods. Having too much phosphorus in your blood can cause problems with your bones making

them extremely fragile. In the long run high levels of phosphorus may lead to build up of calcium in the arteries of your heart.

Foods such as milk, peanut butter, nuts and cheese are high in phosphorous. Your dietician will be able to give you more information on this.

Dialysis can clear phosphorus but in-between dialysis sessions you will need to watch what you eat. In addition you may have to take pills to help you get rid of phosphorous with your meals every day. These medications will be prescribed by your doctor and are taken at the start of your meals. They bind to the phosphorous in your stomach that is in the food you eat. This binding stops the phosphorous from being absorbed into your blood.

Protein

Now that you are on dialysis, you are encouraged to eat high quality protein. You may have been asked to limit your protein before being on dialysis.

Protein helps to keep you nourished, and the better nourished you are the better your health on dialysis will be. Dialysis may also remove protein, and therefore it is important for you to eat a diet with a good amount of high quality protein.

Eating protein causes your body to break it down into a waste product called urea. This is cleared from your blood with dialysis. High quality proteins produce less waste than others. Having extremely high urea levels can cause you to have health problems, so it is important you attend your dialysis sessions and eat the right kind of proteins. High quality proteins usually come from meats especially fish and poultry as well as egg whites.

Vitamins

Because dialysis has limited your diet, you may become deficient in certain vitamins and minerals.

For this reason your doctor may prescribe you vitamins to help maintain your health. Some vitamins can be harmful however, so it is important check with your doctor before taking any over the counter vitamins.

Only take what is prescribed by your doctor, and if you wish to add another supplement to your diet, please review it with your physician before doing so. Regardless of what type of dialysis you are on, you will be monitored frequently. This will include both blood work and visits with your nephrologist. This is an important and integral part of your health on dialysis.

If you are dialysis in a dialysis unit, the nephrologist will see you every regularly. Do not wait to see your nephrologist if you are feeling unwell. Let your dialysis team know or present to the emergency room if you have significant concerns about your health.

If you are on home hemodialysis or peritoneal dialysis you will see you nephrologist in clinic, like you did before dialysis. This will usually be at regular intervals and may become more frequent if you are having problems. You will also do blood work regularly for your nephrologist to review.

Regardless of the type of dialysis you are on, your dialysis team will be taking measurements to make sure you are receiving enough dialysis. This means they will make sure that you are getting enough cleaning of your blood and enough removal of extra electrolytes, water and waste. If you are not getting enough dialysis you may have the frequency of your sessions or the length of your sessions increased. Kidney transplant is when, a kidney is removed from a donor and placed in your body. This new kidney is hooked up to your blood and bladder and performs similar to the way your kidneys did before your transplant.

Kidney transplantation allows you to live life free of dialysis, but there are some risks associated with the surgery which your nephrologist and surgeon will discuss with you in more detail. There are two types of kidney transplants:

Deceased Donor

This is when a kidney is taken from someone who has died but wanted to donate their organs. The kidney is placed on ice to preserve it and then transplanted into your body. This type of kidney transplant lasts on average 8-12 years.

Living Donor

This is when one kidney is taken from an individual with two healthy kidneys and placed inside of you. This person who donates the kidney is usually a close friend, significant other or relative. This type of kidney transplant lasts on average 10-15 years.

Regardless of the type of kidney transplant you get, you will be required to take medications to stop the kidney from rejecting in your body. However, taking these medications will allow you to live a life free of dialysis and potentially improve your quality of life. This is a complicated question and there are a lot of things that are looked at in the decision. To begin with, to improve your chances of getting a kidney transplant you should be as compliant with dialysis treatments as possible. In addition, you should be compliant with your medications, and follow the diet above. If you are overweight you should aim to reduce your weight into a healthier range.

Because a kidney transplant requires a surgery, you will need to undergo many tests to determine if you are fit for the surgery. You will also have to have several blood tests to determine if you will be a match for a kidney. If someone close to you is interested in donating a kidney to you, they can be checked to see if they are a match.

If you are at all interested in kidney transplant you should talk to your nephrologist to get more information and have your testing started. Once you have the appropriate tests done, you will be referred to see a nephrologist that specializes in transplant to determine if you are a suitable candidate.