YOU ARE A DIALYSIS PATIENT

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This booklet is dedicated to Joe Cook, a home dialysis patient, who was an inspiration to all he encountered, and to his mother, Alecia, for her strength, care, and courage to learn.
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INTRODUCTION:

You are not aware of the many things the kidney does until it stops working and you need the help of dialysis to live. It does not matter to those who have working kidneys; they have no clue, but to you it is a life changing experience.

I have practiced nephrology for 37 years. I have been chief of nephrology at a major hospital and medical director of a large dialysis unit for more than 25 years. As a medical director and practitioner, I have treated acute and chronic kidney disease and made dialysis rounds part of my daily routine my entire career. At times, I have felt that dialysis patients do not fully understand what is going on with kidney failure and all the body’s systems it involves, as well as the medications, diet, and lifestyle changes they are facing.
In part, it has been a failure on the medical provider, myself included, to not have the time or worse, not have taken the time, to do the necessary education required to engage the patient more in the process. In part, some patients have little interest in learning or taking a role in their own care. The dialysis unit staff—nursing, technicians, dieticians, social workers, and nursing unit managers are on site and are a great resource for such education. In order to have the best outcome with dialysis, you should have an ongoing dialogue with them as well as your physician, N.P.-nurse practitioner or PA-physician assistant responsible for rounding when you are at the dialysis unit.

It is a physical and emotional challenge to be a dialysis patient. It is a major change in lifestyle. For many, this occurs at later stage in life when learning and retaining new information is more difficult and the whole process can be overwhelming. I have taught medical students, residents, and renal fellows over the duration of my career and attempted to explain concepts that, at times were complicated, in a more understandable way. I have tried to take this approach in writing this guide with the hope it will provide a background resource of medical information relating to kidney failure and dialysis. My intent is for you to have this knowledge to help understand the unique medical challenges you are facing. This will allow more meaningful discussions with your dialysis providers for better decisions in your care and alter behaviors ONLY you have control over toward the same goal.
There will be words you may not yet be familiar with but they are included to be medically accurate and they will be used often by the dialysis providers you will be working with. There are SUMMARY POINTS after the end of most topics. The text before provides an explanation in more detail. A GLOSSARY is included at the end for specific terms in this field.
The kidneys have 2 million filtering units to keep your body healthy in multiple ways. It is like a fish filter purifying the water, removing toxins, and maintaining a balance of water and elements for healthy living. There are many other functions that will be discussed as well to try to give you an idea of what dialysis means to you and the concepts needed to help with understanding your life on dialysis.
Chapter 1

Salt and Water: Why do I have to limit my fluid intake?

Water

Not all patients starting on dialysis have to restrict fluid intake but the majority eventually do. It is, for the most part, determined by how much urine you are still making. Let us assume you make very little urine for the rest of this topic.

Your body is a remarkable achievement in maintaining a balance or equilibrium of intake and output. This will be illustrated repeatedly in the multiple systems the kidney is responsible for. When the kidney fails, that balance is no longer as easily maintained. It requires your effort and that of dialysis to stay in a healthy equilibrium.

Salt and water balance is necessary to prevent excess fluid overload that could result in congestive heart failure and edema - fluid retention. “What goes in has to come out.” All fluids contain water: coffee, milk, soda, beer; anything that is liquid. Many foods have high fluid content as well: fruit, vegetables, but intake of fluid is the major component in most patients.

Before your kidneys failed, you probably noticed that the more you drank, the more urine you made and
the less fluid intake resulted in less urine output. Paying more attention, you may have noticed that with higher fluid intake, the less yellow the urine was; looking more like water, and with smaller volume intake the urine was more yellow or darker with more odor. Clear, higher volume urine is more water and more dilute compared to other components present in the urine. Low urine volume with lower intake caused the kidney to hold on to more water making a concentrated urine; less water compared to the other urine components. Concentrated urine is the kidney’s appropriate defense to avoid dehydration in settings of lower fluid intake. Dilute urine is the kidney’s appropriate defense to prevent over hydration or too much water in your body.

When kidneys are failing, the ability to make a more dilute urine or a more concentrated urine is compromised, so the normal defenses that would help you keep your volume balance stable in low or high intake conditions are no longer present. When you reach the need for dialysis, the amount of urine you make is significantly reduced for most people, and at this point the danger of fluid overload is one of the major balance problems. “What goes in has to come out.” How do you control excess fluid risks without the ability to eliminate water- urine?

If you are a typical dialysis patient on hemodialysis with 3 treatments a week, the fluid problem has solutions that are patient controlled and dialysis controlled. It is important that your intake of fluids be restricted to avoid fluid overload. This is hard as you have never been required to do such a thing.
“Why must I restrict my fluid intake?” The dialysis process can remove fluid during the hours you are on the dialysis machine. Water is removed from your blood as it passes through the dialysis filter. It is part of your dialysis prescription, but it has limits.

The blood running from your hemodialysis access through the dialysis filter includes water. This blood volume supports your blood pressure. Too much volume may cause a high blood pressure. Too little volume will reduce your blood pressure. Removing too much water from your blood volume in a short period of time will cause low blood pressure. If the blood pressure gets too low, you will feel lightheaded and, if not corrected, you will pass out. Your brain and your heart may not get enough blood supply which could cause injury; heart-ischemia; brain-seizure and/or stroke, and/or death. The amount of fluid the dialysis procedure removes is controlled by a machine setting; NOT by your body’s protection systems. Too little thinking and too much machine setting for fluid removal put you at high risk during and after the dialysis procedure.

Weight gain between dialysis treatments, for all practical purposes, is fluid gain since the previous treatment. To stay in balance- “What goes in has to come out-” that weight gain is the amount of fluid that needs to be removed during your dialysis treatment. Removing this amount of fluid will bring you back to the weight that you left after the last treatment and, if you have no problems with fluid overload and stable blood pressures at this previous weight, this is your “dry weight”; weight that is neither too much or too little
fluid in your body. That is your “goal weight” for your dialysis prescription. It takes time to determine the correct dry weight for you, and it is not uncommon that it has to change up or down as your body dictates. It is a reasonable estimate made by your providers. It is not a precise calculation or computer generated number. It is you and your provider’s best guess. This is less than ideal and one of the Achilles heels of dialysis at the present time. There are, however, advances in this field so a more technically accurate means of determining a safer dry weight is in the near future.

The normal kidney removes fluid from the blood volume gently and slowly 24 hours a day. If you drink 2 liters a day, your kidney eliminates most of this during the 24 hours. If you are a dialysis patient making little or no urine and you drink 2 liters a day, your dialysis prescription will require the removal of about 4 liters during one session assuming your last treatment was 48 hours ago. Those 4 liters must come out of your blood volume over 4 hours compared to 48 hours with your kidneys working causing a physiologic challenge to your cardiovascular system. It is a slight stress to your body during and after each dialysis treatment.

Because of the potential of fluid removal stress risk to you and your heart, the amount of fluid removed has limits imposed on the dialysis providers. The limits are based on common sense, a reasonable physiologic assessment, and government imposed restrictions preventing, what has been determined, as an unsafe volume of fluid removal per session based on your weight and dialysis time. You may disagree, and as mentioned earlier, dry weights do change, but it comes
down to what you wish and what the providers feel is in your best interest medically with what restrictions are imposed upon them. YOUR biggest control is how much fluid you take in between treatments. OUT of your control are the restrictions that are physiologic and mandated to your providers. To accommodate individual needs, dialysis times and/or frequency are variables that can help.

If you are on home dialysis – peritoneal or home hemodialysis -where treatments are different in duration and frequency than the typical in center system, the fluid issue is often less of a problem; to be discussed later in this guide.

**SUMMARY POINTS**

- **FLUID OVERLOAD IS A MAJOR ISSUE FOR MANY DIALYSIS PATIENTS.**
- **WHAT FLUID YOU TAKE IN HAS TO BE REMOVED BY THE DIALYSIS MACHINE.**
- **THE WEIGHT YOU GAIN BETWEEN DIALYSIS TREATMENTS IS WATER INGESTED. YOUR BODY DOES NOT CREATE WATER.**
- **YOUR DRY WEIGHT IS WEIGHT WITHOUT SIGNIFICANT FLUID ON BOARD.**
- **THE MORE YOU DRINK, THE MORE FLUID HAS TO BE REMOVED.**
- **REMOVING LARGE VOLUMES OF FLUID ON A DIALYSIS TREATMENT CAN CAUSE HARM TO YOUR HEART, BLOOD PRESSURE. AND BRAIN.**
- **LIMIT YOUR FLUID GAINS FOR SAFER DIALYSIS TREATMENTS.**
Salt

Your daily intake of salt depends on your diet. When your kidneys were working, you could take in as much salt in your diet as you chose, unless medical conditions dictated otherwise. What you took in was eliminated by the kidneys. Now, being on dialysis, that has changed. Salt excess will cause water retention in your body requiring fluid removal by dialysis. Salt aggravates the water balance problem. Salt causes the body to retain water. Salt does not produce water. Your body cannot create water. Water/fluid comes from intake only.

Excess salt is removed along with the excess water from the blood filtered during dialysis. Salt and water go hand in hand. You are being asked to limit fluid intake and salt intake to avoid fluid overload - edema, congestive heart failure, hypertension. It may be tempting to use salt substitutes that are available, but as most of these have potassium rather than sodium, you should not do so as potassium is also of risk to you - to be discussed next.

SUMMARY POINTS

- SALT AND WATER GO HAND IN HAND IN THE RISK OF FLUID OVERLOAD.
- AVOID EXCESS SALT INGESTION AND DO NOT USE SALT SUBSTITUTES IF THEY CONTAIN POTASSIUM.
Chapter 2

Potassium

What is the big deal about potassium? Potassium is responsible for nerve, muscle, and heart function. A high blood potassium can stop your heart without warning. It is a BIG deal.

“What goes in has to come out.”; the familiar theme highlighting the role of the kidney keeping elements in your body in balance. Your kidneys are responsible for eliminating potassium ingested from your diet intake to maintain safe levels. To rid the body of ingested potassium, the kidney has to function at least 15% of capacity and the ability to pass water/urine has to be present. Your kidneys may work less than 15% and potassium may not be a problem if you continue to make significant urine volumes. That is not typical. In some instances, potassium is a problem earlier, particularly in diabetics, or if medications being taken interfere with kidney potassium elimination. Until told otherwise, you should be VERY careful with potassium diet limits.

Fluid restriction and potassium restriction are the most discussed topics for the typical dialysis patient on a schedule of three days a week. As is the case with water and salt, patients doing home dialysis on peritoneal or home hemodialysis may have less need for restriction
because of the frequency and duration of those treatment options. This will be discussed later.

On dialysis days, most patients have a relatively high potassium representing diet intake for 48 hours since the last treatment. The dialysis prescription is adjusted for your known individual pattern based on labs drawn previously and is typically planned for potassium removal from the blood by the dialysis filter. If your next dialysis is beyond 48 hours, as occurs once a week with a three time a week schedule, the risk of a higher potassium is increased, and it becomes very important to try harder with your diet at these times.

As discussed above, what makes a high potassium so concerning is that most patients have no warning before a life threatening heart event occurs. Some patients may notice muscle weakness or difficulty walking which may be a clue that the potassium is dangerously high. That should be taken as a serious concern to you to seek immediate medical help and get to the closest hospital, BUT you CAN NOT rely on this being a warning sign and think you can buy some time before a life threatening event occurs. Most patients do not have recognizable warning signs of life threatening high potassium levels in their body.

Your dialysis dietician will review your blood tests which are done at the first treatment and at least monthly, or more if needed, to inform you of what your potassium levels are. This person is a great resource to provide diet written guidelines on topics including potassium related food choices.
You cannot rely on the dialysis prescription to “fix” your potassium problem if you cannot restrict your diet. Just like water removal limitations discussed earlier, there are industry standards based on government oversight that limit how much potassium can be removed safely during a typical dialysis treatment. If not controlled by your diet, your only options are more treatment time and/or more treatment frequency, if available at your facility.

**SUMMARY POINTS**

- POTASSIUM EXCESS CAN KILL YOU WITHOUT WARNING.
- AVOID HIGH POTASSIUM FOODS AND MAINTAIN A DIALOGUE WITH YOUR DIALYSIS NUTRITIONIST REGULARLY
Chapter 3

Dialysis access

Dialysis access depends on the type of dialysis you choose. Home dialysis using peritoneal dialysis will be discussed later. Hemodialysis access, in center or home, is the topic of this section.

Dialysis cleans your blood of excess water, salt, potassium, and waste products from metabolic pathways for day to day living. The kidney did all of this and more 24 hours a day, seven days a week. Typically, dialysis has to do all this work in a few hours three days a week.

The dialysis process depends on an efficient filter to clear your blood as it passes from your body and back to you. The higher the blood flow rate going through the filter, the better dialysis cleaning is done in this relatively short period of time. The major factor in high blood flow rates is the size of the blood vessel that is delivering the blood to the tubing to go through the dialysis filter.

AV fistula- See Fig 1 and 2

What is a fistula?—In dialysis terms, a fistula is a connection between your artery and your vein; usually in the arm or thigh. This connection is made under your skin surgically. Usually, only your vessels/tissue
are used and the fistula is called an AV fistula-arteriovenous. It will make a physical impression under the skin and will become prominent if it matures and develops the way it should. This is where two needles are placed to remove and return your blood through the dialysis machine.

Your blood vessel size and diameter, at first, is not large enough to use for dialysis, but the connection of your artery; a high pressure system, to your vein; a low pressure system, over time, causes the created fistula to enlarge to provide high volume flow for the dialysis process. Typically, it takes 3-6 months for this enlargement or maturation. If possible, having a fistula placed before 6 months of need for dialysis is the best way to go.

Hemodialysis catheter -

If you need dialysis before the fistula is mature and usable or as an emergency from medical complications in hospital, a temporary hemodialysis access used would be a dialysis catheter. A dialysis catheter is a pen size diameter tube placed typically in your neck vein and guided into a larger vein-superior vena cava-where it sits above a filling chamber or atrium of your heart. It is tunneled through the skin before entry into the vein and secured in place to prevent dislodgement. It is not a surgical operation, but a procedure done typically by a vascular radiologist or surgeon familiar with the procedure. The catheter has two opening or ports inside the vein and can be used repeatedly for dialysis, in or out, of hospital.
AV fistula versus hemodialysis catheter-

As discussed earlier, dialysis requires high blood flows to maximize the cleaning of your blood in a short period of time. An AV fistula is a high flow state with a larger access diameter allowing more efficient blood cleaning and fluid removal. The more efficient, the less time on dialysis you may require. A dialysis catheter is a low flow state with a lower access diameter cleaning the blood less over the same amount of time. If your house is on fire, would you use a low flow system to put it out like your garden hose attached to your house faucet or use a fire hose attached to a fire hydrant in your front yard? An AV fistula is the fire hose. A dialysis catheter is the garden hose.

An AV fistula is under your skin so infection entry to that system, when not being used, is minimal. A catheter goes from the outside to the inside through an entry on the skin, and there is a risk of infection, at any time, as long as it is in place. An AV fistula is your native tissue making a chance for infection less. A dialysis catheter is a foreign body and more easily infected and more difficult to treat, often requiring removal and reinsertion at a different site. Because of where the catheter is, a blood stream infection is more likely to happen and the potential of that infection involving your heart is possible as well.

An AV fistula has a longer lifetime. It is a high flow system made of your own tissue. There is no foreign material, which if present, causes the body to form clotting and access failure. A dialysis catheter is a foreign body and its presence in the vein is more likely to cause clotting that may make the catheter stop working and/or cause clots in the vein it is placed in.
AV grafts -

In some cases, your body’s blood vessels cannot support a fistula, but are good enough to be part of an access linked to graft material. The graft material is a foreign body and infection and clotting is more possible than a native fistula, but the risk is less than a catheter as it is all under the skin and no entry from the skin is present when not being used. It provides more efficient dialysis like a fistula does, and better than a catheter would do.

BEWARE -

AV fistula and AV graft, as mentioned, are high flow states. That high flow is due to the size of the vessel and the arterial pressure generated by the heart pumping. When a needle is removed from this type of access, it is imperative that pressure be applied to that site to prevent significant bleeding. Your dialysis staff will reinforce this and help you learn how this is done. If your fistula or graft is cut or punctured by accident, you are at risk of serious bleeding and death if not stopped properly. Again, your dialysis staff and access surgeon will teach you this. It is extremely important

BE AWARE -

Your AV fistula or graft is a constant flowing system. You should be able to feel the blood flowing through it like a steady hum. In essence, it is part of your body and should be monitored as such. You should make a habit of
feeling it regularly to make sure you feel the flow. It has the potential to clot in certain circumstances or without warning. If it does clot, you will notice a reduction or absence of the normal flow feeling. This needs to be addressed as soon as possible to avoid permanent loss of the access. Call your dialysis unit as soon as you notice this potential. If this occurs when the dialysis unit is not operating, call your doctor on call. Do not wait until the next day, regardless of what time it may be. The longer there is less flow or no flow, the less likely the access can be fixed.

Needle insertion in the skin to access the fistula or graft can be made easier and more comfortable with specially formed entry sites on the surface of the skin called “buttonholes” and a topical anesthetic cream applied to the skin prior to needle placement.

**SUMMARY POINTS**

- **THE DIALYSIS PROCEDURE TYPICALLY ATTEMPTS TO DO IN 4 HOURS WHAT YOUR KIDNEY DID IN 48 HOURS OR MORE IN A ROUTINE DIALYSIS WEEK.** THE MORE EFFICIENT DIALYSIS YOU CAN ACHIEVE, THE BETTER FLUID CONTROL, POTASSIUM CONTROL, SALT CONTROL, AND BODY TOXIN CLEARANCE YOU WILL HAVE.

- YOUR MORTALITY IS IMPROVED WITH MORE EFFICIENT DIALYSIS.

- **HIGH FLOW ACCESS LIKE AN AV FISTULA OR GRAFT PROVIDES MORE EFFICIENT DIALYSIS THAN A CATHETER OVER THE SAME PERIOD OF TIME ON THE DIALYSIS MACHINE.**
- **RISK OF INFECTION AND CLOTTING IS HIGHER IN PATIENTS WITH A DIALYSIS CATHETER.**

- **NO ACCESS IS PERFECT OR LASTS FOREVER, HOWEVER, YOU ARE MORE LIKELY TO HAVE MORE ACCESS PROCEDURES AND INTERRUPTED DIALYSIS SCHEDULES WITH A CATHETER THAN AN AV FISTULA.**

- **RISK OF ACCESS BLEEDING, IF NOT ATTENDED TO PROMPTLY AND PROPERLY, IS A SERIOUS PROBLEM WITH AN AV FISTULA OR GRAFT.**

- **MAKE A HABBIT OF REGULARLY CHECKING THE FLOW OF YOUR FISTULA OR GRAFT AND CONTACT YOUR DIALYSIS UNIT OR DOCTOR ON CALL IF YOU HAVE ANY CONCERN ABOUT A CLOTTING POTENTIAL.**

- **SOME PATIENTS DO NOT HAVE THE NATIVE VESSELS OR MEDICAL CAPACITY TO HAVE AN AV FISTULA. A DIALYSIS CATHETER IS THE ONLY OPTION IN THIS SITUATION. ALTHOUGH NOT IDEAL, IF YOU ARE IN THIS POSITION, YOU CAN MAKE THE OVERALL CATHETER RISKS LESS TO DO WELL ON DIALYSIS.**
**Chapter 4**

*Bone Health*

You would not think kidney function and bone health are related. Kidney failure has an adverse effect on many of your body’s systems and bone disease is one. The physiology of this process is multifactorial, complex, and changing frequently as new research adds more information to the topic each year. That said, however, a few basic concepts remain which will make your understanding and role in preventing bone disease relatively straightforward. It also makes it easier for your dialysis providers and dietician to make the case to you as it is a complex topic for them also. Not excluding myself from the fray, it makes it easier for me to try to have it make sense to you.

Bone has multiple functions. Although kidney failure affects all of these functions, skeletal stability will be the focus of this discussion. Unhealthy bone contributes to the morbidity of dialysis patients with a significantly higher rate of fractures compared to people not on dialysis.

Normal bone is continuously being broken down and built up. This is a healthy remodeling or turnover that maintains good bone integrity. The hormone system that is responsible for this turnover is Parathyroid Hormone-
PTH. PTH is secreted by four glands around your thyroid gland in your neck. You cannot feel or see these glands

**Phosphate** -

As discussed previously, the kidney maintains a balance by eliminating elements in your diet your body does not need or needs to get rid of for equilibrium. Phosphate is in almost every food ingested. PTH acts on the kidney to eliminate excess phosphate from your body. If the kidney does not function, there is retention of phosphate in your system.

Phosphate retention causes a cascade of events that harms your bone integrity. This is where it becomes complex, but suffice it to say, a high phosphate hurts bone. A major mechanism of this harm is PTH action on bone in this setting. PTH is abnormally high when phosphate levels are high and when there is kidney failure. When PTH levels are high, there is bone injury as there is more bone break down than rebuilding. This abnormal breakdown weakens bone making it more susceptible to fracture.

Control of phosphate is directed at reducing stomach absorption by medications taken with meals. These medications are called phosphate binders. There are multiple choices you and your dialysis dietician will discuss. The goal is to bind the phosphate taken with meals so it is not absorbed into your system. Depending on your calcium level and other factors, your dialysis providers and dieticians will make recommendations, but like many things, as a dialysis patient, your compliance
is needed to make it work. A high phosphate in your system can also cause a life threatening skin disease called calciphilaxis in addition to bone disease. This is a serious complication of poor phosphate control, and at times, not successfully treated. This will also be discussed with you by your dialysis team reinforcing compliance with binder use.

**Calcium and Vitamin D -**

PTH, calcium, and phosphate are related both in bone disease and calciphilaxis. A high phosphate blood level will cause PTH to increase which will cause more calcium to be released from bone. Again, the mechanisms are complex, but bone become less calcified and weaker.

Calcium requires active Vitamin D for proper diet absorption of calcium needed. The kidney is the major site where active Vit D is made and in kidney failure this becomes deficient. Most people on dialysis are Vit D deficient. Low Vit D levels contribute to bone weakening and studies suggest a higher risk of heart disease as well. Fortunately, Vit D can be taken as a medication to replace what the kidney does not make so Vit D levels and calcium balance are better maintained. Your dialysis dietician can advise you on the need for Vit D replacement and, like all of your other labs, these levels are checked regularly to guide replacement therapy as needed.
PTH - Parathyroid Hormone

PTH was introduced previously. Most people with significant kidney disease and patients on dialysis have abnormally high PTH levels. High PTH levels contribute to weaker bones and sometimes calciphaxis in some patients. High PTH levels are associated with higher mortality in dialysis patients. Control of phosphate levels by binders and replacement of Vit. D is often NOT enough to reduce high PTH levels. There are medications you can take or the dialysis providers can give you at dialysis to help control this. If the process has been uncontrolled for a long period of time, these medications may not work and surgical removal of the parathyroid glands in the neck is required. The earlier and better control of PTH, the less likely surgery is needed.

**SUMMARY POINTS**

- **MOST PATIENTS ON DIALYSIS HAVE BONE DISEASE.**

- **CONTROL OF PHOSPHATE, CALCIUM, VIT D, AND PTH CAN IMPROVE THIS BONE DISEASE REDUCING THE RISK OF SPONTANEOUS FRACTURES AND PREVENTING A POTENTIALLY LIFE THREATENING SKIN DISEASE.**

- **DIETARY AND MEDICATION COMPLIANCE IS MOST IMPORTANT FOR YOU TO KEEP YOUR BONE HEALTHY.**

- **CONTINUE AN AGGRESSIVE AND REGULAR DIALOGUE WITH YOUR DIALYSIS PROVIDERS AND DIETICIANS.**
Chapter 5

Anemia

EPO - ERYTHROPOIETIN

The kidney produces the hormone for your body to make blood. That hormone is called erythropoietin - EPO. EPO causes the bone marrow to make new blood cells on a regular basis just like PTH causes the bone to form new bone on a regular basis. When your kidneys fail, the production of that hormone - EPO - diminishes and blood formation decreases resulting in a low red blood cell count or anemia.

Anemia will make you tired, cold, and not able to have the energy you would like to have for daily living. Everything becomes a task and fatiguing. This is one of the earlier and most significant advances in nephrology that has allowed kidney failure patients and dialysis patients to live a more normal life. In my career, except for transplant gains, it is probably the single most important advance in improving the quality of life of a dialysis patient.

The absence of this blood making hormone resulted in patients having a red cell blood count - hematocrit - half or less than normal. Besides the major adverse effect on wellbeing, it contributed to a much higher rate of heart disease and other complications increasing mortality in a dialysis patient. The only treatment was regular blood transfusions. Multiple transfusions resulted in additional
complications and only improved the anemia for a few weeks. For the most part, dialysis patients have been spared this debilitating complication of kidney failure. Fortunately, symptomatic anemia is a thing of the past in dialysis history thanks to EPO.

Your kidney does not make EPO, but the hormone is available to all dialysis patients and is given in a preset schedule to you during your treatment. This form of EPO, which has many names and has evolved pharmacologically, essentially provides what your kidney does not, to prevent significant anemia. There are very few adverse reactions. It is given to you on a regular schedule during your dialysis procedure or you give it to yourself as a home dialysis patient.

Iron -

In order for EPO to make red blood cells, iron is needed. Without iron, the EPO will not work. Almost all patients require regular dosing intervals of iron based on levels monitored for each individual. There are many preparations of iron. Some patients have an allergy to one type of iron so different forms are available should that happen. All iron must be given by vein. Oral intake of iron will not work. Your dialysis staff will advise you on what your iron levels are and when more iron may be needed.

Bleeding, infection, and illnesses requiring hospitalization contribute to anemia often requiring more iron and EPO dosing to keep your blood count in
a safe range. EPO and iron do not create blood immediately. It takes time for the blood to be made (roughly 7 days) as it does naturally in patients not on dialysis. It is important to not fall behind on your scheduled doses of EPO and iron because of the time required for natural blood formation. If you are in need of immediate blood, that can only be accomplished by a blood transfusion.

SUMMARY POINTS

- DIALYSIS PATIENTS DEVELOP ANEMIA FOR MULTIPLE REASONS.

- THE KIDNEY MAKES THE HORMONE – EPO-THAT CAUSES BLOOD FORMATION BY THE BONE MARROW AND, IN KIDNEY FAILURE, THE LEVELS OF THIS HORMONE ARE TOO LOW TO MAKE ADEQUATE BLOOD.

- THIS HORMONE CAN BE GIVEN TO YOU WITH YOUR DIALYSIS TO PREVENT YOU DEVELOPING ANEMIA DUE TO LACK OF EPO.

- THIS HAS BEEN A MAJOR IMPROVEMENT IN QUALITY OF LIFE FOR DIALYSIS PATIENTS.

- EPO NEEDS ADEQUATE IRON STORES TO WORK.
Chapter 6

Clearance - Adequacy of dialysis; your dialysis clearance calculation.

Why do I have to stay on dialysis longer?

I am not a big fan of clearance but try to endure this, as it is something you may be asked to make decisions about for your dialysis prescription.

How much dialysis does a person need?

The simple but unrealistic answer is: as much as possible.

Your kidneys, when working normally, provided 100% filtering/cleaning of your blood. Hemodialysis in center with the typical schedule of 3 times a week at 4 hours or home peritoneal dialysis, provides about 9% of the normal working kidney or 9% of filtering your blood. Home hemodialysis, depending on the frequency, may provide a little more, but all dialysis modalities do NOT come close to “normal” kidney capacity. The more the dialysis, the more the filtering/clearance and the healthier you will be. The next milestone researchers are working on is a wearable kidney hemodialysis filtering device that works 24 hours a day, 7 days a week to
more closely provide that 100% capacity that normal functioning kidneys do. It is not available yet but on the horizon.

Early in my career, dialysis clearance was not a hot topic. Essentially, people managed to do pretty well on a dialysis schedule that was determined by patient survival, patient wellbeing, functional capacity, fluid, and potassium control, and dialysis unit scheduling to accommodate the growing population of dialysis patients. That framework was 3-4 hours 3 days a week - MWF or TTS. Each shift had a “weekend” where an extra day was skipped. The dialysis unit was not open on Sundays. This remains as the starting point for building your dialysis schedule, but clearance data has changed the specifics of what is set up for you in those prescribed times.

We have looked at salt, water, phosphate, calcium, and potassium; only a few of the many elements your kidneys are responsible for maintaining neutral balance. The inability of your kidneys to eliminate normal metabolic waste products made daily by your body has profound effects on your neurologic system and brain functioning. In kidney failure these toxins are not eliminated and when high toxin blood levels occur, neurologic symptoms/signs including twitching, seizures, confusion, and coma may result. Retention of these neurologic toxins is called uremia and the goal of adequate dialysis to prevent a high level of these toxins with regular dialysis so the neurologic damage does not occur.

Investigators have tried to label, measure, and speculate about what these “toxins” are. Indeed, some
are unknown and how do you measure an unknown? Regardless, they proceeded and developed multiple mathematical equations to attempt to define a dialysis clearance model to reduce these elements to an amount determined to be an acceptable standard. Dialysis time, blood flows, before and after measurements of elements like urea (sounds like uremic), and many other factors were included in the calculations. They then applied these models with different dialysis times, blood flows, filter clearances, and more, to patient trials to see if a certain model would result in a less “uremic” patient population. The results of multiple studies ushered in a goal or “minimum amount of clearance that had to be obtained with each dialysis procedure to produce the best result in the realistic time constraints of a typical dialysis schedule.

These calculations are performed with the help of a computer during your dialysis at least once a month. If the mathematical clearance minimum or goal is not reached, your dialysis prescription may be altered. You may need a higher blood flow which you can achieve with a fistula or a graft access compared to a catheter. You may need a bigger dialysis filter. You may need more time to stay on dialysis on the days you are scheduled to come. These measurements will be discussed with you on a monthly basis with your dialysis team.

SUMMARY POINTS

- CLEARANCE STUDIES OF YOUR DIALYSIS ARE DONE REGULARLY.
IF THE RESULTS DO NOT MEET THE MINIMUM STANDARD, YOU WILL BE ASKED TO MAKE SOME CHANGES TO YOUR DIALYSIS PRESCRIPTION TO ATTAIN THE GOAL.
Chapter 7

Home dialysis

At present, home dialysis (home therapies) is increasing in popularity. Instead of going to the dialysis facility 3 or more times a week for 4 hours or more, your dialysis is done at home by YOU. There are two options of dialysis for the home setting.

Home hemodialysis -

Home hemodialysis has the same access for blood flow described above. The dialysis machine and filter are much smaller than the facility equipment. You typically do dialysis 4-5 times a week in shorter intervals 3-4 hours. This frequency and duration depend on your fluid gains and clearance results of whatever schedule you start. This is variable to the individual and may need to change for the same individual over time as results dictate.

You typically have a home partner with you. You are taught to place the dialysis needles in your own access or have your partner do it for you, or both. You set up the dialysis machine, connecting tubing, and all that is needed for the dialysis procedure. Your training takes several weeks to a couple months depending, and you have the home therapies staff at your dialysis facility available for support as well as home visits. All of the equipment
and supplies are provided to you by the dialysis unit. Typically, you come in to the home therapies unit to meet with the nursing and support staff as well as your dialysis doctor once a month.

It sounds difficult and complex. It certainly requires compliance and commitment on your part to do this. It is not as difficult as you may imagine if you are motivated to learn and want to enjoy the advantages of schedule independence, and for many, the convenience of being at home for your treatments. It is not for everybody. You, your doctor, and the dialysis nursing staff decide if this is appropriate for you.

At some point, if you wish or medically have to change to the routine in center program, you may do so.

**Peritoneal Dialysis - See Fig. 3 and 4**

Peritoneal dialysis is a form of dialysis where an indirect exchange from your blood to fluid placed in the free space of your abdomen - peritoneum- takes place. The peritoneal cavity is like a barrel where organs and blood vessels are located in an open space. This open space is where the dialysis fluid is placed and the transfer to clean your blood occurs slowly. There is no needle placed in a blood vessel access. The spider web complex of blood vessels supplying your intestines in the peritoneal cavity is the source of exchange to dialysis fluid you place into the peritoneum through a tunneled catheter entering the peritoneal space from the skin site on the abdomen. The excess fluid and elements your body needs to have removed leaks out of the blood capillary membranes into
the peritoneal dialysis fluid leaving the actual red blood cells – your blood - behind undisturbed in the circulation.

It sounds complicated, but is actually pretty simple. You, or a machine you have at home, place 2 liters of clean dialysis fluid into the free space of your abdomen (the peritoneal cavity) and it stays there for about 4 hours where exchanges of good fluid for bad elements take place and then the fluid is drained from your body through the catheter and discarded. If it is done manually by you during the day, you go about your business while the fluid transfers take place. The fluid goes into the free space of the abdomen NOT your stomach. The excess potassium, salt, and water as well as other elements including renal failure toxins needed to be cleaned from your body are eliminated during each time fluid is put in, which is called an exchange. There are typically four exchanges a day that can be done manually or set up to take place overnight, when you are sleeping, by a dialysis cycler machine so you typically can be free of doing the dialysis exchanges during the day.

This also requires learning, compliance, and commitment. You will be taught sterile technique with the device designed to put fluid in and out to minimize the chance of infection. It is typically done every day of the week. With the cycler set up at night, your independence during the day is a great advantage. Many of my patients who worked full time chose this option. The catheter placement into the peritoneum is a minor surgical procedure.
Peritoneal dialysis most closely resembles what your kidneys did. It is a slow process and able to manage removal of excess fluid, potassium, salt, other waste elements, and renal toxins over 24 hours rather than pushing all of this task into a 4 hour hemodialysis treatment 3 times a week. Fluid removal is better tolerated and low blood pressure complications are less AS LONG AS THE PRESCRIPTON IS CORRECT. That will be determined by your doctor. It is safer for unstable heart patients with less heart stress.

Not everyone can do peritoneal dialysis. If you have had multiple abdominal surgeries, the free abdominal space may not support it. If you have inflammatory bowel disease or diverticulitis, it will not be a choice you would be offered.

A survey was conducted asking nephrologists - kidney doctors - what form of dialysis they would choose if they had to do dialysis. The majority selected peritoneal dialysis. I would choose the same.
Chapter 8

Your routine medications

Do I still take all my medications I have been taking before dialysis?

Most people require the medications they have been prescribed before becoming a dialysis patient. There are some significant changes possible, however. If you have been taking medications for hypertension, you may not need as much. Fluid retention worsens hypertension and because excess fluid is removed with dialysis, you may need less medication to control your hypertension. If medications are still required, you will likely need to change the timing of the medication on dialysis days to prevent low blood pressure with dialysis fluid removal. This is something you will need to clarify with your doctor and dialysis nursing staff.

As kidney failure worsens, diabetics often need less insulin or diabetic medications as your insulin levels remain higher in your system than when kidney function was normal. Again, you will need to discuss this with your medical/dialysis providers.

If you have been taking a diuretic or “water pill” and you no longer make urine or make very little, it is likely you do not need to continue this. Confirm this with your doctor.
The above are some of the more frequent medication examples that dialysis may influence. You should go over each of your individual medications with your medical provider and dialysis staff. If new medications are given to you while you are a dialysis patient, it is very important the dialysis medical staff is aware and kept up to date.

**SUMMARY POINTS**

- SOME MEDICATIONS YOU WERE TAKING BEFORE STARTING DIALYSIS MAY NEED TO BE ADJUSTED AS TO DOSE AND TIMING OF TAKING THEM.

- CHECK WITH YOUR DOCTOR TO DISCUSS EACH OF THEM.

- ANYTIME YOUR MEDICATIONS ARE CHANGED OR IF A NEW ONE IS ADDED INFORM THE DIALYSIS STAFF.
Chapter 9

Transplant

This is a relatively small chapter to discuss the largest medical achievement for dialysis patients. In my practicing career, the advancements in this field have been major and continue to develop.

Dialysis does not, nor ever will, replace all of the important roles the kidney plays in your day to day health. Patients are better medically and live longer with a functioning kidney. A transplanted kidney is a single organ. People who are born with a solitary kidney or have only one kidney do well, as long as that kidney is healthy.

You may not be a transplant candidate. There are many factors that determine your ability to receive a kidney transplant. The most important factor is what other medical problems you have besides kidney failure. You will need multiple tests and consultant medical evaluations to determine your suitability. Advancing age, to a limit, is not a hard exclusion. A diagnosis of active cancer, unstable heart or severe vascular disease will exclude you. The actual surgery is not the biggest risk. It is not a very complicated procedure unless you are having a pancreas transplant at the same time for diabetes. It is the medication needed to suppress your body from rejecting the kidney that poses more of a long term risk for infection and other complications.
Sources of the transplanted kidney include cadaver, living related, or living unrelated. The cadaver source is the most common and, at the time of this writing, the unit I have been affiliated with has about a 2 year waiting list in the common organ donation system it is part of. Living related is the second most common source. Based on tissue matching compatibility parents, siblings, and children are in the living related category. Living unrelated can be from a random common pool of unknown donors through network organ donation system or more often from friends or spouses. A living unrelated kidney from a friend or spouse or a living related kidney does not result in the waiting time associated with the cadaver option. If such a donor is known well enough in advance before you need to start dialysis and has the required work up completed, you may not have to be on dialysis before the transplant occurs but this is uncommon.

Most patients are on dialysis at the time of transplantation. If you have not been compliant with your dialysis regimen; missing treatments or not taking medications suggested while a dialysis patient, you will not be considered a serious candidate to receive a kidney transplant.

Part of your initial orientation at dialysis will include discussion of the transplant option. You may have had some of that conversation with your kidney doctor in the office setting before starting dialysis.
SUMMARY POINTS

- Dialysis can help replace some of the critical functions of the kidney but a transplant is medically superior.

- Before starting dialysis discuss your potential options for transplant with your doctor.
Chapter 10

Stopping dialysis

Not an uplifting topic but you have the right to know, and to avoid the subject would make this booklet incomplete.

Some people do well with dialysis for decades. Some do not. Some people develop terminal cancer while they are dialysis patients. Some people suffer the ravages of other organ failure from the same disease that damaged their kidneys or new illnesses unrelated. Some people get tired of the whole process and decide for many reasons they have had enough.

Stopping dialysis will result in your death. The period of time this takes is different for various reasons. If you make urine you will typically survive longer than if you have no urine volume. How long is that? No one can tell you but stopping dialysis will cause your death as early as a few missed treatments or weeks. Unless there is significant fluid overload, and to a degree you can try to prevent that, it is generally painless. The most common cause of death is a high potassium stopping your heart.

If you decide to stop dialysis, you will need to talk with your dialysis doctor. For obvious reasons, social work and nursing will be involved. They, like your doctor, will want to make sure that it is truly your wish and be certain your
family is involved. It is, however, your decision as long as you are mentally competent. There is no complicated legal procedure. You will need to have DNR-Do Not Resuscitate-order on record which the social worker and your doctor can assist you with.

**Deciding NOT to start dialysis -**

Some patients choose not to start dialysis when medically necessary. This decision may be made in the hospital setting where kidney failure is likely permanent and other organ damage is irreversible, making life prolongation with dialysis futile in their opinion. The decision may be made in the office when early kidney failure is diagnosed and, for whatever reason, they choose not to pursue it, if and when needed. Again, mental competence must be present, and all information provided by medical providers is complete before such a decision is made. They choose this fully aware death will result as it will in stopping dialysis discussed earlier in this section. There are multiple services available, including hospice, to help them with this plan.

**SUMMARY POINTS**

- THERE MAY BE A TIME YOU WISH TO DISCONTINUE DIALYSIS.
- YOUR DOCTOR AND DIALYSIS SUPPORT STAFF WILL DISCUSS THIS AT LENGTH WITH YOU TO BE CERTAIN OF YOUR MENTAL CAPACITY AND INTENTIONS.
- HOSPICE SUPPORT IS AVAILABLE TO YOU AND YOUR FAMILY.
Chapter 11
Common questions not covered so far:

Will my kidneys improve so I can come off dialysis?

If you had acute kidney failure as a result of a serious illness, accident, or complications of a hospitalization and your kidneys were working normally prior to the event, there is a chance your kidneys will recover enough function to not need dialysis. There are “acute kidney failure” programs included in some outpatient facilities for such situations. If none exist in your area, you will be followed in the outpatient dialysis center by your doctor and staff to watch for the possibility of recovery. This is determined by regular blood tests and you continue to be a dialysis patient until it is determined you have enough improvement to stop dialysis. If no improvement is seen within the first six months, the likelihood of recovery is less, but regular labs will still be done to monitor that potential.

How am I going to pay for this? I need help with transportation. This is a bit overwhelming. Who can I talk to for practical and emotional support?

The dialysis is covered by your insurance and/ or Medicare. Your social worker is an invaluable source for these concerns and more. The needs of a dialysis patient
are unique. These trained individuals are part of your treatment plan and available on site from day one of your dialysis.

Why do I feel cold all the time?

Anemia was the predominant reason patients felt chilled. With EPO, discussed previously, that is now better treated. Even with improved blood counts, it remains a complaint in some patients. No good explanation for this has been described to my knowledge.

My legs are jumping especially at night. Why?

Kidney failure affects your nervous system in variable degrees. Uremia, discussed previously, is associated with toxins that can contribute to this form of neuropathy and the common term is “restless leg syndrome”. More dialysis clearance may help but often medications need to be prescribed to help this. Not all dialysis patients have this and in some diseases, like diabetes, this occurs more frequently.

I just finished my routine hemodialysis dialysis treatment. What are some potential problems I am not aware of?

You may have a lower blood pressure than you are used to, making you lightheaded or at risk for passing out. As discussed previously, fluid has been removed from your blood circulation during your treatment time.
It takes time—minutes to hours—for your body to adapt and restore your normal blood pressure. The more fluid you gain between dialysis treatments, the more has to be removed and the more likely your body may take time to adapt in restoring your blood pressure.

Most hemodialysis treatments use an anticoagulant or blood thinner like short acting heparin to keep your blood from clotting the cleaning filter as your blood passes through the dialysis machine. For a short period of time AFTER your treatment, you may be at risk for bleeding if you have a procedure like dental extraction or another form of tissue injury. For the same reason, if you have had a significant fall or trauma BEFORE your next hemodialysis treatment, let the dialysis staff know before starting the dialysis treatment.

How do I watch for infection of my dialysis access?

Infection at the site of a dialysis access or in the dialysis access does occur and you need to be very watchful for this potential. Sometimes, the skin around the access becomes infected, and depending on its course, it can cause an infection inside your body and/or blood stream requiring the access to be removed to cure it. Hemodialysis catheters are more likely to have infection issues than an AV fistula or graft. Peritoneal catheters also have infection potential.

Hemodialysis catheter patients may develop an infection at the skin entry area called the exit site. Redness, soreness, or pus like drainage are signs of infection. The infection can enter your blood stream
causing a serious infection. This usually requires hospitalization for IV antibiotics, catheter removal, and replacement at another site. Patients with a hemodialysis catheter cannot swim in a pool or take a shower with water exposure to the entry site because of the risk of infection potential.

An AV fistula or graft can also have infections. The skin site over the fistula or graft can become infected as needles are placed through the skin, but the chances are less if good sterile technique is used. An AV fistula is less likely to be infected than an AV graft, as the graft is foreign material. If infected, part or all of the graft has to be removed. Warning signs are redness, soreness, and pus drainage. The infection of the skin over the fistula or graft can also lead to blood stream infection.

A peritoneal catheter can have a skin related infection at the exit site with the same warning signs. If the infection enters the body from the skin it will cause an infection of the free space in the abdomen where fluid is placed to do the exchange. This infection is called peritonitis and warning signs are significant abdominal pain and a cloudy, hazy fluid appearance of the drained exchange compared to normal clear drain fluid. Patients on peritoneal dialysis cannot swim in lake water because of higher risk of infection than a chlorinated pool.

An infection at the exit site of a hemodialysis catheter, AV fistula, AV graft, or peritoneal catheter requires prompt recognition and antibiotic treatment. Sometimes this does not require hospitalization. As soon as any of the warning
signs appear, you should contact your dialysis nursing staff or kidney doctor on call.

What happens if I have to be hospitalized?

Not infrequently, you may find yourself in hospital, and depending on the reason, having to stay several days. You will have your needed dialysis in the hospital. The treatment schedule will be determined by your medical condition and the in-hospital schedule. The medical dialysis providers managing your dialysis while in the hospital may not be the same ones you have been seeing as an outpatient for logistic reasons.

Medications that you had been receiving in the outpatient setting to manage your anemia, bone disease, and other systems will be available to you while you are in the hospital, BUT you should confirm with the in-hospital dialysis staff those will be continued.

Unless you have a very extended stay; months typically, when discharged you will have your regular outpatient dialysis schedule.

I want to travel. How does that work?

Patients on in-center hemodialysis or home therapies hemodialysis or peritoneal dialysis can travel pretty easily in the United Sates. International travel may present some obstacles but not insurmountable depending on where you are going. Your social workers are your travel agents
from the dialysis point of view. Travel, including cruises specifically designed for dialysis patients, are popular.

*Can I become pregnant if I am on dialysis?*

The hormonal changes that occur with kidney failure make the likelihood of conception less but not impossible. Patients with advanced kidney failure and those on dialysis can become pregnant. The incidence of miscarriage is higher because of the uremic environment necessitating daily hemodialysis (six times/week) to optimize the potential of a successful pregnancy outcome. It is uncommon, but I have seen a few in my career.

*What about my flu shot?*

You will be given vaccines for influenza, hepatitis, pneumococcal, and other potential infection risks on a regular schedule by the dialysis staff at your unit.

*What if I am too sick to go to dialysis at my scheduled time?*

If you feel you have need to go to the hospital instead of dialysis for an emergency, then, of course, you should do so. If it is not emergent, skipping your dialysis scheduled appointment puts you at more risk for serious medical problems. You cannot afford to miss a regular dialysis treatment for all the reasons discussed in this booklet.
What is the problem if I show up to dialysis later than my scheduled time?

Your time slot on dialysis is yours. If you come late, you will not be able to either get your treatment, or the treatment will be shortened. Other patients are scheduled the same day, and there is little wiggle room to do the correct dialysis prescription you have other than in your dedicated time slot. If you know of a scheduling conflict, call the dialysis unit in advance, so you can still get your full treatment at a different time that works for you and the facility.

Why am I being put on dialysis at a later time than my scheduled time?

Hopefully, this does not occur often. It is understandably frustrating to you. The dialysis unit schedule is a tight one. Many patients are done during the day and evening. Sometimes, events occur that are out of anyone’s control that will delay starting you on time.

What does my doctor do?

Your doctor, nurse practitioner, or physician assistant oversees your dialysis prescription and your dialysis related medical progress. You will see that person on a regular basis at the unit rounding on you and other patients. Typically, you do not need to be seen in the kidney doctor’s office once you start dialysis. Your labs, which are done at least monthly, are reviewed by your doctor, the dialysis nursing staff, and dieticians.
Now that I am on dialysis do I need to see my family doctor anymore?

Yes. Your regular family doctor and other doctor specialists continue to treat the issues that remain in their field of expertise. Your kidney doctor can manage specific topics related to kidney failure like bone health or other topics discussed previously in this booklet, but medical problems unrelated are usually best handled by your other providers.
GLOSSARY OF TERMS:

ACCESS - The surgical device used for your dialysis procedure.

AV FISTULA - Arteriovenous fistula - A surgical connection between your artery and vein to create a high blood flow vessel under the skin where dialysis needles are placed for the hemodialysis treatment. Once created, it takes about 3 months before it enlarges to be usable for hemodialysis.

AV GRAFT - Arteriovenous graft - A surgical connection between your artery and your vein which uses synthetic material to create a high blood flow vessel under the skin where dialysis needles are placed for the hemodialysis treatment. This is used if the native blood vessels will not support a fistula. Once created, it can be used within days, but this is more prone to clotting compared to a fistula above.

CALCIPHYLAXIS - A complication dialysis patients are at risk for in the setting of uncontrolled high phosphate levels and PTH levels that involves the subcutaneous tissue- tissue under the skin-and the skin overlying. The tissue has abnormal amounts of calcium deposits blocking the small feeding blood vessels or capillaries of the tissue resulting in pain at sites involved; abdomen, thigh, leg more commonly. This process can lead to tissue death, infection of the area involved, and life-threatening infection to you.
CLEARANCE - The measured value of your blood cleaning during the hemodialysis procedure or peritoneal dialysis procedure. It describes how well your dialysis prescription is working. If the value is not meeting certain required standards, changes to your dialysis prescription will be needed.

CLOTTED FISTULA/CLOTTED GRAFT - The formation of a blood clot in the hemodialysis access that blocks the blood flow through that system. That lack of blood flow prevents you from having dialysis until it is opened up by a surgeon, vascular radiologist, or another access specialist. If not attended to in a timely fashion, it may fail permanently requiring a new dialysis access procedure.

DIALYSIS PRESCRIPTION - The specific orders for your dialysis procedure including time on the machine, dry weight goal, filter size, blood flow rate, and medications to be given during the procedure – EPO, Iron, etc. For peritoneal dialysis, this is similar but in a format specific for this mode of dialysis.

DRY WEIGHT - The body weight that is considered to be your normal weight without excess fluid. It is the goal the dialysis is set to attain with fluid removal for each treatment. Weight in most units is measured in kilograms. One liter of fluid weighs one kilogram which is about 2.2 lbs.

EPO- ERYTHROPOIETIN - The hormone that is responsible for creating new blood formation in your body. It is made in a normally working kidney but not in a
failed kidney. It is available to dialysis patients as a medication supplement to their dialysis prescription to prevent the severe anemia kidney failure patients would otherwise have.

PARATHYROID – PTH - four glands in your neck that regulate calcium, phosphorus, Vit. D, and bone turnover.

PERITONEUM - The free space in your abdomen where small blood vessels, intestines and other organs reside. This is the space peritoneal dialysis fluid is placed for dialysis exchanges.

PERITONITIS - An inflammation; usually infection in peritoneal space. In peritoneal dialysis the infection usually comes from outside the body into the space, but on occasion, the infection comes from bowel disease within the peritoneum.

PHOSPHATE BINDERS - Medications taken with meals to lower phosphate absorption from the stomach used to prevent high levels of phosphate that can lead to medical complications with renal failure.

UREMIA - a neurologic term to express kidney failure toxin accumulation affecting a patient in various forms.
Terms not referred to in this booklet but in common use in kidney disease:

CKD - CHRONIC KIDNEY DISEASE - A term that describes various levels of kidney failure -1 through 5 -as kidney functions worsens.

ESRD- ENDSTAGE RENAL DISEASE - A classification of kidney failure describing patients dependent on dialysis to live.

PERMCATH - This is the tunneled catheter placed under your skin and into the large vein discussed under ACCESS in this booklet. I did not use the term “Permcath” as it is short for ”permanent catheter” and there is nothing “permanent” about them. They are less than ideal for dialysis as discussed, and as they are prone to infection, they need to be replaced on occasion. In some circumstances, however, this is the only option you may have, and all efforts will be directed to make it work for you.

RENAL - Pertaining to kidney.
Figures 1-4 used with permission.
Fig. 2
Fig. 3 and 4
I hope this booklet has provided information to help. You have much living to do as a dialysis patient. Ask questions, be informed, and play an active role in making this therapy work for you.