

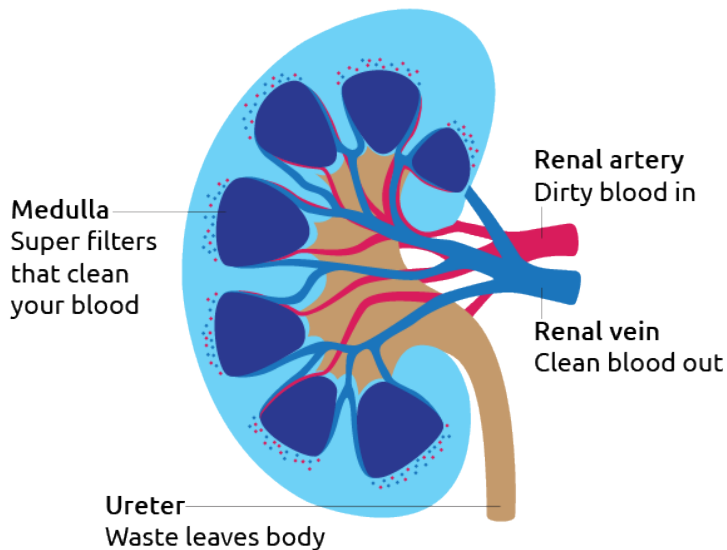
Living with Kidney Disease



Living with kidney disease can be challenging and overwhelming at times. Major lifestyle changes, complex medical decisions, and multiple medications can be a lot to navigate. We want to help you be an active and informed member of your healthcare team. We have put together this booklet for you and your loved ones to help understand your diagnosis, plan for your future, and live your life to the fullest.

This booklet will tell you more about:

- Chronic Kidney Disease
- Your Care Team
- Treatment Choices (Including Dialysis, Kidney Transplant, and Conservative Treatment) and Appendices I and II
- Your Medications
- Living with Chronic Kidney Disease
- Additional Resources



The Kidneys

What are my kidneys?

You have 2 kidneys, each about the size of your fist. They sit in the middle of your back, just below your ribcage. Your kidneys:

- filter your blood by removing waste and extra water
- keep your chemicals balanced
- help control your blood pressure
- make hormones
- clear medications out of your body

What is Chronic Kidney Disease?

If your kidneys are damaged and can't filter your blood as well as they should your doctor may diagnose you with Chronic Kidney Disease (CKD). CKD is a chronic condition which means it is long term and you will likely

have it for the rest of your life. It may get worse over time. There are five stages of CKD and End Stage Renal Disease (ESRD - sometimes called kidney failure) is the last stage. This is the time when dialysis or transplant is needed to stay alive.

Your doctors will use a blood test called eGFR (glomerular filtration rate) to see how your kidneys are working. Your eGFR level tells your healthcare provider how much kidney function you have. Because CKD is an on-going condition, your kidney function will often get lower over time.

What causes CKD?

There are many reasons why someone may get kidney disease. Here are some common causes:

- Diabetes
- High blood pressure- also called hypertension
- Glomerulonephritis- a disorder where the kidneys become inflamed and damaged
- Polycystic kidney disease- a disease that runs in families that causes lumps on your kidneys

If your kidney disease is caused by another health problem like the ones listed above, your doctor will try to treat the problem to help improve your kidney function. For example, if you have high blood pressure, your doctor may ask you to take blood pressure medicine, change your diet and quit smoking to help your kidneys improve.

Living with Kidney Disease

Stages of kidney disease

Kidney function is categorized into 5 stages (see table below). As the numbered stage of kidney disease increases, kidney function decreases. Remember, your eGFR level is a measure of how well your kidneys are working.

Stage	What's happening in your body	Your eGFR
1	Some kidney damage but a normal eGFR	90 or above
2	Kidney damage with a slightly lower eGFR	60-89
3	Medium decrease in eGFR	30-59
4	Large decrease in eGFR	15-29
5	Kidney failure- also called End Stage Renal Disease (ESRD)	Below 15

What will happen to my body as my kidney function decreases?

As you move into later stages (stages 3, 4, and 5), you may start to develop other medical issues related to your chronic kidney disease. You may need more medication for blood pressure control, it may be harder to control any swelling and you may need more aggressive therapy for heart disease. Other medical issues often develop as well including anemia (low blood count) and decreased bone health (also called secondary hyperparathyroidism). Most patients who move to stage 4 CKD feel very tired and have low energy. You may also not feel hungry. Some patients feel sick in the morning or occasionally vomit. Others notice a change in the way foods taste. All of these factors make it hard to eat a healthy diet. You may lose interest in your usual activities and feel like you can't do the things you used to be able to do. This can develop slowly over time or progress quickly depending on your overall health. This is why we like to talk about the best treatment options for you as your kidney's start to fail. Some options include:

- Kidney transplant
- Dialysis (medical treatment that removes waste and extra water from your blood)
- Conservative therapy (managing symptoms without using transplant or dialysis)

You can learn more about these different treatment options in the next pages of this booklet.

Finding out what option is best for you takes time- sometimes between 6 and 12 months. Our care team will spend lots of time teaching you and your family about each of these treatment options and discussing your treatment goals, before deciding which treatment option is best for you.

Your care team

As kidney function declines, care becomes more complex. You will be working with a support network of providers and specialists to help you stay as well as possible. This care team includes you, your family, your primary care provider, your nephrologist (kidney doctor), the dialysis unit staff, clinical charge nurse, social worker, care manager, dietician, and others.

The combined goal of this team is to provide the best care possible for each individual. Here is a place for you to keep track of your kidney care team:

Team Member	Description	Name	Contact #/email
Patient:			
Health Care Power of Attorney (POA)	Person to make decisions for you if you are unable to		
Primary Care Provider (PCP)	Healthcare specialist often a doctor, Nurse Practitioner, or Physician Assistant		
Nephrologist	Kidney doctor		
Physician Assistant and Nurse practitioner	Assists in Medical Care		
Dialysis Facility	Where you go for dialysis		
Clinical Charge Nurse	Head nurse at your dialysis unit		
Care Manager	Nurse team leader who coordinates care at home		
Social Worker	Assesses and coordinates patient needs, social support		
Dietician	Educates and guides healthy food choices		
Other			

Living with Kidney Disease

Treatment choices for Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD)

Because chronic kidney disease is usually caused by another condition, the first step is to treat the disease that is causing the kidney damage. This can be done through certain medicines and lifestyle changes. If your kidney disease gets worse, you will need to start thinking about different treatment choices like transplant or dialysis. This section will explain the different treatment options.

When a person with chronic kidney disease reaches End Stage Renal Disease (ESRD), the kidneys are no longer able to filter and clean the blood well enough to keep people feeling well. Without treatment, toxins that are normally removed by the kidneys build up in the body and sicken people and even become life-threatening. When this happens, the treatment options include dialysis, kidney transplantation, or conservative therapy.

Dialysis

Dialysis works by using a filter to remove toxins and excess fluid from the body. There are 2 types of dialysis; peritoneal dialysis and hemodialysis. Insurance covers both therapies. Many people will choose the type of dialysis they do depending on their lifestyle at some point. Just because you choose one type of dialysis to start does not mean that can't change in the future. The best type of dialysis is the one that fits your lifestyle and health needs. Please see Appendices 1-3 to read more about the pros and cons of different types of dialysis therapy.

	Peritoneal dialysis	Hemodialysis
What is it?	This type of dialysis uses the lining of your abdominal cavity (also known as the peritoneum) as a natural filter to help remove toxins from the body.	This type of dialysis uses a dialysis filter on a machine called a dialyzer.
How does it work?	A peritoneal catheter is surgically placed into the abdomen. A special fluid is then passed through the catheter and into the abdominal cavity. Toxins and extra electrolytes move from the blood into the fluid and then the fluid is removed from the abdomen.	Blood is continuously moved from your body, through the filter, and back to your body through a set of sterile tubing to remove toxins from the body.
Where do I get it?	This type of dialysis can be done at home with a machine while you sleep. Peritoneal dialysis allows the most flexibility with schedule and can be done at home, work, or even while traveling.	Hemodialysis can be done at a dialysis center by a team of medical professionals. It can also be done at home with the help of a partner to monitor the treatment.

Access for Dialysis

For both types of dialysis, you will need to have a surgery to place what is called dialysis access. Dialysis access provides a way to clean waste out of the body. The access is different depending on what type of dialysis you are having.

1. Peritoneal Dialysis Access

- You will need minor day surgery
- You will have a flexible, hollow tube called a catheter placed in your lower belly area about 1-2 months before you start dialysis
- The catheter can usually be hidden by a shirt
- You have to wait to start dialysis until the catheter is healed up.

2. Hemodialysis Access

There are 3 types of hemodialysis access: catheter, fistula or graft

- A catheter is usually temporary and only used until a fistula or graft is ready for use
- A fistula is considered the best choice for hemodialysis access. It's made with your own blood vessels and has the lowest chance of getting infected. It can take 2-3 months for a fistula to be ready for dialysis.
- A graft is when a surgeon connects your artery to a piece of tubing. It can take 2-3 months for a graft to be ready for dialysis.

Choosing which dialysis is right for you:

Starting dialysis may mean big changes to your lifestyle. Some of these changes may impact which treatment option feels right for you. The more you know about the different ways treatment can impact your lifestyle, the more likely it is you will choose the best option. Remember: Both types of dialysis can have similar outcomes. This means the decision about what type of dialysis you get is mostly based on how you see it fitting in with your lifestyle and goals. Though dialysis is a significant change, patients can often continue to work, exercise, travel, and live in a manner that is fulfilling and meaningful.

Here are some things to keep in mind when making treatment choices:

- Time: Both types of dialysis take time and commitment from you.
- If you are getting hemodialysis in a center, you will have a pretty regular treatment schedule. Most people need to come in 3 times a week and plan to spend 5-6 hours at the center each visit. You may need to arrange transportation to the treatment center for your visits. If you choose to have your hemodialysis at home, you will need to plan on about 3-5 treatments each week for 3-4 hours at a time.

If you are having peritoneal dialysis, you will likely have it at night while you are sleeping. You may have more flexibility in your schedule with peritoneal dialysis but you will need to have it each night.

- Possibility for complications:
Each type of dialysis has its own set of challenges. Talk about the possibility of complications with your doctor to help find the type of dialysis that is best for you.

Living with Kidney Disease



Kidney Transplantation

A kidney transplant is a surgery to give you a healthy kidney from someone else's body. A kidney can come from someone who is alive (called a living donor) or from someone who has died. Many patients (but not all) choose to have a kidney transplant because it is a safe and usually very successful surgery.

Some patients receive a transplant before or soon after starting dialysis, usually from a living donor. Other patients receive a kidney transplant after being on dialysis for several years. These are often deceased donor transplants. In general, health insurance covers these surgeries and transplant-related care.

Kidney transplantation is a major surgery. There are many steps you need to take to get ready for a transplant and many things you need to do after the surgery to stay healthy, including taking medications. Not all patients are candidates for kidney transplantation. Some reasons why people may not be candidates are:

1. Severe heart disease
2. Active cancer
3. Poorly-controlled diabetes
4. Medical non-adherence (not able to take medication or follow medical care plans)
5. Tobacco use

For more information on kidney transplantation, please go to
<https://mainehealth.org/maine-medical-center/services/nephrology/maine-transplant-program>

Lifestyle Changes for Patients Receiving a Kidney Transplant

Patients undergoing a kidney transplant can expect their lives to change a great deal. Patients and healthcare providers need to work together closely to get the most out of a kidney donation and this requires a lot of work. Patients need close follow up throughout their transplant life: Right after surgery you will have appointments several times a week and eventually 4 times per year. In addition, patients are required to take multiple different medications (often 3 types,

several times per day) to keep the kidney functioning and prevent rejection (a process by where your immune system attacks the donated kidney). It is very important to take all medications as prescribed. We understand some of these changes may be hard and it may feel like a lot of work. But we know that patients who are able to qualify for a kidney transplant generally live longer and enjoy a better quality of life compared to those who remain on dialysis.

You can read more about the different medications you may need to take after a kidney transplant on page 9.

Conservative Therapy

Some patients choose not to have dialysis or a kidney transplant. This is a very personal decision that a patient will make often after consultation with their family and care team. Patients may choose not to pursue kidney replacement therapy for a variety of different reasons:

- They have other health problems which prevent them from having a kidney transplant and make long term quality of life and survival on dialysis unlikely. Some examples include terminal cancer, dementia, or severe heart or liver disease.
- The expected lifestyle is not aligned with the patient's goals of living.
- They have chronic pain syndromes that cannot be controlled medically

If you choose conservative therapy, our goals for your care include minimizing the symptoms of kidney failure and pain, preventing any further progression of renal failure if possible and continuing aggressive non-dialysis care as appropriate.

It is common for patients to be confused and overwhelmed when considering all of these options. With help from your care team and family however, we hope you can make choices to help direct and plan for your future care needs.

Medications for Chronic Kidney Disease (CKD) or End Stage Renal Disease (ESRD)

If you have CKD or ESRD, you will most likely need to take medicines to help keep you healthy. Some of these medicines will be prescription and some you can buy at a grocery store or pharmacy (over the counter). For prescriptions, be sure to follow the instructions on the bottle about how to take the medication. If you have any questions about your medications, feel free to call your kidney care team.

The following pages of this handout will give you information about:

- Medicines to avoid
- Commonly-prescribed medicines
- Possible medication side effects
- Strategies for success

Medications to avoid

Make sure you talk with your kidney team before taking any over the counter or prescription medicines not listed on this sheet. They could interfere with other medicines you are taking.

In general, you should not take any of these medicines unless prescribed by your doctors:

- NSAIDs including:
 - Naproxen (Aleve, Naprosyn)
 - Ibuprofen (Motrin, Advil)

Living with Kidney Disease

- Aspirin (unless prescribed by your doctor)
- Decongestants like Pseudoephedrine (Sudafed)
- Antacids and laxatives with magnesium, phosphorus and aluminum including:
 - Mylanta
 - Milk of Magnesium
 - Alka-Seltzer
 - Fleet enema products
- Salt substitutes
- Vitamins and food supplements that contain magnesium and potassium
- Herbal medications that may contain potassium

Your kidney care team can tell you what medicines are safe to take for when you are having certain problems like pain or indigestion.

Common Medications for CKD or Dialysis:

1. Erythropoietin Stimulating Agents (ESAs)

The kidneys help to make red blood cells in the body. When you are on dialysis, your kidneys are not working well enough to make enough red blood cells. This is called anemia. ESAs can help increase the amount of red blood cells in your body (your red blood cell count) so you don't get anemia.

Your kidney team will let you know which of the ESAs below you might need to take. Your prescription will come from your nephrologist. Here is some more information about the different types of ESAs you may need to take:

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Epoetin Alfa (Epogen, Procrit)	If you have ESRD: Your prescription will be filled through the dialysis center pharmacy. If you have CKD: you will not need a prescription because it is usually given to you at a skilled nursing facility or CKD clinic	Either through an IV (into your vein) or subcutaneously (under your skin) 1 to 3 times a week.	Headaches, nausea, increased blood pressure
Darbepoetin Alfa (Aranesp)	If you have ESRD: Your prescription will be filled through the dialysis center pharmacy. If you have CKD: you will not need a prescription because it is usually given to you at a skilled nursing facility or CKD clinic	Either through an IV (into your vein) or subcutaneously (under your skin) once a week to once every 4 weeks.	Increased blood pressure, swelling in the legs

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Methoxy PEG-Epoetin Beta (Mircera)	If you have ESRD: Your prescription will be filled through the dialysis center pharmacy. If you have CKD: You will not need a prescription because it is usually given to you at a skilled nursing facility or CKD clinic.	Either through an IV (into your vein) or subcutaneously (under your skin) once every 2 weeks to once every 4 weeks.	Headaches, increased blood pressure, diarrhea

2. Vitamin D

If you have CKD, your body has a harder time using Vitamin D because your kidneys are not working as well. Vitamin D is important for strong bones. Taking a Vitamin D supplement can help keep your bones strong. Your kidney team will let you know which type of the Vitamin D supplement(s) listed below you might need to take:

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Ergocalciferol	Over the counter at your local pharmacy. It will range in dose from 400-50000 units and may say Vitamin D2. Your nephrologist will let you know what dose you should take.	This is a pill that you take by mouth anywhere from once daily to once monthly depending on your dose	Your bloodwork might show higher than normal calcium and phosphate levels
Cholecalciferol	Over the counter at your local pharmacy. It will range in dose from 400-50000 units and may say Vitamin D3. Your nephrologist will let you know what dose you should take.	This is a pill that you take by mouth anywhere from once daily to once monthly depending on your dose	Your bloodwork might show higher than normal calcium and phosphate levels
Calcitriol	This is prescription given to you by your nephrologist. If you have ESRD: Your Calcitriol prescription will be filled by your dialysis pharmacy. If you have CKD: Your Calcitriol prescription can be filled by your local pharmacy.	This can be taken as a pill or given to you in an IV daily or up to 3 times a week. If you have ESRD: You will get your Calcitriol at your dialysis center If you have CKD: You will be able to take your Calcitriol at home.	Your bloodwork might show higher than normal calcium and phosphate levels

Living with Kidney Disease

3. Iron

Many patients coming to dialysis have low iron. Iron is an important mineral needed for good health and healthy blood cells. Iron helps your body make hemoglobin, which is found in red blood cells. When there is not enough iron, red blood cells will not have enough hemoglobin to carry oxygen.

Your kidney team will let you know which of the different types of iron supplement(s) listed below you might need to take:

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Ferrous Sulfate	Over the counter at your local pharmacy. There are a few different types. Your doctor will tell you which of these to buy: <ul style="list-style-type: none">• Feosol 200 mg (65 mg elemental iron)• Various 325 mg (65 mg elemental iron)• Slow FE 160 mg (50 mg elemental iron)	You may take this a few times throughout the day depending on your dose	Nausea, vomiting and constipation
Ferrous Gluconate	Over the counter at your local pharmacy. The label will say Various 325 mg (36 mg elemental iron).	You may take this a few times throughout the day depending on your dose	Nausea, vomiting and constipation
Polysaccharide Iron	Over the counter at your local pharmacy. The label will say Polysaccharide iron or Niferex 150 mg (50 mg elemental iron).	You may take this a few times throughout the day depending on your dose	Nausea, vomiting and constipation
Iron Sucrose (Venofer)	Your nephrologist will prescribe iron sucrose to you.	If you have CKD: through an IV at an infusion center If you have ESRD: through an IV at a dialysis center	Nausea, vomiting and constipation.
Ferumoxytol (Feraheme)	Your nephrologist will prescribe Ferumoxytol to you.	If you have CKD: through an IV at an infusion center If you have ESRD: through an IV at a dialysis center	Headache and dizziness

4. Phosphate/Calcium Binders

Dialysis patients often have trouble with too much phosphate in the blood. Too much phosphate in the blood can narrow your blood vessels. Phosphate/calcium binders help with the build-up of phosphate in the blood. They attach themselves to phosphate in your food to prevent it from being absorbed by your body.

All of these medicines are taken as a pill by mouth and should be taken with food. It's a good idea to carry some of these medicines with you at all times so that you don't forget to take them.

Your kidney team will let you know which of the phosphate/calcium binders listed below you might need to take:

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Calcium Carbonate	Over the counter at your local pharmacy. The label will say Tums, Oscal or Caltrate and will range in strength from 500-1500 mg	Take 3 times a day with meals	Diarrhea, nausea, vomiting, higher calcium levels, and constipation.
Sevelamer Carbonate (Renvela)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	Take 3 times a day with meals	Diarrhea, nausea, vomiting, and higher calcium levels
Sevelamer Hydrochloride (Renagel)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	Take 3 times a day with meals	Diarrhea, nausea, vomiting, and higher calcium levels
Lanthanum Carbonate (Fosrenol)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	Take 3 times a day with meals	Diarrhea, nausea and vomiting
Auryxia (Ferric Citrate)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	Take 3 times a day with meals	Diarrhea, nausea, vomiting, and darkening of stools
Sucroferric Oxyhydroxide (Velphoro)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	Take 3 times a day with meals	Diarrhea, nausea, vomiting, and darkening of stools

Living with Kidney Disease

5. Hypotensive Regulators

It's common to experience low blood pressure (hypotension) during dialysis sessions. We will check your blood pressure during each dialysis session to make sure it is in a normal range. Here is some more information about these medicines:

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Midodrine	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	Take 1 pill 15-30 minutes before your dialysis session. May also be given more often as directed by your nephrologist	Increased blood pressure and a tingling or numbness in your skin

6. Hyper-parathyroid regulators

Some patients on dialysis have increased parathyroid hormone levels. If your hormone levels are high for a long time, this can lead to bone disease. Here is some more information about the medicines used to prevent this:

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Cinacalcet (Sensipar)	<p>This is a prescription given to you by your nephrologist.</p> <p>If you have ESRD: this medicine will be supplied through the dialysis pharmacy</p> <p>If you have CKD: You can pick it up at your local pharmacy</p>	This is a pill that you take by mouth daily with food or after a meal. The dose may be increased over the course of a few weeks to maintain proper levels. Your nephrologist will tell you how to take this medication.	Diarrhea, nausea and vomiting

7. Antihypertensive Agents

Sometimes fluid can build up in your body between dialysis sessions which can cause high blood pressure (hypertension). If blood pressure stays high for a long time, you have a higher chance of getting heart disease, having a heart attack or stroke. If you have ESRD, your nephrologists will manage these medicines. If you have CKD, your nephrologist will manage these medicines along with your primary care doctor or your cardiologist.

There are many different types of antihypertensive agents. Your nephrologist will find the right medicines that work for you.

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Lisinopril (Zestril)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Dry cough, dizziness and headache. If your cough does not go away, call your nephrologist.
Enalapril (Vasotec)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Dry cough, dizziness and headache. If your cough does not go away, call your nephrologist.
Losartan (Cozaar)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Cough and dizziness. If your cough does not go away, call your nephrologist.
Metoprolol (Lopressor, Toprol XL)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice. There are 2 kinds: Immediate Release and Extended Release.	This is a pill that you take by mouth daily.	Dizziness, fatigue, and headache
Carvedilol (Coreg)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice. There are 2 kinds: Immediate Release and Extended Release.	This is a pill that you take by mouth daily.	Dizziness, nausea, and headache
Amlodipine (Norvasc)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily. This medicine should be taken in the morning. Do not drink grapefruit juice while you are taking this medicine.	Dizziness, nausea, and fatigue

Living with Kidney Disease

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Verapamil (Calan)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice. There are 2 kinds: Immediate Release and Extended Release.	This is a pill that you take by mouth daily.	Dizziness, fatigue, and headache
Hydralazine	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Dizziness, nausea, and headache
Minoxidil	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Nausea and vomiting
Isosorbide MN ER (Imdur)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Dizziness, fatigue, and headache

8. Diuretics (also called water pills)

Diuretics can help remove extra fluid and salt in your body. This helps lower your blood pressure. If you are taking these medicines, your nephrologist will want to closely watch your potassium levels to make sure they do not get too high.

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Furosemide (Lasix)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Dizziness and headache
Bumetanide (Bumex)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth 1 to 2 times a day.	Dizziness
	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Dizziness, sun sensitivity, and headache
Spirolactone (Aldactone)	This is a prescription given to you by your nephrologist. You can pick it up at your pharmacy of choice.	This is a pill that you take by mouth daily.	Dizziness and headache

9. Cholesterol-lowering medications

Too much cholesterol can build up in your blood vessels. This build-up can narrow vessels and lead to a blockage, preventing blood from getting to a certain area of your body. When this occurs in your heart vessels, it is called coronary heart disease and can cause a heart attack. In people with chronic kidney disease, heart disease is very common. These medicines are usually prescribed by your cardiologist or primary care doctor.

Most of these medicines are types of statins. Statins can cause muscle pain which might feel like muscle soreness or tiredness. Tell your doctor right away if you notice this symptom. **Do not drink grapefruit juice while you are taking these medicines.** It can interfere with how your body uses the medicine.

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Atorvastatin (Lipitor)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Nausea, diarrhea, muscle pain
Rosuvastatin (Crestor)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Nausea, diarrhea, muscle pain
Simvastatin (Zocor)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Nausea, diarrhea, muscle pain
Pravastatin (Pravachol)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Nausea, diarrhea, muscle pain
Lovastatin (Mevacor)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Nausea, diarrhea, muscle pain
Pitavastatin (Livalo)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Headache, constipation, diarrhea
Ezetimibe (Zetia)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Fatigue, diarrhea

Living with Kidney Disease

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Gemfibrozil (Lopid)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth 2 times a day.	Indigestion, upset stomach, nausea, vomiting
Fenofibrate (Tricor, Lofibra, Trilipix)	This is a prescription medicine that you can pick up at your pharmacy	This is a pill that you take by mouth before bedtime daily.	Indigestion, upset stomach, abdominal pain

10. Multi-vitamins

If you have kidney disease or are on dialysis, your diet may be limited somewhat. Your nephrologist will give you a prescription for multi-vitamins to make sure you get all of the vitamins and mineral your body needs.

Medicine Name:	Where do I get it?	How do I take it?	What are the side effects?
Nephro-vite	This is a prescription medicine that you can pick up at your pharmacy.	This is a pill that you take by mouth once a day. Take it after a dialysis session and be sure to take it at the same time every day.	Nausea, vomiting
Rena-vite	This is a prescription medicine that you can pick up at your pharmacy.	This is a pill that you take by mouth once a day. Take it after a dialysis session and be sure to take it at the same time every day.	Nausea, vomiting
Nephrocaps	This is a prescription medicine that you can pick up at your pharmacy.	This is a soft gel that you take by mouth once a day. Take it after a dialysis session and be sure to take it at the same time every day.	Nausea, vomiting
Triphrocaps	This is a prescription medicine that you can pick up at your pharmacy.	This is a soft gel that you take by mouth once a day. Take it after a dialysis session and be sure to take it at the same time every day.	Nausea, vomiting

Living with Chronic Kidney Disease

Don't Forget About Your Emotional Health

At times, you may feel anxious, depressed or have a hard time processing the changes to your lifestyle and overall health. If you notice any of these feelings, talk to your kidney care team.

Navigating Energy changes

You may feel tired after dialysis. This is because dialysis changes the amount of fluid and electrolytes in your body. You may notice this more if you are having hemodialysis.

Diet is important for CKD and ESRD Patients

If you have CKD or ESRD, your kidneys have a harder time removing extra fluid, nutrients and waste products from the body. You can help lessen the load on your kidneys by following what is called a renal diet to help prevent buildup of fluid, nutrients and waste products between dialysis sessions.

A renal diet is low in these nutrients:

- potassium (less than 2000 mg per day unless your care team says otherwise)
- phosphorus
- sodium
- fluid
- protein (depending on your stage of chronic kidney disease)

A renal diet may seem confusing at first, but the better you educate yourself, the easier the diet will be. It is very important that you meet with your dietitian on a regular basis to make sure you have all the information you need to eat well and stay healthy.

Here are some basic steps to help you understand the renal diet. Ask to speak with your dietitian for more information.

1. Eat low potassium foods. Potassium is found mostly in fruits and vegetables. It is important to continue to eat fruits and vegetables, just make sure they are low in potassium.

Below is a list of foods and the amount of potassium they contain.

High potassium foods to avoid	Low potassium foods to include
Bananas, Melons, Oranges, Mangos	Apples, Berries, Grapes, Pineapple
Tomatoes, Broccoli, Spinach	Cucumbers, Green/wax beans, Peas
Potatoes, Pumpkin, Winter squash	Summer Squash, Zucchini, Cauliflower

Patients who are having peritoneal dialysis can usually have a normal daily potassium intake. Check with your doctor to find out more.

Living with Kidney Disease



2. **Limit foods high in phosphorus.** Ask your dietitian for a full list of high phosphorus foods. Dairy products, whole grains and nuts are high in phosphorus. It is best to limit these foods to no more than 1-2 servings a day. Each day, do not eat more than:

- 1 cup of milk
- 1 cup of yogurt
- 2 slices of whole wheat bread
- ½ cup of nuts

3. **Limit foods high in sodium (salt).** High sodium foods can cause the body to retain fluid which is harmful. Sodium is found in table salt and processed foods. Read food labels and don't choose foods that have more than 300 milligrams (mg) of sodium per serving. Limit your total daily sodium intake to less than 2000 mg unless your care team suggests otherwise. Ask your dietitian about following a low sodium diet. Try to avoid these foods all together:

- Table salt and salt blends
- Condiments like soy sauce, pickles and ketchup
- Canned soups and vegetables
- Deli meats

4. **Eat the right amount of protein.**

If you have CKD stage 3 or 4, you will need to watch your protein intake to make sure you are not eating too much. Eating more protein than you need may make your kidneys work harder. The amount of protein you need depends on your body size. Ask your dietitian about how much protein your body needs.

If you are on dialysis, your protein needs will be higher. Dialysis will remove some protein from your body, so it is very important to replace it by eating high protein foods. Try to eat a protein-rich food at each meal, such as:

- beef, chicken, pork and turkey
- fish
- tofu
- eggs

Avoid meats with added salt such as sausage, bacon, ham and hot dogs.

5. Follow your fluid restriction guidelines. Your doctor will tell you how much fluid you can drink each day. Anything that is liquid at room temperature counts as a fluid. Here are some examples of fluid:

- Water, coffee or tea
- Milk
- Jell-o
- Popsicles
- Soup

Use the chart below to help understand how much fluid you can have based on the restriction given by your doctor.

If your fluid restriction is:	You can have this many 8-ounce cups a day:
2000 milliliters (2 Liters)	8.5
1500 milliliters (1.5 Liters)	6.5
1000 milliliters (1 Liter)	4

Make Sure to Plan Ahead if you have CKD or ESRD

Providing good care for our patients means helping them plan for the future. Our team is here to help you think about what you may want in your advance directive. Let us know how we can best assist you in this important part of care planning.

Advance Care Planning is a process to help you:

- Understand future healthcare choices
- Reflect on those choices based on your personal values and beliefs
- Discuss your choices with those close to you

Living with Kidney Disease

- ✓ An Advance Directive is a document that would tell us what type of treatment(s) you want in the event that you are no longer able to speak for yourself.
- ✓ An Advanced Directive ensures that your wishes are carried out at the end of your life in a way that you feel is best for you.
- ✓ Advance Directives are legal documents. An Advance Directive does not need to be notarized in the State of Maine. However, if you travel or live part of the year out-of-state, it would be wise to have it signed by a notary. Some states require advance directives to be notarized.
- ✓ Your Advance Directive allows you to designate a Power of Attorney (POA). POA may also be called:
 - “health care proxy or agent”
 - “health care surrogate”
 - “durable power of attorney for health care”
- ✓ You should have an advance directive in place even if you are in good health. If you wait until you are hospitalized for an illness, you may become too ill to complete an advance directive. That’s when it’s most important to have one. The best time to prepare an advance directive is when you are healthy and able to think through what care you want – or don’t want.
- ✓ Advance directives are only intended for decisions related to healthcare. The health POA cannot make decisions related to money or property. You need a financial power of attorney to make these decisions, using a different form.
- ✓ Communication is essential for completing your advance directive. Talking with loved ones about choices and explaining why those options are important informs them about what you want and why.
- ✓ Advance Directives should be reviewed frequently and updated and/or revised as your wishes or preferences change.

In the event that difficult medical choices need to be made without you being able to do so, a living will provides comfort to loved ones and providers that your choices and values are being respected. Consider your completing your



Additional Resources for Patients and their Families

- NKF patient link
- ASN patient link
- MTP patient link
- Palliative Care Resources
- The Integrative Nephrology Clinic at Maine Nephrology Associates is another resource you can access if you are interested in a holistic approach to your health and whole being. This special clinic offers additional guidance to help you more fully integrate nutrition and exercise into your treatment plan, and find tools to manage pain and bouts of sadness and anxiety that harness the power of the connection between your mind and your body.
- Other resources:

APPENDIX I: Learn More about Peritoneal Dialysis

How does peritoneal dialysis work?

A small tube called an abdominal catheter is surgically placed into your abdomen. A small portion of this catheter is left outside of the body and is covered when not in use. This soft plastic tube allows a solution called dialysate to flow into the peritoneal cavity.

The dialysate remains in the cavity for several hours, this is called dwelling, and is when dialysis takes place. The dialysate is later drained from the peritoneal cavity through the PD catheter. The procedure of filling, dwelling, and draining is called an exchange. Several exchanges are either done during the day or at night while you sleep.

Specialized home dialysis nurses will teach you how to do your dialysis and provide 24 hour phone support.

What else do I need to know?

Peritoneal Dialysis is a treatment option for people who want to do their dialysis at home.

Living with Kidney Disease

There are 2 types of Peritoneal Dialysis:

1. **Continuous Ambulatory Peritoneal Dialysis (CAPD)**

This is the simplest form of dialysis because it does not use a machine. You will have 4-5 exchanges throughout the day at home, work, or when traveling. Since you are not attached to a machine you can go about your normal daily activities.

2. **Continuous Cycling Peritoneal Dialysis (CCPD)**

CCPD uses a machine called a cycler. The cycler does the exchange for you which allows you to have treatments at night while you are sleeping.

Here is a chart to help you compare the advantages and disadvantages of Peritoneal Dialysis as you make your treatment decisions:

Advantages of Peritoneal Dialysis	Disadvantages of Peritoneal Dialysis
Fewer restrictions to your diet	Requires you to perform daily treatments
Fewer fluid restrictions	You will need to take extra steps to keep your access site clean and healthy
Usually painless	You will need storage space in your home for supplies
You can have treatments in your own home	There is a risk of an infection in the peritoneal cavity called peritonitis
Flexible treatment schedule to maintain your existing lifestyle	You will be consuming extra calories from dextrose in peritoneal dialysis solution which may cause weight gain
More travel options	
Spending more time in your own home	
Less time traveling to the dialysis center	
A bloodless form of treatment with no needles required	
Gentle treatment more like “normal” kidney function	
A partner is generally not required	

APPENDIX II Learn More About Hemodialysis

How does hemodialysis work?

Hemodialysis uses a machine and tubing to remove a small amount of blood from your body. The blood outside of your body passes through a filter called a dialyzer. The dialyzer removes the waste products and extra water from your blood. The filtered blood is then returned to your body.

There are 2 ways to do hemodialysis in a clinic:

- 1) During the day, 3 times per week, for 4- 4.5 hours per session
- 2) At night, while you sleep. This is called Nocturnal In-center Hemodialysis. It is provided 3 times per week for 6-8 hours per session.

Creating Access for the Dialyzer:

There are three ways a surgeon can create this bloodstream access: a fistula, a graft, or a catheter.

1. Fistula	2. Graft	3. Catheter
Joins a vein and an artery in your arm	Uses soft tubing to connect an artery and a vein in your arm	Tube is placed permanently in your neck, chest or groin
Preferred choice for hemodialysis	Works if your veins are too small	May be used temporarily until surgery for fistula or graft is preformed
Lowest risk of infection, clotting		Higher risk of infection
Allows for ideal blood flow		Higher risk of clotting
Healing time: 6-8 weeks before use	Healing time: 4-6 weeks before use	Healing time: can be used immediately

Living with Kidney Disease

Choosing Hemodialysis

Here is a chart to help you compare the advantages and disadvantages of hemodialysis as you make your treatment decisions:

Advantages of Hemodialysis	Disadvantages of Hemodialysis
Trained clinicians do treatments in the dialysis center	Less schedule flexibility-set treatment times
No home equipment or supplies needed	More travel time to/from dialysis center 3 times/week
You will have your non-dialysis days free for work and other activities	Most restrictive fluid and dietary limits
Opportunity for more social interaction with other dialysis patients	More routine needle sticks: 2 needles are inserted into the fistula or graft and are then removed when each treatment is complete
	More time spent away from loved ones and activities.

Is hemodialysis at home an option?

Specialized home dialysis nurses will teach you how to do your dialysis and provide 24 hour phone support.

The amount of treatments you need and the length of time for each treatment is different for everyone. On average, you can plan on having treatment 5-6 days a week. Home treatments can last between 2 and half and 3 hours.

To access the blood stream for dialysis your doctor will refer you to a surgeon to create an access; a fistula, a graft, or a catheter. See Appendix II, page 24 for a chart explaining each of these different surgical procedures.



Choosing whether Home Dialysis is for you:

Advantages of Home Hemodialysis	Disadvantages of Home Hemodialysis
Your diet will not be as limited (compared to clinic hemodialysis)	5 week required training class
Fewer limits on your fluids (compared to clinic hemodialysis)	At home storage space for supplies necessary
More flexible treatment schedule, less lifestyle disruption	Routine needle sticks (2 with every treatment)
Can save time and money by not having to travel to dialysis center	Dedicated space for hemodialysis machine needed in your home
Able to dialyze in the comfort and privacy of your own home	Hemodialysis equipment may require changes in your home's plumbing and electrical systems

*Providing the highest quality care for those
with kidney disease and hypertension.*





MaineHealth

mainehealth.org/services/nephrology

Maine Nephrology Associates

☎ (207)774-5222

mainenephrology.com