



kidney
FOUNDATION™

Book Two

LIVING WITH KIDNEY FAILURE

5th Edition





Here to help you

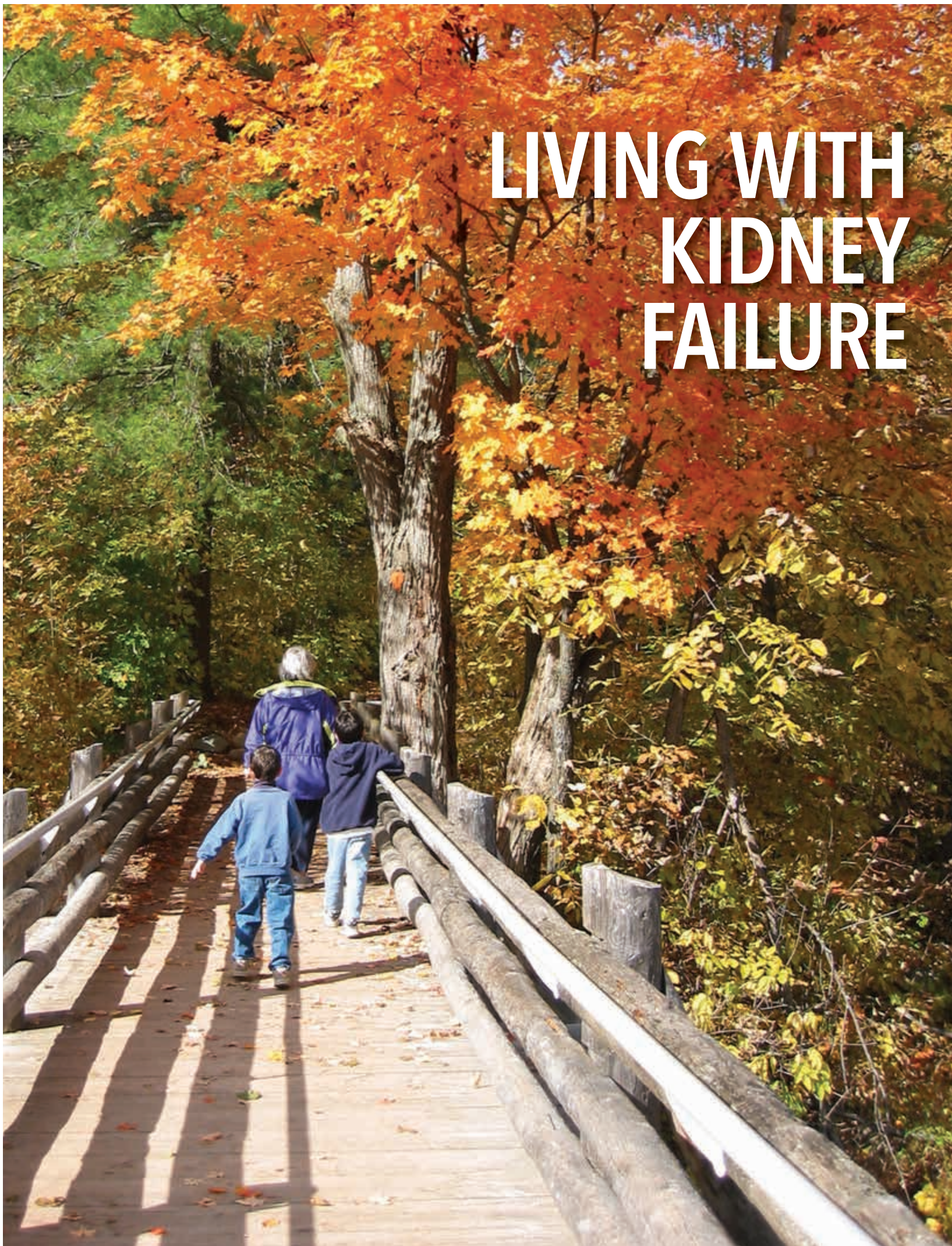
Your healthcare team including your primary care provider, nephrologist (kidney doctor), dietitian, nurses, pharmacist, social worker and others can help you with planning, answer your questions, and identify resources that can provide you and your family with the support you need.

The Kidney Foundation of Canada is also here to help by providing information and educational material, short-term financial assistance, peer support and a number of other programs and services. There are Kidney Foundation Branches and Chapters all across Canada. Look up the address of your provincial Branch office on our website at **kidney.ca** or call toll-free 1.800.361.7494 and find out what's available.

There is also an active online kidney community that is supported by The Kidney Foundation. The Kidney Community Kitchen provides kidney-friendly recipes, meal plans, diet information and discussion forums: **kidneycommunitykitchen.ca**. The Kidney Connect social network for people living with kidney disease is available at **kidneyconnect.ca**.

kidney.ca

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LIVING WITH KIDNEY FAILURE



My personal information

Name _____

Address _____

Phone Numbers _____

Personal Health Number _____

Primary Care Provider _____

Kidney Doctor _____

Kidney Nurse _____

Kidney Dietitian _____

Kidney Pharmacist _____

Kidney Social Worker _____

Transplant Surgeon _____

Transplant Coordinator _____

Donor Coordinator _____

Dialysis Unit _____

Next of Kin & Phone Number _____



Thank you

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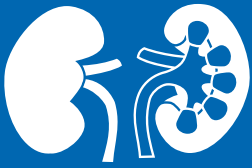
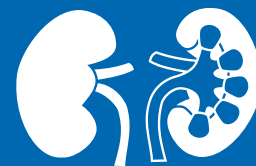


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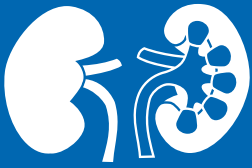
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FEEDBACK



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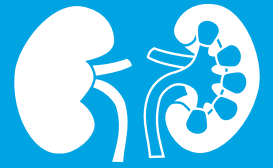
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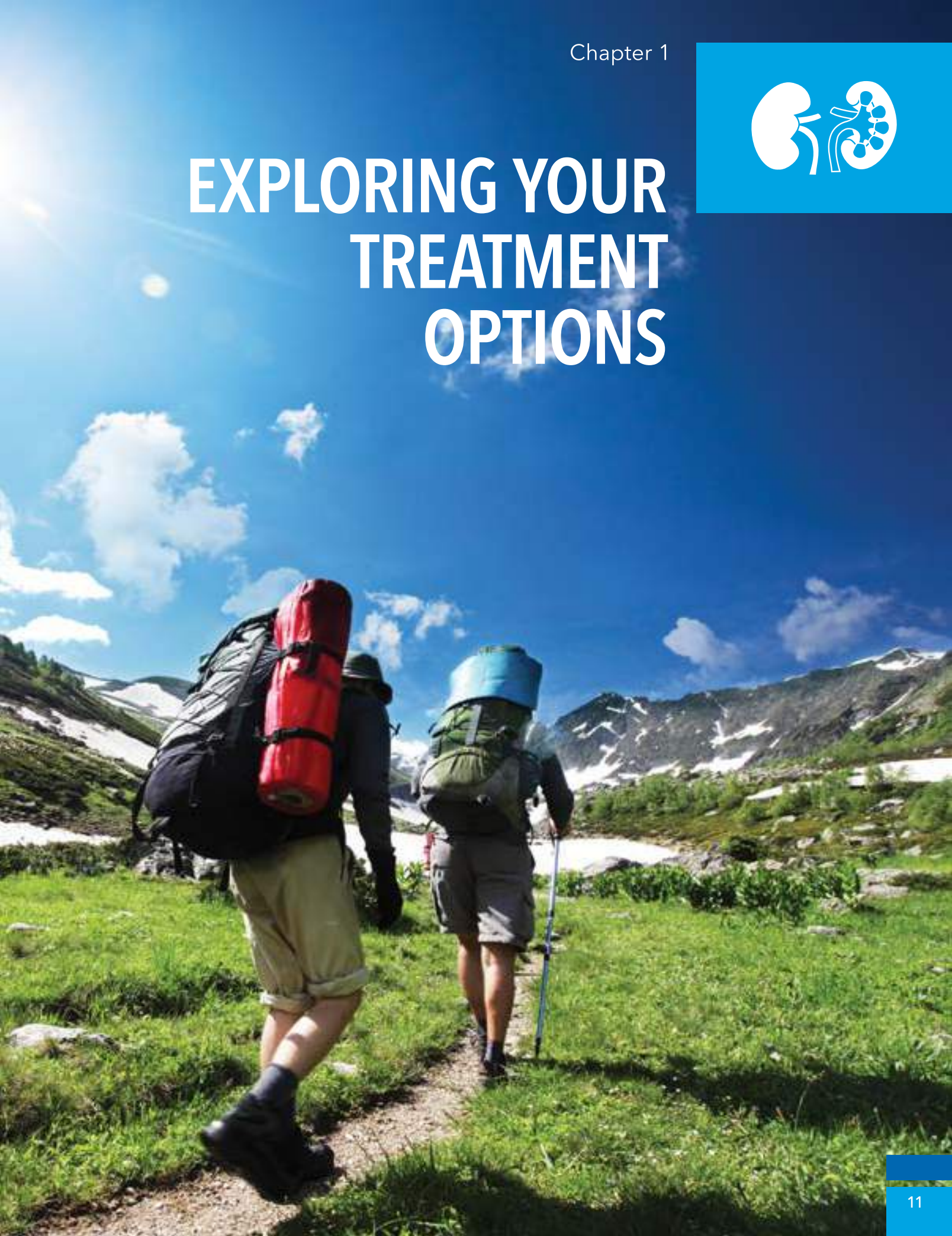
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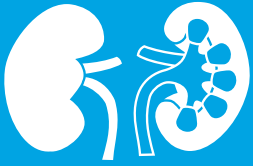
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EXPLORING YOUR TREATMENT OPTIONS



Exploring your treatment options



HELPFUL TIP

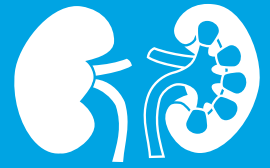
There's a lot to think about when discussing your best treatment options with your healthcare team. You'll need to consider other medical conditions you may have, your health goals and personal circumstances. Take time to explore all of your options. Ask a lot of questions and talk with others with kidney disease about their treatment. You can do this through the Kidney Connect peer support program, which will match you with a trained volunteer. See kidney.ca or call the peer support number at 1-866-390-PEER (7337). You may also want to participate in our online community at kidneyconnect.ca.

Many people can manage their kidney disease for years with diet and medication and never need to look at other treatment options. But if your kidney function drops to 15%-20% of normal capacity, your kidney healthcare team will discuss additional treatment choices with you for when your kidneys fail. Although you may feel well now, when your kidney function drops below 10%-15% of normal, you may start to feel symptoms such as fatigue and nausea, although this varies from person to person.

It's important to discuss potential treatment options with your healthcare team early on. That way, you'll have time to prepare, plan and ensure that you're making the treatment choice that's best for you, your lifestyle, health and personal circumstances. If you don't make a decision and prepare for your treatment method in advance, and your kidneys fail, you may have no choice but to start dialysis on an emergency basis, and this can be stressful.



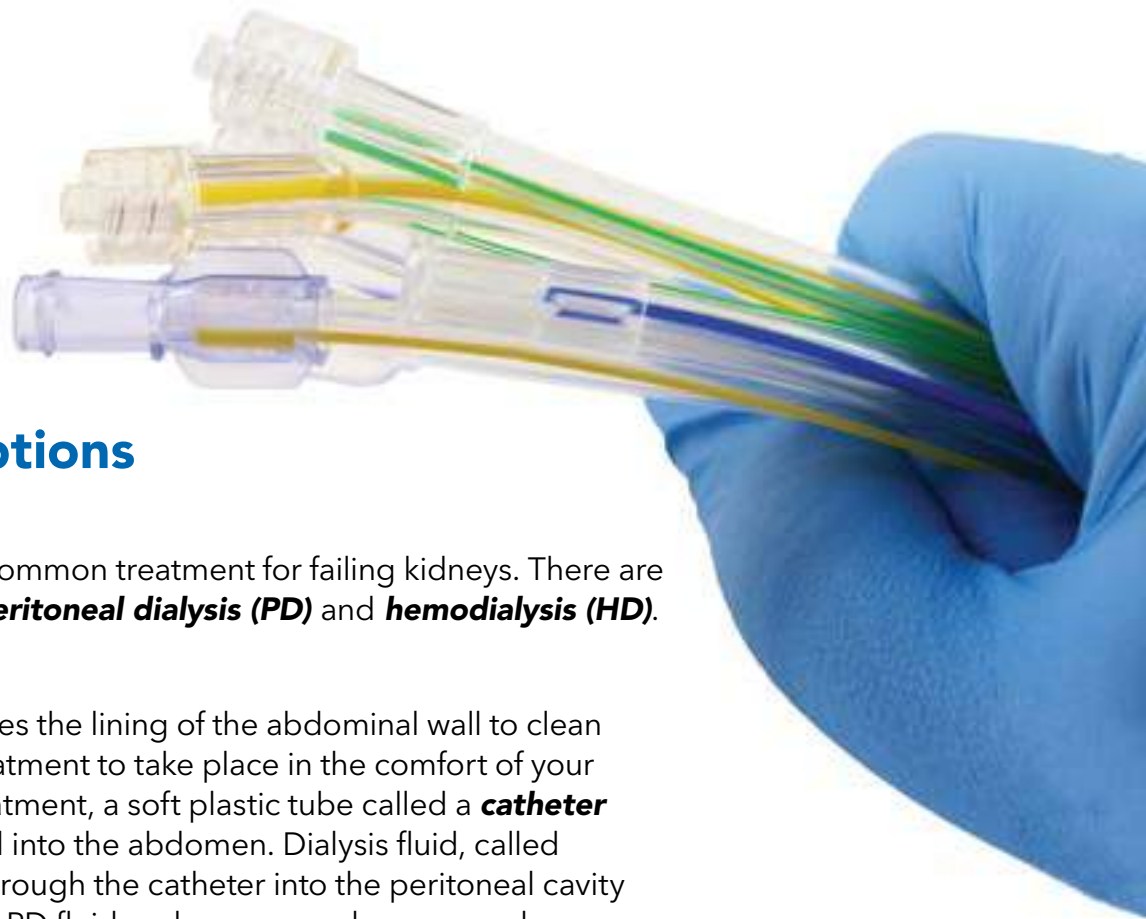
Exploring your treatment options



There are three main treatment options: **dialysis**, a **kidney transplant** and **non-dialysis supportive care** (often called **conservative care**). This chapter will help you consider your options and different factors which may affect your decision. Regardless of which option you choose, everyone should do some **advance care planning**. Advance care planning is a *process* in which you think about what you would like to have happen, or not happen, if you become unable to make decisions about your healthcare treatment, or if you are unable to communicate your wishes.

See **Chapter Six:**

Advance care planning for more information about planning for your future care.



Treatment options

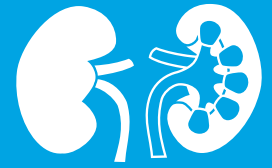
Dialysis

Dialysis is the most common treatment for failing kidneys. There are two types of dialysis: **peritoneal dialysis (PD)** and **hemodialysis (HD)**.

Peritoneal dialysis

Peritoneal dialysis uses the lining of the abdominal wall to clean the blood, allowing treatment to take place in the comfort of your own home. For this treatment, a soft plastic tube called a **catheter** is permanently inserted into the abdomen. Dialysis fluid, called **dialysate**, is inserted through the catheter into the peritoneal cavity and “cleans” the blood. PD fluid exchanges are done every day or every night, although there is always fluid in the abdomen to remove toxins.

Exploring your treatment options



The advantages of a transplant include better quality of life with fewer limitations than dialysis. For example, a transplant won't take hours of treatment time out of your week, and you may feel physically stronger, able to work, travel and stay more active. The main disadvantage of a transplant, in addition to the general risks of surgery, is that you will have to take medications every day, which may increase your risk of infection, and have other side effects.

Non-dialysis supportive care (conservative care)

The focus of non-dialysis supportive care is on quality of life for the time you have, rather than on trying to live longer. Performing dialysis can be a burden for some people, and may lead to a decreased quality of life. If you choose non-dialysis supportive care, your healthcare team will help you use diet and medication to slow the kidneys' decline, manage any symptoms you may have and provide support to you and your family as you plan for the end of life.

People who choose non-dialysis supportive care are not able to have a transplant. Many have multiple illnesses and/or advanced age and dialysis may not be able to extend their lives. People who choose this option often feel that the burden of dialysis outweighs any potential benefits. They decide instead to focus on quality of life for whatever time remains.

See **Chapter Four:**

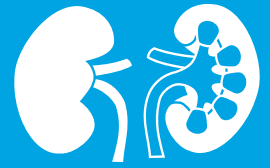
Transplant for more information about kidney transplantation.

NOTES:

See **Chapter Five:**

Non-dialysis supportive care for more information about this option.

Exploring your treatment options

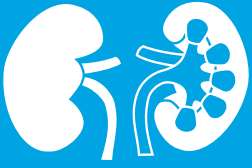


What's important to me?

Take some time to think about what's important to you and write down your thoughts.

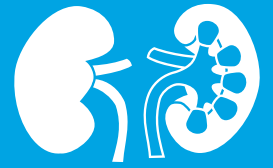
TOPIC	THINGS TO CONSIDER	NOT IMPORTANT	IMPORTANT	VERY IMPORTANT
Work, school, and/or looking after others	Daytime obligations (school, family, work) may limit your availability. Peritoneal and home hemodialysis allow you to choose what time to do your treatments and work them around your schedule.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				
Leading an active life/energy level	Treatment options such as peritoneal and home hemodialysis allow you to do dialysis more frequently. More dialysis does more of what kidneys do to clean your blood. This means you may have more energy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				
Independence	Some people prefer to manage their own treatment (with support) whereas others prefer or need to be cared for in a clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				

Exploring your treatment options



TOPIC	THINGS TO CONSIDER	NOT IMPORTANT	IMPORTANT	VERY IMPORTANT
Travel (for pleasure or for work)	If you need or want to continue to travel, peritoneal dialysis provides more flexibility than hemodialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				
Starting a family	More frequent dialysis is needed when you are pregnant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				
Diet and fluid restrictions	In-centre hemodialysis has more diet and fluid restrictions than peritoneal dialysis or home hemodialysis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				
Side effects	Home hemodialysis and peritoneal dialysis may mean fewer overall side effects than in-centre hemodialysis (blood pressure, heart issues).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				

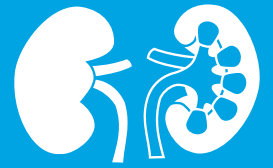
Exploring your treatment options



TOPIC	THINGS TO CONSIDER	NOT IMPORTANT	IMPORTANT	VERY IMPORTANT
How close I live to the dialysis clinic	If you choose in-centre hemodialysis, you will need to travel to treatment at least three times a week.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				
Quality of life	Choosing a treatment that best suits your medical and personal needs will help you achieve your best possible quality of life, even at the end of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My thoughts				
Anything else?				
My thoughts				

(Adapted with permission from Kidney Health Australia)

Exploring your treatment options



8. Do you have any questions or concerns about your treatment options that you would like to ask your kidney healthcare team?

a)

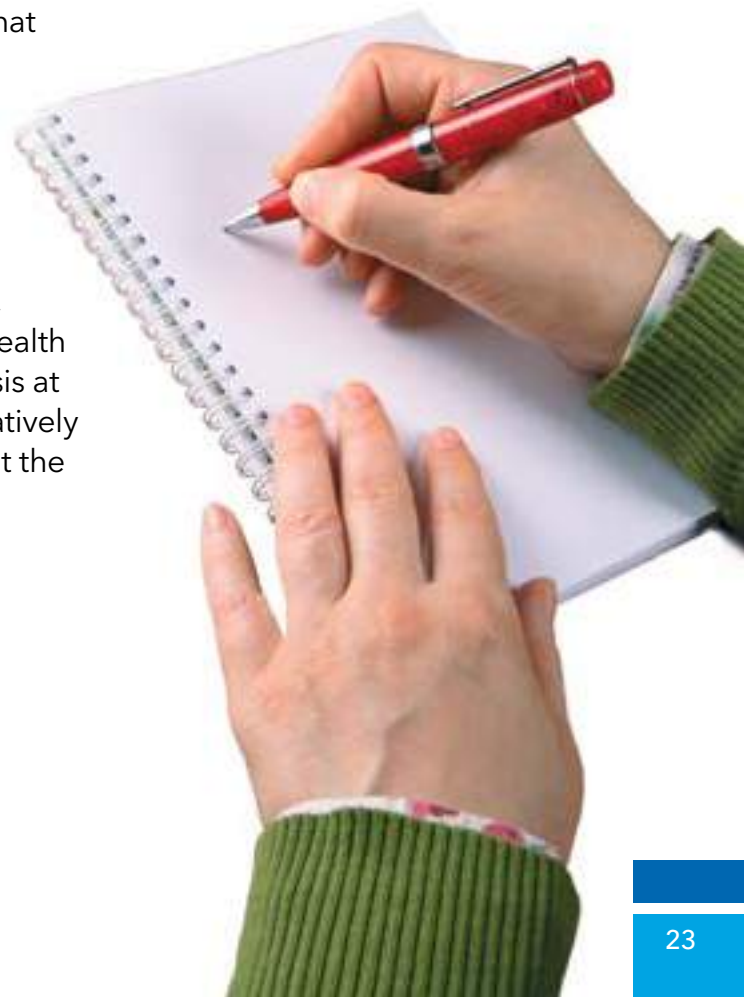
b)

c)

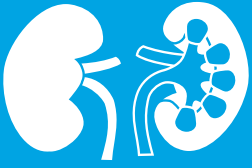
d)

e)

These questions are meant to help you explore what might be your best option given your current circumstances. Many people will have more than one type of treatment in their life, and in many cases, it is possible to change your treatment choice if things change. A transplant may become an option if, for example, you lose weight and take steps to maintain a healthy weight. Most people can, and do, switch dialysis types when their lifestyle or health calls for a change. You can also choose to stop dialysis at any time if you feel that the burden of dialysis is negatively affecting your quality of life. However, this means that the disease will run its course until the end of life.



Exploring your treatment options



Summary

- There are three treatment options: dialysis (either peritoneal dialysis or hemodialysis), a kidney transplant and non-dialysis supportive care.
- There are advantages and limitations to consider for each option.
- Choosing the option that's right for you depends on your wishes, your health and other medical conditions and your personal life circumstances.
- Your healthcare team will discuss all the options with you and help you make a treatment decision.

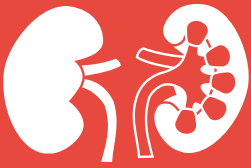
NOTES:



DIALYSIS



Dialysis



HELPFUL TIP

Choosing a home-based dialysis option may make you feel nervous. You might worry about managing on your own, or what you would do if an emergency arose. Write down your questions and concerns and talk with others who have chosen the type of dialysis you're interested in. You may be able to do this through your clinic. Or contact the Kidney Connect peer support program at 1-866-390-PEER (7337) where you'll be matched with a trained volunteer. More information is available on kidney.ca. You can also ask questions and/or share your concerns with our online community at kidneyconnect.ca.

When your kidneys start to fail and are functioning around 15%-20% of their normal capacity, your kidney healthcare team will be closely monitoring your condition and will help you determine when you may need to start dialysis. It is recommended that you start dialysis when you have symptoms of kidney failure, not just when your kidney function drops below a certain percentage.

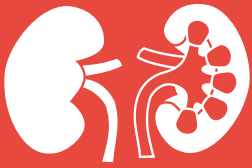
Symptoms to watch for

- Severe fatigue
- Nausea
- Decreased appetite and weight loss
- Shortness of breath
- Itchiness

Dialysis is a treatment: it does not cure kidney disease or make kidneys well again, and it does not fully replace your kidney function. Unless you receive a kidney transplant or choose non-dialysis supportive care, you must continue to have dialysis for the rest of your life.

In this chapter, we discuss **independent dialysis** (peritoneal dialysis and hemodialysis at home) and **dependent dialysis** (hemodialysis at a hospital or clinic). The type of dialysis that's best for you will depend on other health factors as well as your personal circumstances and lifestyle. Talk to your healthcare team about which type might be best for you.

Dialysis



NOTES:

Your peritoneal cavity is filled with a special dialysis fluid called dialysate. Excess water and wastes pass from the blood through the lining in the peritoneal cavity and into the dialysis fluid. The fluid is then drained from your body and discarded.

How is access to the peritoneal cavity established?

Dialysis fluid enters the peritoneal cavity through a tube called a catheter. The catheter is surgically inserted in your abdomen, usually below and to one side of your navel. It stays there for as long as you are using this form of dialysis. Catheters are made of a soft non-irritating plastic.

Catheters are inserted either at the hospital bedside using local anesthetic, or in the operating room, depending on which type of catheter is best for you, and on your individual situation. Your doctor and your peritoneal dialysis team will assess your situation and explain the options to you.

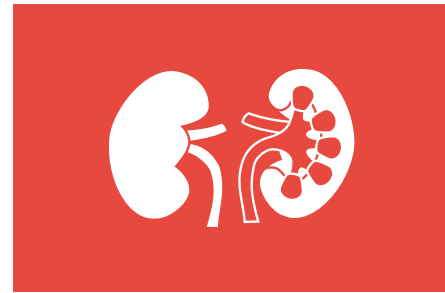
The insertion of the catheter may be briefly uncomfortable, but peritoneal dialysis is not painful. You will need to take proper care of the catheter area to avoid infection.

What are the types of peritoneal dialysis?

With peritoneal dialysis you always have dialysis fluid in your peritoneal cavity, so your blood is constantly being cleaned. The fluid is changed at regular intervals. There are two types of peritoneal dialysis:

- **Continuous ambulatory peritoneal dialysis (CAPD)**
- **Automated or continuous cycler peritoneal dialysis (APD, CCPD)**

Dialysis



Continuous ambulatory peritoneal dialysis (CAPD)

In CAPD, you carry about two to three litres of dialysis fluid in your peritoneal cavity all the time. An **exchange** is usually done four times a day by draining out the old fluid and refilling your peritoneal cavity with fresh fluid. The exchanges are done regularly throughout the day - often early in the morning, lunchtime, late in the afternoon, and at bedtime. Each exchange can take from 20 to 45 minutes. During this time you can do other things like eat your meals or get ready for bed. Sometimes an extra exchange is done while you sleep. This involves the use of special equipment - see below. Once you have completed an exchange, you are not connected to any tubes or bags and can carry on with your normal activities.

There are different ways of doing CAPD and training usually takes about one week. Ask your healthcare team for more information.

Automated or continuous cyclor peritoneal dialysis (APD, CCPD)

In APD or CCPD, a machine called an automatic cyclor performs exchanges every night while you sleep. In the morning when you come off the machine, some dialysis fluid is usually left in your peritoneal cavity for the day. How much fluid is left will somewhat depend on your size. In the evening, you drain this fluid out when you connect yourself to the automatic cyclor for the night. While CCPD allows you to do dialysis at home with no interruptions to your day, it does require that you be attached to the machine every night for eight to ten hours. Some people may also do an additional exchange or two during the day. These people need that extra amount of dialysis to provide adequate removal of waste products.

The decision to do CAPD or APD will be made with your healthcare team. Some people do better with one type and others do better with the other. A special test called a PET (Peritoneal Equilibration Test) and measures of dialysis adequacy will help your healthcare team decide which method is best for you.

NOTES:

Dialysis



NOTES:

How is excess water removed from the body?

One of the functions of normal kidneys is to remove excess water. When your kidneys are not working well, your body may not produce very much urine and so your body doesn't have a way to remove excess water. Excess water is removed during dialysis by a process called **ultrafiltration**. Blood entering the dialyzer is placed under pressure to push excess water through the dialyzer membrane. Settings on the dialysis machine can be adjusted to remove as much or as little water as necessary.

How are you attached to the dialysis machine?

You can be attached to the dialysis machine in several different ways. The commonly used methods of providing access to the bloodstream for hemodialysis are:

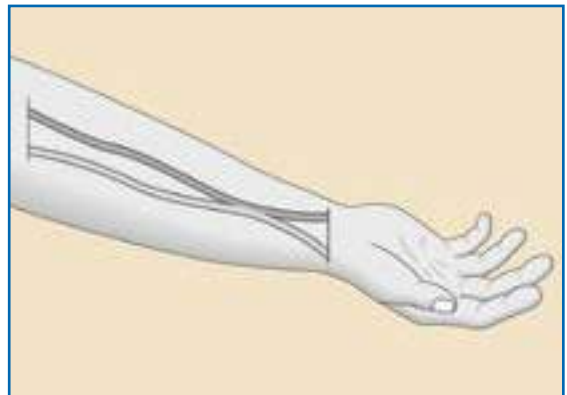
- Fistula (arterio-venous fistula or AVF for short)
- Graft (arterio-venous graft or AVG for short)
- **Central venous catheter (CVC)**

Arterio-venous fistula

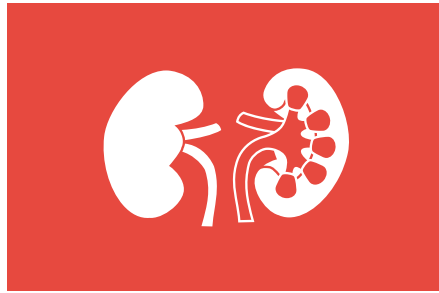
The fistula is the best method of providing access to the bloodstream. Of all the options, it has the smallest chance of infection or clotting. To make a fistula, an **artery** and a **vein** in your arm are surgically connected.

The flow of blood in arteries is much faster and stronger than the flow of blood in veins.

So when the two are joined, blood from the artery causes the vein to become larger and stronger. The enlarged vein is then used as the access site for inserting needles to connect you to the dialysis machine. Fistulas can be used about six to twelve weeks after surgery.



FISTULA



Arterio-venous graft

A graft is another way of providing access to your bloodstream. Sometimes it's used because a person's arteries and veins are not suitable to make a fistula.

To make a graft, a short piece of special tubing is placed under the skin to connect an artery and a vein. This graft is used as the site for inserting needles for hemodialysis. Grafts can normally be used within two to four weeks of surgery, if necessary, because there is no need to wait for them to enlarge - the graft is already the right size.



GRAFT

Care of fistulas and grafts

Once established, fistulas and grafts need very little special care. You can work, exercise and bathe normally. However, since your fistula or graft is your lifeline for hemodialysis, you will need to protect it. Your healthcare team will give you more information on how to care for your fistula or graft.

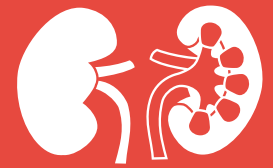
IMPORTANT

During aggressive sports or heavy manual work, there may be a chance that your fistula might be damaged. You should discuss the risks with your healthcare team. They might suggest you use a fistula guard to protect your fistula.

NOTES:

To care for your fistula or graft, avoid...

- Having your blood pressure taken on that arm
- Having blood drawn or IVs inserted in that arm
- Wearing tight watches and sleeves on that arm
- Sleeping on that arm or keeping it bent for long periods of time



Dependent (in-centre) hemodialysis

There are dialysis units in many hospitals across the country. They have everything you need for dialysis, including specially trained nursing staff and technicians to look after you and connect you to the dialysis machine. Many hemodialysis programs have satellite units (also called regional centres or community units) some distance from the main unit.

For in-centre hemodialysis you will typically have to travel to the hospital or satellite unit at least three times per week. Each hemodialysis treatment normally takes four to five hours. Some people call a treatment a “run”. Your blood circulates through the dialysis machine many times during each run, being cleaned a little bit more each time.



NOTES:

TRANSPORTATION

Many people have issues with transportation to and from hemodialysis treatments. Parking may also be difficult and/or expensive. Your social worker may be able to offer helpful suggestions for these challenges.

Dialysis



NOTES:

When it comes to foods, phosphorus and phosphate mean more or less the same thing. Check the labels of the foods you eat and avoid products that contain “phosphate” or “phosphoric”. See page 54 for a more complete list of ingredients to avoid.

Iron

Since iron is an important building block for red blood cells, you may be prescribed iron, either in pill form or intravenously, to maintain your iron stores. Iron pills are best absorbed on an empty stomach and must be taken *at least two hours before or after any other medications*, especially calcium, levothyroxine (Synthroid®) and some antibiotics. The main side effect from iron pills is dark stool (this is normal) and constipation. If you suffer from constipation, your pharmacists and/or healthcare team can provide helpful advice on how to minimize this condition.

Chronic kidney disease - mineral and bone disorder (CKD-MBD)

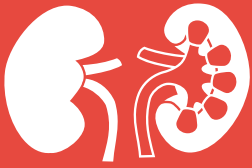
The disordered balance of minerals, specifically phosphate and **calcium**, is another problem often associated with chronic kidney disease. Your body has a complex system to balance these minerals for optimal bone health. Below we explain some important concepts that will help you understand the role of the medications you may be prescribed.

Phosphorus and calcium help to keep bones strong and healthy. Normal kidneys help balance the levels of phosphate and calcium in the blood by controlling the amount of these minerals eliminated in urine. As kidney disease worsens, the kidneys are not able to remove all the extra phosphate (that comes from your food) leading to high phosphate levels in your blood.

In addition, damaged kidneys are not able to activate vitamin D obtained from the sun and your diet. The active form of vitamin D helps your body absorb calcium from your diet. If your kidneys are not able to activate enough vitamin D, this may result in low calcium levels in your blood. The parathyroid glands, located in your neck behind the thyroid, play an important role in regulating the level of calcium in your blood.



Dialysis



NOTES:

Your doctor may also prescribe **phosphate binders** that bind with phosphate in your intestine causing it to be removed in your stool. Phosphate binders work best when they are taken with the first bite of each meal so that they can bind with the phosphate in your food. The most commonly prescribed phosphate binder is calcium. The major side effect of calcium-based phosphate binders is constipation. If you suffer from constipation, your pharmacists and/or healthcare team can provide helpful advice on how to minimize this condition.

If your phosphate is well balanced but your PTH levels are high and/or your calcium levels are low, you may be prescribed an *activated form of vitamin D*, available by prescription only. A commonly prescribed active vitamin D is *calcitriol*.

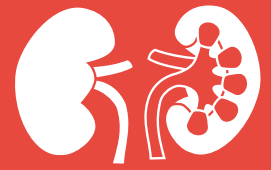
You will have regular blood tests to monitor your mineral balance. It is normal to have ongoing changes in the dosage of your prescribed phosphate binders and/or active vitamin D. Sometimes you will even be advised to stop or restart these medications in order to keep these minerals in balance.

Too much water, too much sodium - fluid overload

An important function of healthy kidneys is to remove excess fluid and sodium (salt) from the body. With advanced kidney disease, the kidneys may not produce as much urine as before. As a result, the body becomes overloaded with fluid.

Fluid overload leads to rapid weight gain, high blood pressure and **edema**. Edema means swelling due to fluid build-up. Sometimes, fluid stays in the lungs causing coughing and shortness of breath. Excess fluid is also sometimes seen as swelling in the ankles and around the eyes.





When on dialysis, you can avoid fluid overload by limiting your intake of sodium and fluid; salt makes you thirsty and holds water in your body.

High blood pressure

High blood pressure (also called **hypertension**) is a common problem for people with kidney disease. Normal kidneys produce a hormone that regulates blood pressure. Diseased kidneys often produce abnormal amounts of this hormone causing high blood pressure. High blood pressure is especially bad for people with kidney disease because it can further damage the kidneys. High blood pressure can also increase your risk of stroke and heart attacks.

High blood pressure is made worse by fluid overload. The excess sodium and water in the body increases the volume of blood in the arteries. The extra volume of blood causes the pressure in the arteries to increase.

For some people, high blood pressure can be controlled by removing more fluid during dialysis to achieve their **target weight** (also called **dry weight**), the weight at which their blood pressure is normal and fluid content is neither high nor low. Some people will also need some type of high blood pressure medication. If you are taking medication for high blood pressure, ask your doctor or other member of your healthcare team about its possible side effects.

WEIGHT SCALE

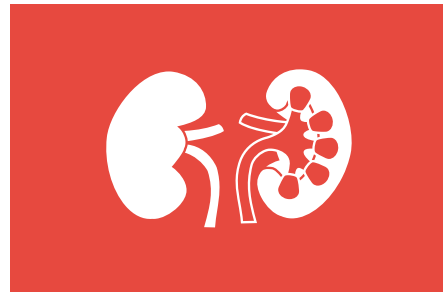
It may be helpful to have a highly accurate scale at home to keep track of your weight. It will help you monitor your overall sodium and fluid intake and understand your dry weight.



MY TARGETS

My Target Blood Pressure is: My Target Dry Weight is:

Dialysis



The most effective way to avoid skin problems is to prevent them from occurring in the first place. Dry skin, especially during cold winter months, is a common problem. People on dialysis are prone to dry skin, which can cause itching.

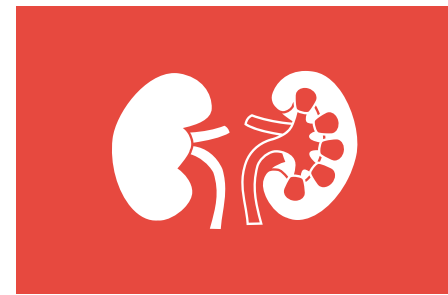
A number of strategies can be used, alone or in combination, to treat itching. A first step is to control the phosphate in your diet, take phosphate-binding medications if needed, and get the right amount of dialysis. If these don't work, your doctor may prescribe special creams, medications or ultraviolet light treatments.

For temporary relief from itching, try using a cold compress. Soak a face cloth in cool water and press it against the itchy area for five to ten minutes. Repeat as often as necessary. Afterwards, apply a fragrance-free, oil-based cream for dry skin.

Tips for healthy skin

- Use a room humidifier to keep the air in your home moist.
- Use a special soap made for dry or sensitive skin.
- Use a scent-free skin cream after your bath or shower when your skin is still damp to keep your skin from drying out.
- Avoid long hot baths or showers - they can make the itching worse.
- Wear soft cotton fabrics - avoid wool and rough polyesters.
- Use as little laundry detergent as possible - it irritates the skin. Or use a fragrance-free detergent formulated for sensitive skin.
- Never use rubbing alcohol on your skin - it dries it out.
- Avoid scented products - the chemicals that produce the scent often irritate the skin.

NOTES:



Contact information

- Make sure your clinic knows how to contact you in an emergency.
- If your regular dialysis clinic is not available, you will be contacted and redirected as to where and when you should go. If you can get online, check your renal program’s web site for updates on emergency procedures.

Medical supplies

- Keep an extra supply of all your medications at home. You may also be prescribed a medication to lower the potassium levels in your blood - you’ll need to keep this medication on hand in case you can’t do dialysis. Your kidney healthcare team will give you instructions on how and when to take it.
- If you do home dialysis, have a seven-day backup of all dialysis supplies.

Medical information

- Keep copies of your medication list and identification cards in an area you can easily access.

Food and water

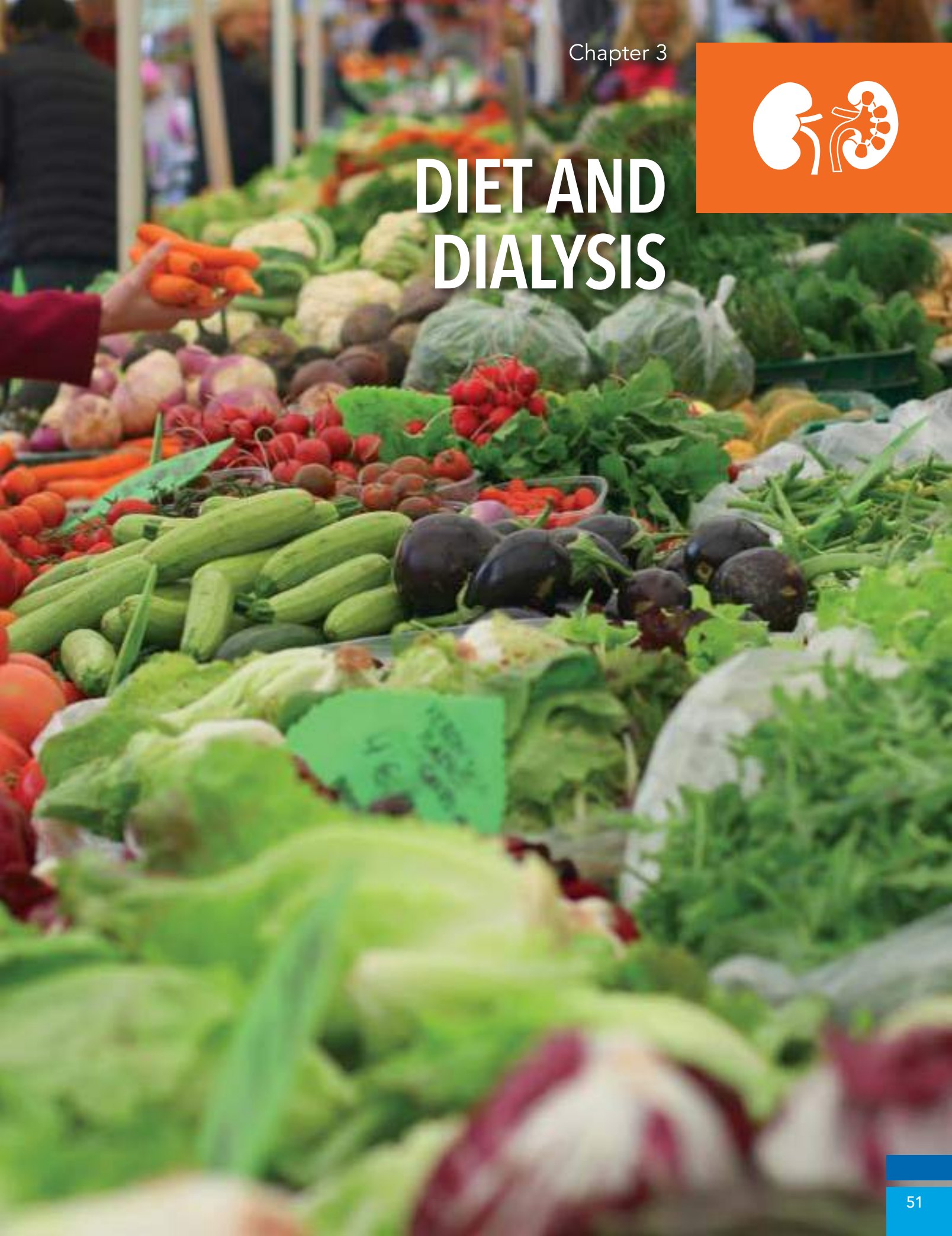
- Have enough food and water to follow the emergency diet for three days.



NOTES:



DIET AND DIALYSIS



Diet and dialysis



HELPFUL TIP

There is no standard “kidney diet”: what you eat may change as your kidney function or your medications change, or if you have other conditions like diabetes. If you’re on dialysis, you’ll need to make some changes to your diet, which can be difficult. But these changes don’t have to take the fun out of food. The Kidney Community Kitchen is a resource that offers kidney-friendly recipes, meal plans and kidney diet and nutrition tips. Check out the meal plans and recipes at kidneycommunitykitchen.ca. And if you sign up to be a member (it’s free!), you also have access to the meal planner tool.

Eating the right foods when you’re on dialysis can be challenging and it’s different for everyone, but you can still enjoy good food. In this chapter we explain the changes you may need to make in your diet and help you choose the right types and amounts of food to meet your individual needs. You’ll also be meeting with a kidney dietitian who will explain your particular requirements.

Why do you need to limit certain types of foods?

Dialysis removes waste products in the blood. In general, the more dialysis hours you do, the more waste products are removed. Peritoneal dialysis and home hemodialysis have fewer diet restrictions because dialysis is done more often and longer. However, dialysis can also remove nutrients the body needs. Depending on your blood levels, you may need to increase or decrease certain types of foods.

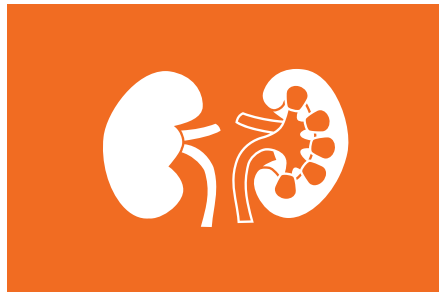


Protein

Everyone needs some **protein** every day to keep healthy. Your body needs protein to help fight infections, heal wounds and keep your muscles strong and healthy. You will likely need to eat more protein than before you started dialysis, especially if you are on peritoneal dialysis. *Why?* Because some protein is filtered out with dialysis. A dietitian will meet with you to determine the right amount of protein for you. Here are some high protein food choices:

- Meat such as chicken, turkey, beef, pork (choose meats without phosphate additives) and fish
- Tofu
- Eggs
- Cottage cheese

Diet and dialysis



Your doctor may also prescribe **phosphate binders**. Phosphate binders are often calcium-based and they bind to phosphate from food in your digestive tract. The bound phosphate leaves the body in the stool instead of being absorbed in the blood. You should take phosphate binders *with the first bite of your meal* so they have an effect on what you eat.

Potassium

Potassium is a mineral that is normally removed from the blood by healthy kidneys. Too much or too little potassium can be dangerous for you. A very high level can cause the heart to beat irregularly or even stop. If your potassium level is too high, your doctor will recommend that you reduce your intake of potassium-rich food and may adjust your medications and/or dialysis as well. It's important to know how much potassium is in different foods because you can reach high levels without feeling any symptoms. Your dialysis team will help you determine the right amount of potassium for you.

MY TARGET

My Target Potassium is:

Potassium is usually removed with dialysis: the more treatment hours you do, the more potassium is removed. With peritoneal dialysis or home hemodialysis, you may not need to limit your potassium intake as much since you are dialyzing more frequently. Some people on peritoneal dialysis may need to follow a *high* potassium diet. With in-centre hemodialysis, you will need to limit your potassium intake to avoid too much build-up between treatments.



NOTES:

Diet and dialysis



HELPFUL TIP

Even if you need to restrict potassium, there are still many fruits and vegetables that you can eat fairly often. Post a list of your favourites on your fridge. That way, you won't feel like you're missing out on foods you enjoy.

See kidney.ca and kidneycommunitykitchen.ca for a fact sheet about low potassium fruits and vegetables and information about potassium and kidney disease.

Almost all foods have potassium, but some have more than others. If you need a low potassium diet, you will need to limit high potassium foods including many fruits, vegetables and whole grains. Here are some tips to help you.

- Eat five to six servings of low potassium vegetables and fruits each day. A serving is ½ cup or one medium piece of fruit.
- Cook vegetables to remove as much potassium as possible. You'll need to “double boil” potatoes (see instructions at kidneycommunitykitchen.ca).
- Replace whole grain pasta, rice, and bread with white or 60% whole wheat pasta, bread, and rice.
- Limit milk and dairy products to ½ cup per day.



Fibre

Fibre is important to your health since it helps to prevent constipation, keeps your gut healthy and helps you feel satisfied after a meal, which can help you maintain your weight. Some high fibre foods that can fit into a kidney diet include:

- Oatmeal, barley, corn bran cereal
- Apples, pears, blackberries, raspberries
- Peas, green or yellow beans
- Carrots, cabbage
- You can also add 1-2 Tbsp. ground flax or natural wheat bran (germ removed) to your food.
- Inulin-based fibre supplements are often acceptable; speak to your kidney dietitian or pharmacist before starting any fibre supplement.

Diet and dialysis



Sodium (salt)

Almost everyone on dialysis should limit their sodium intake to reduce blood pressure and fluid build-up. Sodium attracts water. When you eat salty foods, you feel thirsty and your body holds the extra water. A diet high in sodium can cause high blood pressure, edema (swelling, often seen in the ankles and lower legs), and shortness of breath. There will be more sodium and water to remove during dialysis, which can make the treatment more difficult to perform, or which may cause symptoms such as muscle cramps. Following a low-sodium diet will help control these symptoms.

Limit sodium intake to 1500 – 2000 mg per day or less. Here are some tips to decrease sodium (salt) intake:

- Do not use salt in cooking or at the table. Instead, use fresh or dried herbs and spices to enhance the flavour of foods.
- Choose fresh and frozen vegetables, meat, chicken and fish instead of canned, pickled, breaded or processed foods.
- Avoid convenience foods, canned soups, pickles, sauces, processed cheese and salty snack foods such as potato chips, pretzels, and salted nuts.
- Read food labels to help you choose low sodium varieties of your favourite foods.
- Limit condiments such as soy sauce, barbeque sauce, ketchup, etc.
- Many restaurants provide healthy menu choices. Ask your server for low-sodium choices available on the menu.



Salt substitutes

Many salt substitutes contain potassium and other unsafe minerals. *Don't use salt substitutes unless your doctor or dietitian has approved them.*

Diet and dialysis



Peritoneal dialysis and weight gain

Peritoneal dialysis fluid contains dextrose, a type of sugar. When you do PD, the body absorbs some of the dextrose. *To avoid weight gain, add more physical activity to your day and limit higher calorie foods like sweets, sodas, cakes and cookies.* You can also limit your sodium and fluid intake to help you avoid having to use higher strength dialysate, which contains more dextrose.



If you have diabetes, you may require more insulin or diabetic medications to help balance the extra glucose that results from the breakdown of dextrose. You may need more frequent blood glucose tests while you are starting peritoneal dialysis. Keep a good record of all your blood sugar readings and bring this record to all your clinic appointments. If you are being followed by an endocrinologist, let them know you're starting PD.

See **Chapter Eight:**

Living well with kidney failure

for information about exercise and other general recommendations for maintaining good health. There are many benefits to staying active.

Diet and dialysis



Warning about glucose meters

Some glucose meters interact with a specific peritoneal dialysis fluid (icodextrin) and can give you a false high reading, leading you to take extra insulin that may cause dangerously low blood sugars. Make sure you have a glucose meter that does not interact with your dialysis fluid. Check with your pharmacist and switch to an appropriate glucose meter if needed.

Information for people with diabetes

If you have diabetes, you are at increased risk of low blood sugars before you transition onto dialysis (the pre-dialysis stage) and once you start dialysis. The doctor who takes care of your diabetes may need to decrease your insulin (or other hypoglycemic agent) on a regular basis. *You should report repeated low blood sugar reactions to your doctor.*

It is important to maintain your blood sugar in the range recommended by your doctor and/or diabetes team because this can help to decrease thirst and control fluid intake.

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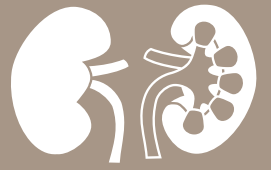
Diet and dialysis



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Summary

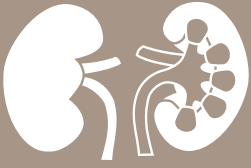
- There is no standard kidney diet. A dietitian who specializes in kidney nutrition can help design a diet that's right for you. They'll provide valuable suggestions, tips and ideas for healthy eating while on dialysis.
- Some changes to diet are needed when you are on dialysis to help prevent the build-up of certain waste products in the blood. Dietary changes may also be needed for those people in the pre-dialysis stage or those receiving non-dialysis supportive care.
- You'll need to pay special attention to the amount of protein, phosphorus, potassium and fibre in your diet. It's also very important to reduce the amount of sodium in your diet to avoid fluid build-up and high blood pressure.
- Peritoneal dialysis can cause weight gain and blood sugar changes because the dialysis fluid contains dextrose, a type of sugar, and some of it is absorbed by the body.
- Another good resource is the Kidney Community Kitchen at kidneycommunitykitchen.ca.



TRANSPLANT



Transplant



HELPFUL TIP

If you're waiting for a transplant, make sure to follow your treatment plan and do your best to stay healthy. Every year you should have a complete physical exam with your primary care provider; have a flu shot and keep other vaccines up-to-date as needed; and, repeat your transplant blood work and tests as directed so that your transplant file is kept up-to-date.

With advances in kidney transplant methods and **anti-rejection medications**, a kidney transplant is considered the best way to treat kidney failure for many people. A kidney transplant involves surgery to place a healthy kidney from a donor into your body. The new kidney takes over the work of your failed kidneys so that you can live a more normal life. A transplant is considered a treatment and not a cure since you will have to take medication for the rest of your life to prevent your body from rejecting your new kidney. There are two types of kidney transplant:

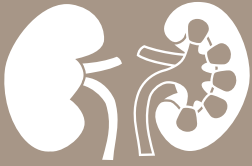
- Transplant from a living donor
- Transplant from a person who has died suddenly; you may hear the terms “deceased donor”, “cadaveric donor” and “non-living donor”

The transplant work-up

While a transplant may offer the best chance of returning to a more normal life, it is not suitable for everyone. Some factors which may affect your suitability for transplant include: general health; history of heart disease, blood circulation problems or cancer; emotional/psychological factors; obesity; and/or, evidence that a person does not or will not follow the medical treatment suggested.

Before being considered for a kidney transplant, whether live or deceased donor, all potential recipients must undergo a rigorous evaluation to determine if they are suitable transplant candidates. This is a detailed medical assessment that could include doctors' evaluations of the heart, lung, stomach, bladder and blood vessels. Many tests and procedures may be needed to make sure you are healthy enough for the transplant surgery and the medications that are needed to prevent rejection of the kidney. You may also need to see a psychologist or psychiatrist before the transplant surgery to explore your feelings about this treatment. The transplant work-up can take up to a year to complete. The transplant team in your community will give you more information about the necessary steps in your own transplant work-up.

Transplant



If blood tests indicate that the recipient and their potential donor do not match, they are called an **incompatible pair**. This means that the donor's blood type is not compatible with the recipient's blood type or the recipient has proteins in his/her blood (known as **antibodies**) that will reject that donor's kidney. However, the potential living donor may still be able to provide a kidney in an indirect way – see below.

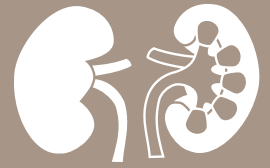
Kidney Paired Donation (KPD) program

The Kidney Paired Donation (KPD) program makes it possible for recipients who have a friend or family member willing to donate their kidney but who aren't a match, to donate to another recipient, and the intended recipient obtains a living donor kidney from someone else. The KPD program registry is a secure computer database that contains medical information about incompatible donor-recipient pairs from across Canada, compares their information, and identifies pairs that might be able to exchange donors. Ask your local transplant team if this is an option for you.



More information about the KPD program is available on the Canadian Blood Services web site at organsandtissues.ca.





Although people with kidney disease are encouraged to approach family and friends about their need for a kidney, potential donors must come forward of their own accord. Talk to your doctor if you know of someone who is interested in donating a kidney to you. Potential donors must be carefully tested before they can donate a kidney. This is to determine if they are healthy enough to donate a kidney and to see if the transplant is likely to work. Your transplant team will arrange for the potential donor to have a series of tests.

Other assessments are done by different members of the healthcare team. This may include the transplant nephrologist, transplant surgeon, clinical nurse specialist, nurse practitioner, social worker and transplant coordinator. In some cases, other specialists such as cardiologists, psychologists or psychiatrists will also see the potential donor. Your healthcare team can supply more information to the potential donor about what is involved.

If the kidney is suitable and the donor is healthy, a date is set for the transplant. You and the donor may be admitted to hospital a day before the transplant to allow time for some final tests.

Deceased donor transplant

A transplant from a deceased donor is also called a **non-living** or **cadaveric transplant**. In this type of transplant, a healthy kidney from someone who has died, often as the result of a sudden brain injury, is transplanted into your body. The family of the donor is asked to consent to the organ donation.

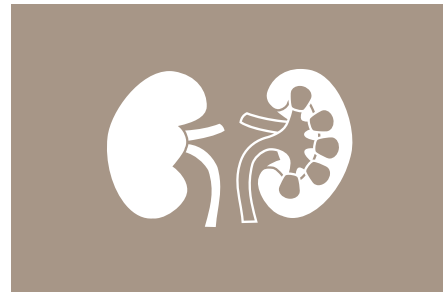
Following a series of tests, you will be put on a transplant waiting list until a kidney is found that is compatible with your body. The length of time you will have to wait is hard to predict because it depends on how hard you are to match and how many kidneys become available.

Transplant programs have an allocation (or matching) system so that distribution of organs is based on fair criteria such as suitable match, amount of time on the waiting list, etc. Ask your transplant team about the specifics in your community.



Anonymity for donors and recipients

In Canada, there is a law to protect the anonymity of both the recipient and deceased donor. Therefore, the identity of the donor cannot be shared with the recipient. However, many programs will forward anonymous cards of thanks from the transplant recipient to the donor's family.



A drainage tube is sometimes placed near the transplanted kidney to remove fluids that build up. In some cases, you may need dialysis following the transplant until the new kidney starts to work.

Your old kidneys are not removed unless they are so large there is no room for the new kidney or they are chronically infected. If you do need surgery to remove your old kidneys, your healthcare team will discuss this with you and the surgery will be carefully planned.

Kidney - pancreas transplant

For people who have kidney failure as a result of Type 1 diabetes (insulin-dependent diabetes) a combined kidney and pancreas transplant can be considered to treat both the kidney failure and diabetes. This procedure is not offered in all centres and is more complicated than a kidney transplant alone. Talk to your doctor for more information about this option.



What is rejection?

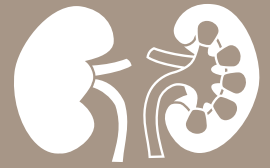
After the transplant, many tests are done to make sure your new kidney is working properly and to watch for any signs of **rejection**.

Rejection occurs when the body recognizes that the transplanted kidney is not its own and mobilizes the immune system to fight against it. Rejection can occur at any time after the transplant, but is more common in the early months.

Different medications are used to prevent rejection, either alone, or in combination. These medications work by blocking the activity of the immune system. However, rejection may occur even when these medications are taken faithfully.

You may feel perfectly well in the early stages of rejection. Rejection is usually discovered by routine blood tests and is treated immediately with special short-term medications. Rejection episodes can usually be treated successfully.

NOTES:



Types of anti-rejection medications

There are three main types of anti-rejection medications and they all have to do with the white blood cells in your immune system. White blood cells do different things. Some white blood cells “read the name tags” on all the things they see in the body. If the name tags show there is something in the body that does not belong, they raise an alarm and send signals to tell the body to make more white blood cells to fight off the “invader”. The invader could be many things: bacteria, a virus, or the organ that was transplanted.

Here are the three main types of anti-rejection medications:

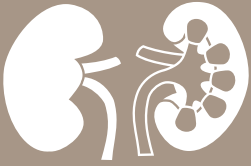
- Medications that make it harder for white blood cells to raise the alarm if they see something that doesn’t belong. Examples: cyclosporine, tacrolimus
- Medications that limit how many new white blood cells your body can make. Examples: azathioprine, mycophenolate, sirolimus
- Medications that make it harder for your white blood cells to talk to each other. Example: prednisone

Many transplant recipients take two, three or four anti-rejection medications. Your transplant team will choose the best ones for you. It’s extremely important to take them *exactly as ordered* to make sure you get the best benefits while trying to avoid serious side effects.



In this handbook, we’ve used the generic name of the medication rather than the brand name because there are often several brands available. Towards the back of this handbook, there is a chart showing examples of brand names.

Transplant



Most common anti-rejection medications

Cyclosporine, tacrolimus and sirolimus

Each person’s body absorbs and breaks down these medications in a different way. This means that people taking the same dose could have very different levels of these medications in their body.

To be effective, these medications must stay at a certain level in your blood. If the level is too low, your new organ may be rejected. If the level is too high, your kidney or liver may suffer or you may have other effects from the medication.

Your blood levels of some of the medications are checked, often just before you take your morning dose of these medications. While you are in hospital, your levels are checked often and, after you go home, you will go to a blood laboratory to get your levels checked before or after visits to the transplant clinic.

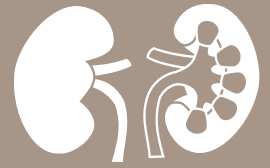
NOTES:

Important

If you take cyclosporine, tacrolimus or sirolimus, you should avoid grapefruit, grapefruit juice and certain types of oranges (Seville oranges). These foods increase the level of these medications in your blood.

Azathioprine and mycophenolate

These medications affect how many new white blood cells your body can make. They may also limit other cells your body makes, such as red blood cells and **platelets** (which are responsible for blood clotting). Blood counts are done regularly to make sure they are within safe limits.



Antithymocyte globulin and basiliximab

Antithymocyte globulin and basiliximab are antibodies that block the function of the immune cells, which are responsible for rejecting a transplanted kidney. Some patients receive several doses of these medications, given intravenously, at the time of the transplant.

In the first two or three days of receiving antithymocyte globulin, people may feel like they have the flu (fever, chills, nausea, headache). These effects generally go away. Medications such as acetaminophen, prednisone and diphenhydramine may be given to help with these side effects.

Side effects

All medications, even vitamins, herbs and natural products, can have side effects. Just because a side effect is possible with a medication, it does not mean that everyone will have it.

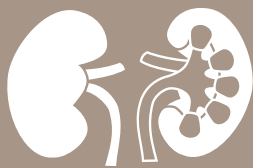
Most people can take anti-rejection medications without any problems. If you notice a side effect or feel different than normal, let your transplant team know so they can help you with it. *It's important for them to know how you are feeling before you take steps to feel better on your own.*

An important possible side effect that can happen with all anti-rejection medications is an increased risk of infection.

- You may need to take antibiotics to prevent serious lung infections.
- You may need to take antiviral medications to prevent serious viral infections.
- Wash your hands often and thoroughly with regular soap and water.
- Avoid being around people who are sick.



Transplant



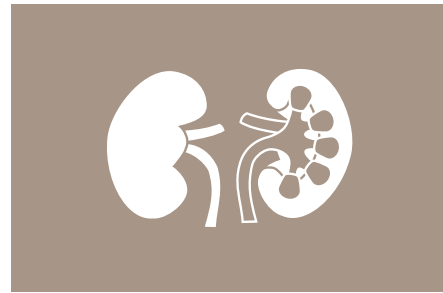
Below is a chart that shows some of the possible side effects from taking various anti-rejection medications. There are also *other* side effects that are not listed below. If you have other side effects or concerns, talk to your transplant team and pharmacist.

Common anti-rejection medications and some of the possible side effects (not a complete list)

	AZATHIOPRINE	CYCLOSPORINE	MYCOPHENOLATE	PREDNISONE	SIROLIMUS	TACROLIMUS
Increased risk of infection	x	x	x	x	x	x
Stomach upset, nausea, heartburn, loose stool, diarrhea			x			
Tremor			x			x
High blood pressure		x				x
High cholesterol		x			x	x
Hair growth		x				
Hair loss						x
Increased cancer risk (skin cancer and lymphoma)	x	x	x	x	x	x
Increased risk of high blood sugar or diabetes*				x		x
Low blood cell count	x		x		x	
Increased appetite and weight gain**				x		
Increased ankle swelling or edema				x		
Skin changes (thinner, acne, slow wound healing)				x	x	
Mood changes				x		
Bruising				x		

* If you have diabetes, make sure to check your blood sugar often, and make a plan with your diabetes team to adjust your diabetes medication after your transplant.

** Make sure to meet with the dietitian to discuss the foods you can and should eat after the transplant.



Important guidelines about medications and your transplant

Interaction with other medications, remedies and foods

Many of the medications you take to keep your transplant healthy will be negatively affected by certain foods and other medications. This includes other prescription medications, over-the-counter drugs and treatments, and herbal remedies.

Here are some examples of how your anti-rejection medications (especially cyclosporine, tacrolimus and sirolimus) interact with many other commonly used medications and some foods.

- Some pills, including St. John’s wort, can make cyclosporine and tacrolimus ineffective (useless). This can cause damage to, or the loss of, your transplant.
- Erythromycin and clarithromycin (antibiotics often used for sore throats) can make cyclosporine and tacrolimus levels increase high enough to cause kidney damage, if not carefully watched.
- As stated earlier, you should avoid grapefruit, grapefruit juice and certain types of oranges (Seville oranges). These foods may cause an increase in the level of cyclosporine, tacrolimus and sirolimus in your blood.

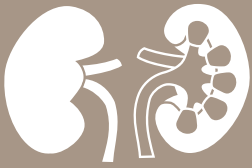
Your transplant team keeps an up-to-date list of all the medications you take. You should check with your transplant team *before* taking any new medication, even if it’s prescribed for you by another doctor, or is an over-the-counter pill or herbal remedy. Your team will make sure the new medication, over-the-counter pill or herbal remedy is safe for you.

When any doctor or pharmacist prescribes a medication or other treatment for you, always make sure they have considered your transplanted kidney and the other medications you’re taking.

NOTES:



Transplant



See the online version of

**Book One:
Living with reduced
kidney function,
Chapter Four:
Managing your
medications for kidney
health** for more tips
on managing your
medications: kidney.ca.

Taking anti-rejection medications

It's very important to take all of your anti-rejection medications and at the correct times of the day, as determined by your transplant team. Missing doses and taking doses too late can let your immune system start to attack your transplant. You might not feel any different and your blood tests may look fine to start with. The damage can build up and you may lose your transplant later.



If it's hard to remember to take your transplant medications, talk to your transplant team about making the schedule easier. Using alarms or smart phone apps can help. You may also want to ask your pharmacist about using a bubble pack for your medications.

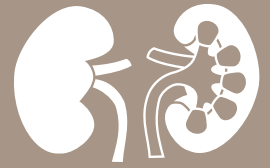
If you are having side effects from your transplant medications, talk to your transplant team about ways to help you feel better.



Keep an adequate supply of medications

Make sure to always have a supply of your anti-rejection medications so that you never run out. You should usually allow at least one week when reordering from the pharmacy.

Make sure to talk to your transplant team about coverage of anti-rejection medications. Sometimes the medications can *only* come from the transplant hospital and sometimes they come from your local pharmacy. You may be responsible for paying for your anti-rejection medications and they can be very expensive. Your transplant team can work with you and your insurance plan to sort out medication coverage.



TRAVEL TIP

If you travel after your transplant, bring an extra supply of medication in case your travel plans change. Always keep your medication in the original containers with labels that come from the pharmacy. Carry your medication with you in your carry-on bag.

Living well with a kidney transplant

It is important to get plenty of rest after a transplant. You may tire easily as a result of the operation and your stay in the hospital. Your energy will return however, and you will find you need less rest. After you have recovered from the transplant operation and are used to taking your anti-rejection medications, you'll find yourself returning to a more normal lifestyle. While you'll have to take medications every day and visit a transplant clinic regularly, you won't need dialysis anymore.

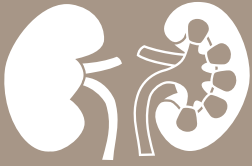
Stay active

Walking is the best exercise at first. You can also do light housework, but avoid any heavy lifting for at least two months following the transplant. After the recovery period you should aim for 30 minutes of exercise each day. Try brisk walking, cycling, swimming, tennis or gentle aerobics. Talk to your doctor before doing any strenuous exercise.

See **Chapter Eight:**

Living well with kidney failure for more information about travel-related topics.

Transplant



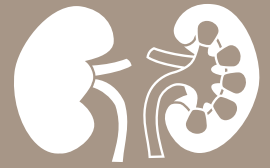
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Some people are worried they will get hurt while exercising. While you should avoid contact sports that could bruise your new kidney, regular exercise is the best way to protect your health as well as your kidney. Exercise will protect your bones, lower blood pressure, control your blood sugar and cholesterol levels, and help control your weight. Staying active also gives you more energy and can help lift you out of a depressed mood.



Aim for a healthy weight

After your transplant, you may have a better appetite and you may gain unwanted weight. Losing weight is difficult but it can have health benefits for you and your kidney. If you are overweight, losing just 10% of your current weight has been shown to lower blood pressure, control blood sugar and cholesterol levels and reduce the risk of heart disease. If you need help losing weight, ask your doctor to refer you to a weight loss program or speak with a dietitian.



Follow a healthy diet

Here are some guidelines to help you follow a heart-healthy diet that can help reduce your risk of heart disease:

- Aim for at least five servings of fruits and vegetables each day.
- Eat a wide variety of raw and sometimes cooked vegetables and fruit. Include dark green leafy vegetables like spinach, chard, and kale. Include colourful vegetables like beets, tomatoes and sweet peppers.
- Include fatty fish (salmon, mackerel, anchovy, sardines) regularly.
- Snack on nuts and seeds (almonds, hazelnuts, walnuts, pumpkin seeds).
- Use olive oil in your cooking.
- Include whole grain breads, pasta and brown rice.
- Include low-fat dairy products like yogurt and cheese.

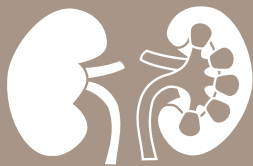
While a heart-healthy diet may include having an occasional glass of wine or beer, the effect of alcohol on a transplanted kidney is not really known. It is best to limit alcohol. If you have any questions, speak with your doctor or dietitian about how much alcohol is safe for you to consume.

HEART-HEALTHY DIET

If you want to learn more about a heart-healthy diet, talk to your doctor or dietitian about DASH (Dietary Approaches to Stop Hypertension) or the Mediterranean diet.



Transplant



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Calcium and phosphorus

As long as your new kidney is working well, the levels of calcium and phosphorus in your body will return to normal. After your transplant, it is no longer necessary to restrict phosphorus or to take phosphate binders. In fact, it is important to consume an adequate amount of these minerals. The main sources of these minerals are milk and milk products.

Cholesterol and fat

You may develop an elevated **cholesterol** level after your transplant. Anti-rejection medications may contribute to this. You can lower your cholesterol level by losing weight, making healthy food choices and staying active and by reducing the saturated fat in your diet. You may need to take prescription medication if changes in your diet do not lower your cholesterol level.

Fluid and sodium

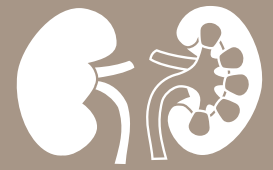
You do not need to restrict your fluid intake as long as your new kidney is working well. In fact, it is important to drink a lot of fluids for your new kidney to work well. Anti-rejection medications may increase your blood pressure after a transplant. To help lower your blood pressure, you may need to continue to limit the amount of sodium in your diet.

Potassium

Anti-rejection medications sometimes increase the potassium level in the blood. Therefore, you may need to limit your potassium intake after your transplant. Your dietitian can help you make lower potassium food choices.

Protein

For the first two months following a transplant, you will need slightly more protein in your diet. Protein is necessary to repair tissue and help the healing process after transplant surgery. After the first two months, you can return to a moderate intake of protein.



General recommendations for good health after a transplant

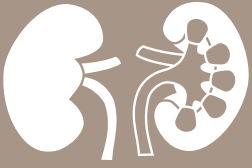
- Wear a Medical ID bracelet that identifies you as the recipient of a kidney transplant.
- Avoid prolonged exposure to the sun. Anti-rejection medications can make your skin more susceptible to sun damage and skin cancer. If you do spend time in the sun, apply a good sunscreen first, preferably one labelled SPF 45 or more (and reapply as needed). Wear a hat and clothing which blocks the sun.
- Wash your hands regularly to help avoid infections.
- Prepare, cook, serve and store food in a safe manner. Also, since you are immunosuppressed (your immune system is weakened due to the anti-rejection medications you are taking), do not eat raw meat, fish, poultry, eggs and raw cheese since these foods could contain bacteria that could make you ill.
- Report fevers, sore throat, cold, flu, or unusual bleeding to your doctor.
- *Avoid over-the-counter medications or herbal remedies.* Many contain substances which can harm your new kidney or which might interfere with other medications you are taking.
- Inform your transplant team or pharmacist of any medications prescribed by other doctors.

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FOOD SAFETY

For more information about food safety, especially for people with weakened or vulnerable immune systems, visit healthycanadians.gc.ca

Transplant



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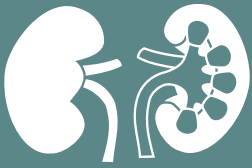
Summary

- Before a transplant can be considered, potential recipients will undergo a rigorous work-up to determine their suitability. This is an intensive and lengthy process. Many people with end-stage kidney disease will not be eligible for a transplant.
- A healthy kidney for transplant may come from a live donor or a deceased donor.
- A kidney transplant is a treatment, not a cure for kidney disease. It means you will no longer need dialysis, but you will always have to take anti-rejection medications to help prevent your body from rejecting the donated kidney.
- It is very important to take anti-rejection medications exactly as prescribed.
- Following a kidney transplant, it is important to get enough rest, stay active, eat a healthy diet, maintain a healthy weight, attend all your doctors' appointments, have your lab work done regularly and take your medications.



NON-DIALYSIS SUPPORTIVE CARE





Non-dialysis supportive care

PEACE OF MIND

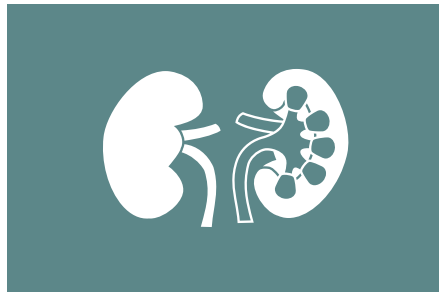
You have the right to make decisions about your own treatment, including the decision not to start or to stop dialysis. Death and dying are not easy things to talk about. Yet it's important to speak with your family, friends, and healthcare team about your treatment choice, so that you can plan for **end-of-life care** with peace of mind.

Non-dialysis supportive care is an active treatment choice in which kidney disease is treated with medication and diet, with no plans for a transplant or dialysis. In many communities it's called **conservative care**, *conservative treatment* or *conservative management*. However, people sometimes think that the term *conservative* implies that your care will be limited, which isn't the case, so we prefer the term *non-dialysis supportive care*.

If you choose non-dialysis supportive care, either because you decide not to start dialysis or because you've decided to stop, you will receive high quality medical care and, as your kidney function gets worse, your healthcare team will help you prepare for the end of life.

The goal of non-dialysis supportive care is to preserve kidney function for as long as possible through diet and medication, knowing that this can slow the decline in kidney function, but may not prevent it. You may continue to feel well for quite some time. It is a treatment choice that may not prolong life but will help to manage symptoms, both physical and emotional, so that you can live the way you want for your remaining time, without the disruption of dialysis treatments. The goal is to live the way you want, right up to the end of life.

Non-dialysis supportive care



Why do people choose non-dialysis supportive care?

Some people choose this type of care because they have other serious medical conditions, are not candidates for a transplant, are elderly, and/or feel the burden and discomfort of dialysis outweigh the potential benefits. This may include the difficulty in performing dialysis, symptoms and life disruption with dialysis, including travel time. They decide that non-dialysis supportive care is a reasonable choice for them because they will receive active, supportive physical and emotional care right up until the end of life. In short, it may offer them greater quality of life.

Depending on where you are in life and other reasons like your overall health, it is wise to consider several factors as you make your treatment decision. Sometimes it could be your doctor who raises the subject, especially if they feel that dialysis treatments will not provide any further benefit for you. But the final decision is yours and you can change it at any time.

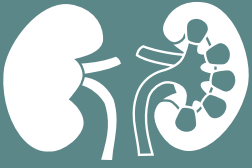
Choosing not to start dialysis

Some people choose not to start dialysis. Dialysis requires surgery to provide access to the bloodstream (for hemodialysis) or a catheter inserted into your abdomen (for peritoneal dialysis). After surgery, there is often a recovery period before dialysis can be started. Then there are the treatments themselves, which take up time throughout the day or week, depending on the type of dialysis.

Dialysis is a treatment intended to improve life, not cause more harm or suffering. Sometimes people have other health complications which dialysis will not help. Others feel that the burden of dialysis treatments will not provide any real health benefit or give them the enjoyment of life they would like.

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Non-dialysis supportive care



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After a thorough discussion with your doctor, other members of your healthcare team and your loved ones, you may decide not to start dialysis. You will then receive non-dialysis supportive care.

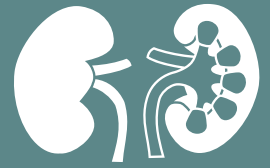
Dialysis trials

Sometimes it is possible to do a short trial period of dialysis to see if it helps to improve your quality of life. Please speak with your kidney doctor and other members of your healthcare team for more information.

Choosing to stop dialysis

If you are on dialysis and do not feel it gives you the health benefits and quality of life that you wish, you may choose to stop the treatments. This may be a difficult decision because it means preparing for the end of your life. Because each person is unique, no one can say exactly when death will occur. When a person stops dialysis, it could be one to two weeks, or less or more. Your doctor can give you an estimate but no healthcare professional can accurately say when death will occur.

Non-dialysis supportive care



If you choose non-dialysis supportive care

If you choose this type of care, you'll continue to have the full support of your healthcare team, including regular doctor visits and routine tests. You will continue to take medication for kidney disease and make healthy food choices, including some occasional food treats. You may still need to restrict the amount of fluid you drink to avoid breathing difficulties. Medication is always available to help manage any pain you may have. Machines like respirators will not be used. At some point toward the end of life, you will begin to receive palliative care.



Palliative care

Palliative care (which is also called *end-of-life care* or *comfort care*) is the special physical, emotional and spiritual care that is given to people at the end of their life. The goal is to maintain the quality of living and ensure dignity in dying. It may include managing pain or discomfort, help with breathing and other supportive treatments.

Palliative care can be offered in hospital (sometimes in a special palliative care unit at the hospital), in a hospice, nursing home or at home. However, there may be limitations on the specific kinds of care that can be given in these different settings and not every type of care is possible at home.



NOTE

If you have an advance care plan, you might want to review it. If you don't have one, read **Chapter Six: Advance care planning**. It provides a more complete list of questions for you to think about.



Non-dialysis supportive care

NOTE

Choosing non-dialysis supportive care (which means no dialysis) is not considered suicide because the cause of death is kidney disease. Everyone has the right to decline or discontinue medical treatment. Insurance companies pay out insurance policies because the cause of death is kidney disease, not suicide.

Death from kidney disease is usually painless and peaceful. You might experience sleepiness and longer periods of sleep. You may or may not feel like eating or drinking. In all cases, you will receive help for whatever is troubling you. Your dignity is respected at all times.

Your healthcare team will introduce you to the palliative care resources available in your area when you need them.

Questions to ask yourself

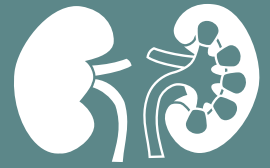
- Do I want to try in-centre hemodialysis knowing it will mean surgery, then travelling to a hospital or dialysis centre for hemodialysis treatments at least three times a week? Do I have someone to drive me and keep me company? Will this option allow me to do the things I want to in life?
- Am I willing to learn how to do peritoneal dialysis at home and do I have the energy to do it several times a day? Do I have someone who can help me, including managing my supplies?
- If I choose non-dialysis supportive care, what are the most important things I would like to do in the days, weeks or months remaining to me?
- Do I have people available to help me, no matter what I decide - family, friends, loved ones, professional support services?

Your feelings

It is very common to have a range of emotions when thinking about and deciding on treatment options and what they mean. You might feel anger, fear, sadness, confusion, anxiety or depression. Or you may have feelings of relief, acceptance and peace. You may experience any or all of the above. It can be good to talk about these feelings with your healthcare team because they can provide emotional support, practical suggestions, further information (which may ease your mind) and even medication or other treatments for anxiety or depression. Your healthcare team will also want to be sure that your decision is made voluntarily and that you aren't under any unusual stress or suffering from severe depression.

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Non-dialysis supportive care



Regardless of your treatment option, it is the quality of your life and your time that is important. If you have chosen no dialysis, this may give you the time to live and do the things you want to do with your loved ones until the end of life. It can be a time of peace with no surgeries and no machines. It can be a special time spent with family, loved ones and friends.

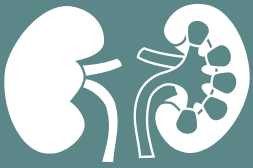


Talking with your family and loved ones

Although you are the ultimate decision-maker about what kinds of treatment you want or don't want, you may wish to consider how your family and loved ones will be affected by your decision. Talking with them about these matters can be difficult and painful, and sometimes, family members may not agree with your decision - they may be afraid, angry or unwilling to discuss it. You will want to help them understand the reasons for your decision. Many people like to involve their doctor, social worker or other healthcare team members in these discussions. They can answer questions, provide more details and discuss what resources are available to support you and your family.

Take your time - there is no need to rush the conversation. You can simply explain how you are feeling, what you would like to do with your time and why you feel that your decision is the best one for you.

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Non-dialysis supportive care

Where to go for more information

Your healthcare team is the best source of information about the kinds of support that are available in your region for non-dialysis supportive care, and later for palliative care. In particular, your social worker will have details about local resources.



Summary

- Non-dialysis supportive care is an active treatment choice in which kidney disease is treated with medication and diet, with no plans for a transplant or dialysis.
- You may choose not to start dialysis, or to stop dialysis treatments at any time.
- As the end of life approaches, you will receive palliative care, which is the special physical, emotional and spiritual care that is given to people at the end of their life.
- You and your family may find it difficult to deal with and talk about your feelings at this time; your healthcare team can support you throughout this process.



ADVANCE CARE PLANNING



Advance care planning



National advance care planning day

April 16th is national advance care planning day in Canada: a day to reflect on what gives your life meaning, your values, and your wishes for your care at the end of life; a day to share these reflections with friends and family; a day to think about what you want, talk about your wishes, write them down and review your plan every year.



Advance care planning ensures your voice is heard, even when you can't speak for yourself.

Regardless of treatment choice, advance care planning is important, especially if you are living with a chronic disease. Many Canadian adults have a will and some may have a power of attorney. However, very few Canadians know about advance care planning and less than half the Canadian population has ever had a conversation with a family member or friend about what healthcare treatments they would want, or not want, if they were to become ill and unable to communicate their wishes.

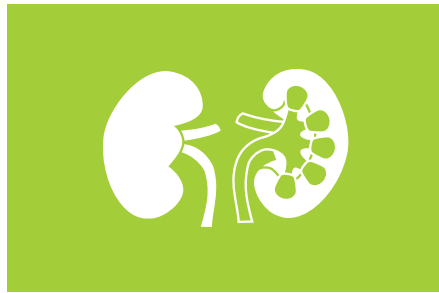
No one really likes to think about the end of life because many of us are uncomfortable thinking about our death. Nevertheless, since death comes to us all, it is a good idea to make some plans for this eventuality. And increasingly, advance care planning is becoming part of routine healthcare.

What is advance care planning?

Advance care planning is a *process* in which you think about what you would like to happen to you, or not happen to you, if you become unable to make decisions about your healthcare treatment or if you are unable to communicate your wishes.



Advance care planning



It's also about *making decisions* before this happens, *writing them down* (or recording them by voice or video), and *talking about your wishes* with your family, friends and healthcare team (so your wishes can be put on your medical record). One of your decisions will be to name a **Substitute Decision Maker**, someone you know well and trust, whom you would want to make decisions on your behalf if you were unable to.

You may have to get more information about what kinds of healthcare treatments and support might be available and needed in the future before you decide what you want to include in your advance care plan.

Some facts about advance care planning

- Your plan will only be used when, or if, you become unable to make decisions for yourself or to communicate your wishes.
- Your advance care plan might never be used. For example, you may always have the capacity to make your own decisions and to communicate them. Or you may pass away in your sleep and never need the plan.
- You can change your mind and change your plan at any time. In fact, it's a good idea to review your advance care plan regularly as you move through life's stages, or if there are changes to your family status through births, deaths, divorce, etc. Also, your health may change over time or new medical treatments may become available.
- No one can do advance care planning for another person. You have the right to do it for yourself and to have your wishes respected.
- Everyone, regardless of his or her current health or age, should probably have an advance care plan.

HELPFUL TIP

It's a good idea to have a small wallet-size card that states who your Substitute Decision Maker is and their telephone number. Keep this card in your wallet with your healthcare and hospital cards.

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Advance care planning



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Questions to think about for your advance care plan

Making an advance care plan gives you the opportunity to think about what is really important to you in life and to reflect on your personal values and beliefs. Take your time and don't feel you need to make these decisions all at once. Allow yourself time for reflection. Remember that advance care planning is a process, not a single event.

The decisions are about you and what you want. For some people, life is precious under any condition and they would not want to limit any kind of life-saving treatment. For other people, they may not want treatments that may prolong their life when death is near or the life they would like to have is no longer possible. For example, the time may come when dialysis is no longer medically possible or when it can no longer prolong life. There is no right or wrong choice - it is up to you.

Advance care planning



Here are some questions to help you think about what is right for you. You may find that other questions arise as you go through the thinking process.

- How would I like to spend my remaining time towards the end of life? Will I continue to work or will I retire? Work part-time? Volunteer work?
- What kinds of activities would I like to be doing? Travel? Outdoor leisure activities like gardening or golf? Reading?
- Where would I like to live? At home? Move to a smaller living space or an assisted-living environment?
- Who would I want to spend my time with? Family, friends, children and grandchildren, pets, community groups, etc.



- What kinds of practical help might I need?
 - Shopping and food preparation?
 - Household cleaning and maintenance, bill-paying, etc.?
 - Getting to doctor visits or treatments?
 - Getting to social or business events, cultural or sports events?
- Who would be available to help me? Spouse, partner, family, friends, home-care professionals?

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Advance care planning



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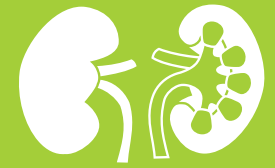
- What kinds of treatments or life-sustaining measures would I want or not want? Why? Do I have enough information about these treatments or do I want to talk to my healthcare team to get more details?
 - Dialysis?
 - Breathing assistance (for example, with the help of a respirator)?
 - Cardio-pulmonary resuscitation (CPR) if my heart were to stop?
 - Feeding tube if I could not eat?
- Would I feel differently about these treatments if they were only for a short time rather than permanently?
- If I were terminally ill with no chance of recovery, where would I prefer to pass away? At home, in hospital, or in a hospice? Somewhere else?
- Is there anything special I would want in the last days, weeks or months of life? Visits from children and grandchildren? Pets? Friends? Music? Religious rites?

End-of-life care

(also called palliative care or comfort care)

This is the special physical, emotional and spiritual care that is given to people at the end of their life. The goal is to maintain the quality of living and ensure dignity in dying and to support the person's comfort, peace and dignity. It may include managing pain or discomfort, help with breathing and other supportive treatments. Sometimes end-of-life care can be done at home and other times it is beneficial to be in the hospital. That's because there may be limitations on the kinds of care that can be given in different settings such as nursing homes, hospices, at home or in hospital. Not every type of care is possible at home.

Advance care planning



- What do I worry about most in the dying process?
- If possible, do I want to donate my organs and/or tissues?
- Do I have any cultural, religious or spiritual beliefs and traditions that will affect my choices and decisions?

Some benefits of advance care planning

Completing your advance care plan can give you peace of mind knowing that you have made some personal decisions about what you would like or not like to happen to you. You have also written down or recorded those wishes (so that they are very clear) and talked about them with your family, friends and healthcare team. Many people feel a sense of relief, knowing that their family and doctors are well-equipped with the right information to make good decisions on their behalf and that their wishes will be respected.

The process can also help to avoid later emotional distress, conflict or confusion for you, your family and your healthcare team. In fact, you might encourage other family members to do advance care planning for themselves so that you would know what they would want if you had to make decisions on their behalf.

Talking with family, friends and your healthcare team

Talking with your family, friends and healthcare team about your wishes and concerns is a very important part of the advance care planning process. Sometimes it can be difficult and painful to discuss these matters. It’s often better to have these discussions while you’re in good health rather than when the end of life is near. You then have the time and peace of mind to think about and discuss your future care and get more information if you need it.

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Advance care planning



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Here are some suggestions to help start the conversations with your family, friends, and healthcare team:

- With your family, you might start by saying that you have been reading about advance care planning and you feel it is something you would like to do. You can then say that you would like to talk to them about your advance care plan once you've finished it.
- While you're working on your plan, it's sometimes helpful to discuss your questions with your doctor to make sure you're working with accurate information about possible treatments, etc. And most people will talk to their spouse, partner or a close family member while they're thinking about and writing down their plan. You don't have to do your plan alone, but you can make all your own decisions.
- Once you've finished your plan, you might start by sharing it first with your spouse, partner or other close family member.
- You may then wish to share your plan with other family members and friends, either a few people at a time or in a group setting. Try to organize things so that everyone is comfortable, in a calm emotional state and there are no interruptions.

Advance care planning



- You can provide copies of this chapter or other documents about advance care planning to give others some background information on the process.
- You can also let them know that you can get together with your doctor or other members of the healthcare team at a later date to get answers to any questions they may have. Sometimes people prefer to have their doctor present when they discuss their plan with their family.
- Allow time for reflection – for you and for your family. You may want to get together again at a later date to continue the discussion.
- Be prepared to listen, too, so that you can understand others' concerns.
- Make sure to give a copy of your plan to your doctor, your kidney healthcare team and/or others involved in your care (i.e. home care).
- You should review and re-evaluate your plan as changes in treatment or changes in your personal life occur.

Other documents and suggestions to help put your affairs in order

Here are some suggestions about the kinds of documents you should have and how to put your affairs in order. Ideally, we should all do this kind of planning and organization on a regular basis and review it every few years.

- **Will:** This is a legal document, usually prepared by a notary or lawyer, which explains how you would like your assets to be distributed after your death. It can also include any special wishes or bequests (gifts) that you would like to make to specific people.
- **Power of Attorney:** This is a legal document in which you appoint one or more people to make decisions for you about money, property and other financial issues so that they can act on your behalf.

NOTES:



Advance care planning



NOTE

Each province/territory may have different laws about the topics and documents mentioned here and the documents may have different names. Look into your provincial/territorial regulations. There are many sample documents available and many of them are free. You can ask your kidney healthcare team and/or social worker if you would like more information about this.

- **Power of Attorney for Personal Care:** This document is similar to a regular *power of attorney* but in this case you identify a Substitute Decision Maker who you authorize to make personal and healthcare decisions for you if you become unable to make these decisions yourself or are unable to communicate your wishes. *A power of attorney for personal care* is part of advance care planning. Depending on your province/territory, it may be called a *living will*, *advance directive*, *personal directive*, *mandate* or some other name.
- Organize your financial records, bank accounts, safety deposit boxes and keys, insurance policies, real estate, deeds of sale and all other important papers.
- Make a list of all your usernames and passwords for all your devices like mobile or cell phones, computers, tablets or other devices, all your online social media sites, specific web sites, bank machines/ATMS, etc.



Advance care planning



- Assign a specific person to have all the contact details of people who will be involved in settling your estate, including your lawyer, accountant, the executor of your will, etc. This person can be the same as your Substitute Decision Maker or someone different.
- Discuss your preferred funeral arrangements and service with your family.
- Consider organ and/or tissue donation and discuss your wishes with your family.

Where to go for more information

There are specific national and provincial organizations that specialize in advance care planning such as advancecareplanning.ca and you can find them by searching online. You can also get information from your social worker or your local Kidney Foundation office. This information may include brochures, guides and workbooks where you can simply fill in your information and decisions.

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Advance care planning

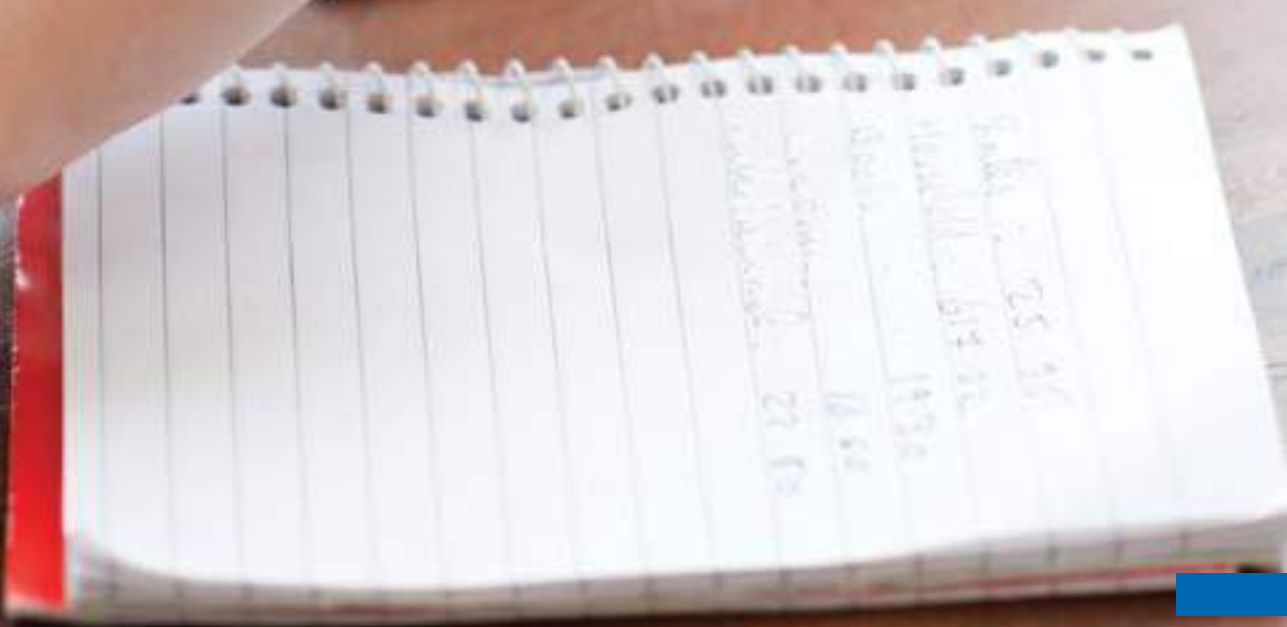


Summary

- Advance care planning is a process in which you think about what you would like to happen to you, or not happen to you, if you're unable to make decisions about your healthcare treatment or if you're unable to communicate your wishes.
- You reflect on what you want in life, write down your thoughts and wishes and share these reflections with your family and your healthcare team.
- Many people feel a sense of relief, knowing that their family and doctors have the right information to make good healthcare decisions on their behalf, if they become unable to communicate their wishes.
- Several other documents can help you organize your personal affairs including a will, power of attorney, power of attorney for personal care and others.



PRACTICAL MATTERS: WORK, MONEY AND INSURANCE





Practical matters: work, money and insurance

Find out what you're eligible for

When you're living with kidney failure, work (or school), finances and insurance may seem overwhelming. Your income may decrease just as your expenses are increasing for medications, transportation to treatment and other costs. To avoid some of the frustration and stress this can create, make sure you understand any insurance coverage you may have, such as deductibles, co-payments, etc. Keep track of your monthly out-of-pocket expenses so that you can try to plan for extra costs such as parking at the clinic. Make sure you obtain any benefits, tax credits or other assistance that you may be eligible for.

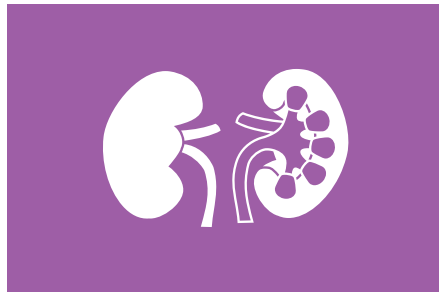
Living with kidney failure is about more than just managing your physical symptoms with treatment. Many questions arise about the practical side of life including work, finances, taxes and insurance when living with a chronic illness. This chapter includes helpful information about these practical matters.

Working with kidney failure

The decision to continue to work or not, or to change jobs, is an important one and there are several factors to consider. To help you think about your choices, we'll examine several aspects of working and living with kidney failure.



Practical matters: work, money and insurance



When you first find out that your kidneys are failing, the idea of continuing to work may seem overwhelming. While you are adjusting to dialysis or transplantation, your initial feelings about continuing to work may be different than how you'll feel later. This is not the time to make a decision to permanently stop working. Therefore, before you make any permanent plans, carefully consider all the options.

Treatment type & working

The type of treatment you're receiving may affect your ability to continue working. Some types of treatment, such as home hemodialysis, can allow some people to return to work or school full time. You may want to review the earlier chapters concerning the advantages and limitations of the different treatments.

Temporary leave of absence

If working doesn't seem feasible at this point, consider a temporary leave of absence. Your employer has invested a lot in you and probably doesn't want to lose you. You might even qualify for temporary disability payments. Some people on dialysis may draw disability benefits for a time. However, if they successfully receive a transplant, they may no longer be eligible for disability benefits.

Flexible treatment and work arrangements

Before making a decision to take time off work, talk to your healthcare team. They might be able to adjust your treatment schedule to allow you to continue working either full time or part time.

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Practical matters: work, money and insurance

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Leaving work

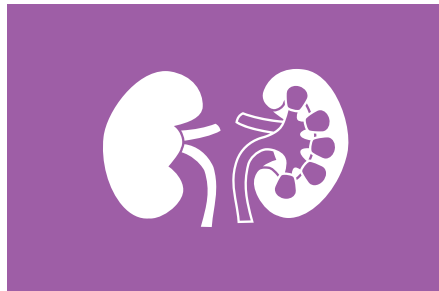
For different reasons, some people leave work or decide to change to a less demanding job. Sometimes anemia or the side effects of medications leave them with less energy. Sometimes people with diabetes and kidney failure have problems with poor vision or nerve damage. Whatever the reason, if you are thinking about leaving work, there are issues for you to consider.

Many employers provide extended health benefits including drug plans. If you leave your job, you will no longer have access to those benefits.



Sometimes people wonder why they should work if disability benefits are available. If you continue to work while on dialysis, you will have a job to go back to if you have a transplant (instead of having to look for a job). In addition, for most people, jobs provide not just income, but a sense of identity and self-esteem as well. Returning to work (or continuing to work) when it is medically, physically and emotionally possible may help improve your sense of self-esteem and reduce depression. Before you decide to leave work, consider what your job means to you, besides income.

Practical matters: work, money and insurance



What vocational resources are available?

The federal and provincial governments have programs to help people return to work or learn a new skill. Talk to your social worker about the programs in your region.

What should I tell my employer?

You may be wondering what to tell your employer about your health or how to handle questions that arise during a job interview. During an interview, potential employers may ask if there are any particular circumstances that would impair your ability to do the specific job you are being hired for. No one with a chronic illness should put others at risk by withholding such information. For example, poor vision would affect your ability to operate heavy machinery. However, what you tell your employer or potential employer about your health is up to you. If you feel that as a dialysis or kidney transplant patient you can handle the job and will not require special consideration (such as scheduling work around hemodialysis), you may not need to say that you have chronic kidney disease or are on dialysis. What you do on your personal time may not necessarily be important to your employer.

Honesty is important and there may be implications concerning insurance coverage. If you think you will need special consideration, then you should be prepared to discuss it. If you run into problems or need to discuss this further, talk to a member of your healthcare team.

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Practical matters: work, money and insurance

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If you require help completing your applications or need more information about the different government programs, speak to your social worker.

What happens if I cannot work?

Employment Insurance Sick Benefits

If you are unable to work, you may qualify for Employment Insurance Sick Benefits for a period of time. You can find more information through Service Canada at servicecanada.gc.ca or by contacting your local Service Canada office.

Canada Pension Plan Disability Benefits

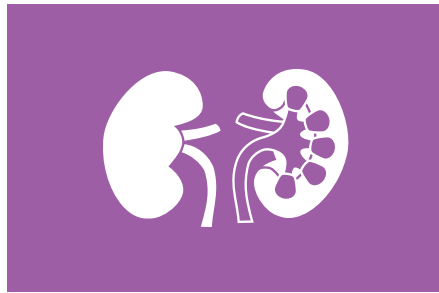
If you are not able to do work of any kind, have paid into Canada Pension, and your condition is considered “severe and prolonged”, you may be eligible for Disability Benefits under the Canada Pension Plan. Contact your local Service Canada office or visit servicecanada.gc.ca for an application or information.

Other resources

If you are not eligible for Employment Insurance Sick Benefits, or Canada Pension Plan Disability Benefits, or if you require short-term assistance, you should contact your municipal and/or provincial/territorial social services programs.



Practical matters: work, money and insurance



Resources for caregivers

Employment Insurance (EI) provides Compassionate Care Benefits to people who have to be temporarily away from work to provide care or support to a family member who is gravely ill with a significant risk of death. If you are caring for someone who has decided not to start or is choosing to stop dialysis, you may qualify for Compassionate Care Benefits. More information is available at serviccanada.gc.ca.

Income tax credits and deductions

Whether you work or not, there are various tax credits and deductions for which you may be eligible. These are briefly described below. Tax credits and deductions can be a confusing subject (even for tax experts!). We encourage you to talk to your social worker and to consult the appropriate federal and provincial/territorial government offices for more detailed information. In addition, each year during tax season The Kidney Foundation prepares general tax tips for dialysis and transplant patients. You can obtain a copy of this document from your local Kidney Foundation office or the web site at kidney.ca.

NOTES:

Seek professional tax advice

The information provided here is general in nature and does not necessarily cover all circumstances. While we make every effort to be accurate, we recommend that you seek professional tax advice for your individual questions. The Canada Revenue Agency (CRA) also provides detailed instructions for claiming the available tax credits and deductions. These can be obtained from the CRA web site at cra-arc.gc.ca or your local tax services office, or by calling the CRA.



Practical matters: work, money and insurance

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What you can claim if you have an income

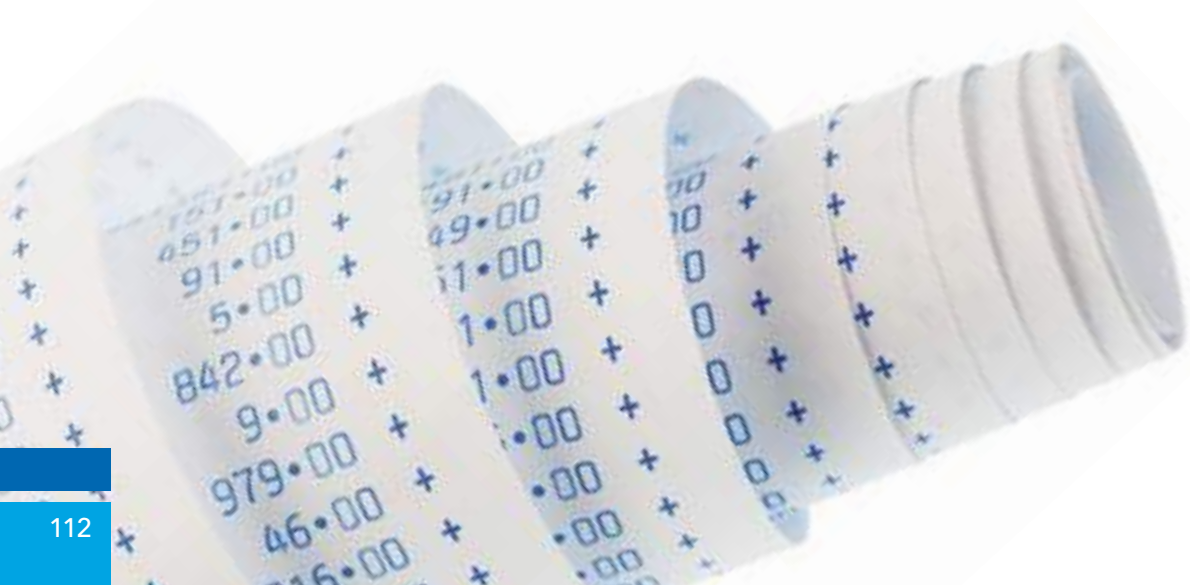
If you do have an income, you may be able to obtain a Medical Expense Tax Credit for medical expenses that have not been covered by your provincial/territorial health plan or extended health benefits. The Medical Expense Tax Credit is a non-refundable tax credit that can be claimed for a wide range of medical and related expenses such as healthcare services, travel expenses, home renovations to install a hemodialysis machine, medications, dental services and health insurance. Expenses incurred out of the country over and above provincial/territorial coverage may also be included. You can claim expenses for yourself, your spouse, and with some limitations, for your other dependents.

Refundable Medical Expense Supplement

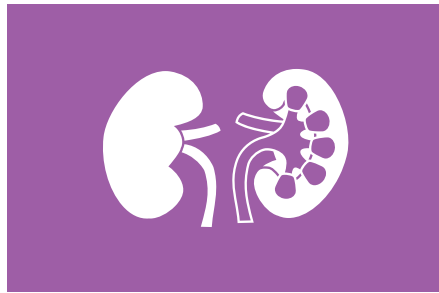
You may be able to claim a refundable credit for eligible working people with low incomes and high medical expenses. For more information, see the General Income Tax and Benefit Guide available from Canada Revenue Agency at cra-arc.gc.ca.

What you can claim if you have no income

Even people who do not have an income or pay taxes should usually file an income tax return. This is because there are various tax credits available, such as the Child Tax Benefit and the GST/HST Credit, which can result in money in your pocket. There are also provincial/territorial tax credits available to you.



Practical matters: work, money and insurance



Disability Tax Credit

You may be eligible for a Disability Tax Credit if your medical condition has left you disabled, regardless of whether you have an income or not. The Disability Tax Credit is a non-refundable tax credit that reduces the amount of income tax that may be owed by people with disabilities or the people who support them. If you qualify, the credit may reduce the amount of income tax you have to pay. If you have no tax payable, you may transfer the credit to a spouse or other supporting person. *All dialysis patients qualify under the “life-sustaining therapy” category in the Disability Tax Credit Certificate (T2201).*

Because the eligible medical and disability expenses all have conditions attached, and because these conditions and how they are applied change from year to year, it is best to talk to an income tax specialist when preparing your income tax return.

You may also be eligible for other tax benefits such as gasoline tax rebates and homeowner grants. Your social worker can give you additional information or direct you to your local district taxation office.

For more information, refer to the RC4064 Medical and Disability - Related Information document available from your district taxation office or the Canada Revenue Agency web site at cra.gc.ca.

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Registered Disability Savings Plan (RDSP)

The RDSP is a federal government program that encourages people with disabilities to save in order to become more financially secure. It is similar to paying into a private pension plan and the government matches personal contributions up to a certain amount. Canadian residents under the age of 60, who qualify for the Disability Tax Credit, may be eligible if they meet certain criteria. Parents can open an RDSP for their child. For more information, visit the Canada Revenue Agency web site at cra.gc.ca or speak to your financial advisor.



Practical matters: work, money and insurance

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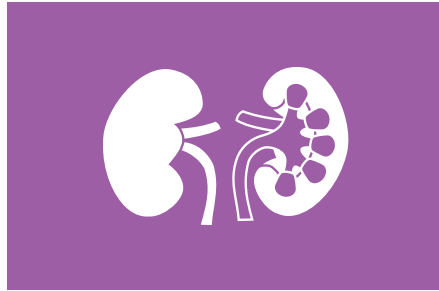
Insurance

Many people think that they cannot get life insurance (or other types of personal insurance such as health, travel or disability) if they have kidney disease. While it can be difficult, it is possible in many situations. The information and tips presented here may help you obtain personal insurance when living with kidney disease. *However, this information is general in nature, does not necessarily cover all circumstances and does not guarantee that you will be insured. It is best to seek professional advice for your individual questions.*

General insurance

- Make sure you understand all the exclusions and limitations of your insurance policy, especially when you have a pre-existing condition.
- Be honest on your insurance application and declare any known health issues. If you do not, you may make the contract invalid and a claim may not be paid.
- Insurance can sometimes be easier to obtain the longer you have been on dialysis or living with a kidney transplant (and your disease is considered "stable" and well-managed).
- Check with your employer about your group insurance plans and coverage. Group benefits are often easier to qualify for and may be issued (up to a certain amount) without the need to provide medical information.
- Shop around. Look for an insurance agent or broker who is familiar with kidney disease and/or other chronic conditions. Some questions you may want to ask a potential insurance agent or broker include:
 - Do you have experience helping people with kidney disease or other chronic illnesses?
 - Do you have access to several insurers/companies? (That way, if an application is declined or costs more than the standard rate from one insurer, you can more easily check with another.)

Practical matters: work, money and insurance



Travel insurance

- *Make sure you understand all the exclusions and limitations of any policy.* For example, some policies will not provide coverage if you have changed medications, stopped taking a medication (even if it is because your condition has improved) or raised or lowered the amount (dose) of the medication within a certain number of weeks or months before travelling. Always carefully check these details.
- If you are relying on travel insurance provided through your credit card, make sure you understand all the exclusions, limitations and clauses for pre-existing conditions so that you know how much you are truly covered for and how the insurance company will handle any pre-existing conditions if you need to make a claim.
- Look for insurance that covers the *person* (which is assessed at the time you apply for coverage) rather than the *trip* (which is assessed at the time you make a claim).
- Most travel insurance policies will limit the number of days of travel coverage. Make sure that your trip does not last longer than your insurance coverage.



If you've had a kidney transplant, it may be difficult to get travel insurance. If you do get travel insurance, some policies will not cover any incidents related to the transplant, but will cover other medical costs.

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Disability or income replacement insurance

- Disability or income replacement insurance may be available under an employer's group insurance plan, however it is unlikely to be portable if you change employers.
- Disability or income replacement insurance may be available to people with kidney disease at an increased cost or with an exclusion for any disabilities relating to pre-existing conditions.
- You may want to explore Long Term Care insurance. It is another form of disability insurance.



Practical matters: work, money and insurance

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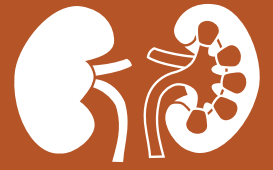
Life insurance

- If you belong to a workplace life insurance plan, you may be able to take your group life insurance with you, even if you switch employers.
- Do not apply and then wait and see if you are declined - it will go on record. A better option is to have your insurance agent or broker explore coverage options before *formally* applying. They can do this by providing all of your information (without your name) to an insurer so that you can get a preliminary decision on whether they would provide coverage, how much it would cost, etc.
- You may want to explore Partner Insurance as an option: a couple shares an insurance plan (even if one has kidney disease) and the benefit is paid to the beneficiaries/estate when both partners have passed away.



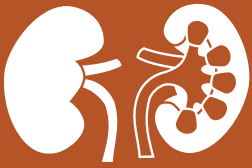
Summary

- If you're deciding whether to continue to work with kidney failure, you may consider a temporary leave of absence, and flexible treatment or work arrangements.
- Leaving work permanently may mean loss of company insurance benefits and sometimes, people may feel a loss of self-esteem.
- If you're unable to work, you may qualify for government benefits such as Employment Insurance Sick Benefits and Canada Pension Plan Disability Benefits.
- Regardless of whether you work or not, there are income tax credits and deductions that you may be eligible for.
- Obtaining insurance (including general, travel, disability or income replacement and life) when you have kidney disease can be challenging, but it is possible in many situations.



LIVING WELL WITH KIDNEY FAILURE





Living well with kidney failure

MANAGING CHANGE

Living well with kidney failure does mean a big adjustment for you and your family - but it is possible. One of the biggest challenges is to accept the differences between your life before kidney failure and your life afterwards. Dialysis, medications, diet restrictions, and/or symptom management need to become part of your new “normal.” To help manage these changes and your feelings about them, it often helps to talk to others. Seek out support. Talk to a social worker about your fears and concerns. Reach out to others who are living with kidney failure, share your feelings with friends and family, and don’t ever hesitate to ask your healthcare team when you have questions.

Kidney disease affects people of all ages and cultural backgrounds. Different people may face different challenges because of their age, location, overall health or personal circumstances. It can feel like kidney failure and its treatment are taking over, but it is possible for you to take control of your life.

You may have questions about where to begin. You might be wondering how you’ll ever return to a state of well-being or enjoy doing the things that once gave you pleasure. To help you on your way, we’re going to discuss several aspects of emotional and physical well-being. We’ll also look at sexuality and fertility, the importance of getting enough physical activity to help keep you strong, and some guidelines for enjoying travel.

Emotional well-being

For many people, finding out their kidneys have failed comes as a great shock. One day they may be feeling fine, with just a bit of difficulty shaking the flu; the next day they are told their kidneys have failed. This news can be very hard to get used to all at once.

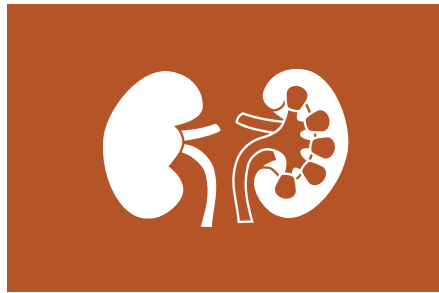
People who have known for years that it was a possibility may have an easier time accepting the diagnosis. They have been informed of the treatment options, have participated in the decisions and have prepared themselves emotionally for the news. With time, most people come to accept that their kidneys are failing or have failed.

However, being told you have end-stage kidney failure is not good news. It takes time to accept the diagnosis and adjust to it.

Common reactions

People have different reactions when they learn their kidneys have failed. Some common reactions to this news are feelings of disbelief, loss of control and a sense of loss or sadness. Anger is another common response - anger at themselves for getting sick, or anger at their doctor because the problem wasn’t found sooner or cannot be cured. There may also be feelings of loneliness, isolation, depression and denial.

Living well with kidney failure



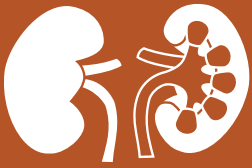
Acceptance doesn't always come quickly or without help. Many people find it useful to talk to someone, besides family and friends, about their feelings. If you need a person to talk to, speak to your social worker or another member of your healthcare team. It can make a big difference, especially if you're struggling with this adjustment, with your emotions, or dealing with depression and anxiety.



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Talk to other people with kidney failure

Talking to other people with kidney failure can be a good source of support and inspiration. Many hospitals and all Branches of The Kidney Foundation of Canada offer peer support programs where you can get in touch with other people with kidney failure. You can also be matched with a one-on-one peer support volunteer or find information about group support by calling 1-866-390 PEER (7337). For more information, contact your local Kidney Foundation office, request support through **kidney.ca** or connect with other patients in our online community at **kidneyconnect.ca**.



Living well with kidney failure

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Dealing with depression and anxiety

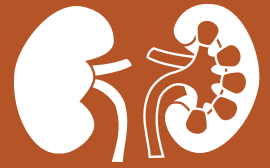
Many people feel depressed when they find out their kidneys have failed. Once the treatments have started – and even if they are feeling much better physically – the thought of having regular dialysis, perhaps while waiting for a kidney transplant, or perhaps for the rest of their life, may leave them feeling depressed.



Some people feel dependent on others for the first time, which may affect their ability to live the life they once enjoyed or lead to feelings of loss of control. They may find it hard to accept support from others. Emotional support from family and friends may also decrease as the shock of diagnosis fades, or they may not know how best to offer support, which can lead to feelings of loneliness.

With time and increased understanding of kidney failure, people do adjust. Each person has different ways of adapting. However, if depression continues for some time, it's a good idea to speak to the healthcare team because depression can be effectively treated. Your social worker is there to help make this transition as smooth as possible.

Living well with kidney failure



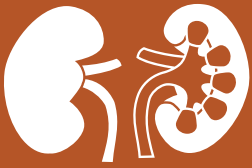
Dealing with family and friends

Family and friends are important during the best of times. During difficult times, they are even more important. We rely on them to be there when we need someone to talk with, and to give us emotional and physical support.

Your family and friends will also need *your* support. Family members may feel helpless because they cannot do anything about the illness. They may be angry that kidney disease has happened to “their” family. They may feel guilty that they did not realize the serious nature of the illness. Living with kidney failure requires changes in lifestyle. Routine chores and activities that require physical strength may be difficult to perform now. Family members or friends may have to take on added responsibilities. Your family will be concerned about you and want to support you, but may not know how. Here are some suggestions that may help:

- Let them know how you’re feeling - be honest. It is useful for both you and your family if you can talk with them about your condition.
- Make sure they get information about kidney failure. Often, just knowing about the disease, its treatment and your dietary requirements will help them relax and be normal with you. Encourage them to read this handbook or read it with them.
- If appropriate, invite them to come with you to the dialysis unit, to education sessions, and/or to appointments with the social worker. They’ll feel involved in your treatment and will know they’re an important part of your healthcare team.
- Let them do something to help you, such as drive you to the clinic or help with home dialysis. Sometimes family members will feel better knowing they’ve been able to do something that is helpful for you.
- Learn to do as many things as you can for yourself. You will feel better knowing that you are as independent as you can be and this will prevent family members from becoming overburdened.
- Recognize that family and friends have to adjust to your disease, just as you do. They may have similar feelings of denial, anger, bargaining, depression, and acceptance.

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Living well with kidney failure

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- Sometimes, it may be helpful for them to talk to someone about their feelings. Suggest that they come and talk to the social worker or another member of your healthcare team, or speak with another caregiver through the Kidney Connect peer support program (**kidney.ca**) or the Kidney Connect online community at **kidneyconnect.ca**.
- Investigate community resources in your area that provide help and support to caregivers.

Common questions about coping

It takes time and patience to adjust to a life with kidney failure. Most people have a lot of questions about how they will cope and whether their feelings are “normal”. In this section we’ve tried to answer some of the most frequently asked questions.

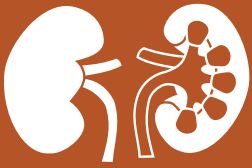
Are mood swings normal?*

Yes, moodiness is common among kidney patients. Many people with kidney disease notice they have a “short fuse” or are cranky, when they were not like that before. And they can’t explain why.

Moodiness is often thought to be a result of the following factors:

- Uremia, or the build-up of waste products in the blood, can affect the nervous system, causing an increase in irritability, mostly in the early stages.
- Some medications may cause moodiness or make you feel depressed.
- You may have difficulty sleeping or feel constantly tired.
- You may be frustrated about changes in your health and your ability to do things.

The stress caused by chronic illness accounts for a wide range of feelings and moods. This includes general irritability, anger and frustration over the problems caused by the illness, and feeling hopeless and helpless when faced with a life-threatening disease.



Living well with kidney failure

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If you feel unable to talk to your children, speak with your social worker. The social worker may be able to help both you and your children learn how to talk openly about the treatment and fears related to it. Your social worker may refer you to other services, if needed. The Kidney Foundation of Canada also has resources to help explain chronic kidney disease to children.

Finally, try to find pleasant activities that both you and your children enjoy doing together. Look for activities that you will be able to continue despite the demands of kidney failure and its treatment.

*Adapted with permission from the National Kidney Foundation, Inc., USA.

See **Chapter Seven:**

Practical matters: Work, money and insurance for more information about employment-related issues.

Can I keep my job or continue going to school?

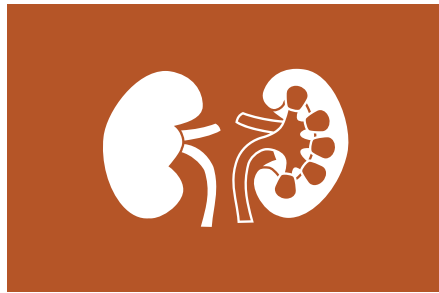
That depends on the type of job or the demands of schooling. You may feel better emotionally if you continue to participate in work or school. You may need to make some changes to your schedule to meet your health and treatment needs. For example, you might need to change your working hours to allow for dialysis treatments. Talk with your healthcare team to see if there is anything that can be done with your treatment schedule to help you fit it into your work or school schedule. It is important not to let your health suffer because of the normal stresses of work, so speak with your doctor and your social worker about this.



How long will I live?

This will depend on many things including your overall health. People can live for many years on different types of treatments. There have been recent advances in treatment strategies, and dialysis and transplant methods. While dialysis doesn't do everything your kidneys did, with the proper diet and medications, you can feel better. If you have a kidney transplant, you require medications and regular visits to the clinic. Both dialysis and transplantation are treatments, not cures for kidney disease, so taking care of yourself is important. Your doctor knows your medical situation the best and would be a good person to answer this question.

Living well with kidney failure



Sexuality and fertility

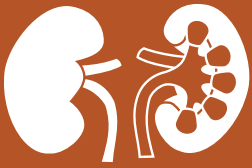
Problems with sexual functioning

Over half of all people with kidney failure experience some problem with sexual function. This can vary from just a lack of interest to a complete inability to reach orgasm. For some people, this can have an upsetting effect on their self-esteem and put further pressure on an already stressed intimate relationship. Talking about it with their partner may feel embarrassing. It can also be hard to talk with the healthcare team about sex and orgasm. Many people choose to ignore this problem because, unlike dialysis, sexual fulfillment is not necessary for survival, so they feel guilty complaining about it.



Sexuality includes many factors, such as how people feel about themselves, intimacy, and how they communicate with others. In addition, sexuality involves a range of activities that may or may not include intercourse, such as touching, hugging and kissing, holding hands and talking.

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Living well with kidney failure

Causes of problems

Sexual problems can have many causes:

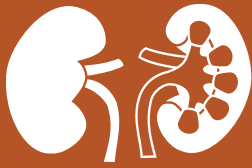
- Fatigue is thought to be a major factor. Any chronic illness is tiring, and kidney failure, which is typically accompanied by anemia and a demanding course of treatment, practically guarantees fatigue. Few healthy adults are interested in having sex when they're very tired, so it's not surprising that people with kidney failure report decreased sexual activity.
- Depression is thought to be another factor. Almost everyone experiences episodes of depression – and one of the symptoms of depression is loss of interest in sexual intimacy. Sometimes it works the other way, too. Loss of sexual intimacy can lead to depression. Either way, it's a problem that should be talked about. Don't suffer in silence.
- Sometimes medications can affect one's ability or desire to have intercourse. If you think this might be the case, talk to your doctor about it because there may be other medications that are just as effective without the side effect of loss of sexual desire. However, you must keep taking your medications as prescribed until you can talk to your doctor.
- Insertion of a peritoneal catheter, or having a fistula or graft, may cause some people to avoid physical contact for fear of feeling less attractive and worrying about what people will think.
- Other medical problems, such as vascular disease and diabetes, can lead to decreased blood flow in the genital area, decreased sexual desire, vaginal dryness and impotence.

Whatever the cause, sexual problems can often be corrected.

How do I get help?

There are resources to help you deal with sexual concerns. The approach might be as easy as changing your medication. Talk to the member of your healthcare team you feel most comfortable with – whether that's your doctor, pharmacist, social worker or nurse. Ask for a referral to someone who specializes in sexual problems.





Living well with kidney failure

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Frequently asked questions

Here are answers to some frequently asked questions about chronic kidney disease as it relates to sexuality, childbearing and birth control.

Can I have a child while on dialysis?

Women with end-stage kidney disease often stop having their monthly periods. However, once a regular pattern of dialysis is established, a normal menstrual cycle might return. Although it is rare, some women on dialysis can become pregnant. Pregnancy on dialysis is difficult and you should talk to your doctor about any plans to become pregnant. Being pregnant while on dialysis is considered a “high risk” pregnancy and you will need regular involvement with an obstetrician who is used to dealing with high-risk pregnancies.

Men with end-stage kidney disease have reduced sperm counts, but this may still be sufficient to result in pregnancy.

Some men and women remain infertile even with regular dialysis treatments. They are therefore unable to have children.

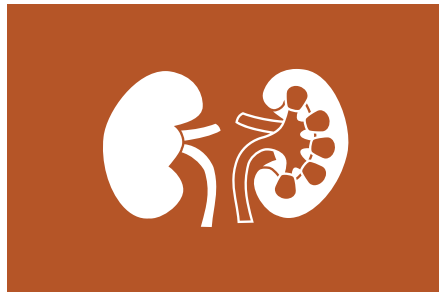
What about sexual intimacy after a kidney transplant?

Intercourse does not harm a transplanted kidney, so you can continue normal sexual activities whenever you want. After a transplant, you may have more energy for intercourse because your uremia and anemia will have decreased. Sometimes the medications used to control high blood pressure can decrease a man’s sexual functioning. If this is the case, speak to your doctor because the medication can often be changed to one that doesn’t have this side effect. Sometimes women experience pain during intercourse. Talk to your doctor about any sexual intimacy problems.

Can I have a child after a kidney transplant?

Women who have had a transplant usually become fertile again. However, carrying a child increases the workload on your kidney. Most doctors will recommend that you postpone childbearing for at least a year or two until your new kidney and new medications

Living well with kidney failure



are very stable. Some anti-rejection medications, or other medications that you are taking, may be harmful to an unborn baby. You should check with your transplant doctor before trying to become pregnant.

After a transplant, a man’s sperm count will return to normal and he may be able to father children.

What about birth control?

Both men and women who are sexually active and do not wish to conceive a child, should use some form of birth control. Since some men and women may continue to be fertile while on dialysis, or become fertile again after a transplant, using birth control is essential for anyone who does not want to become pregnant. Talk to your healthcare team about the best method of birth control for you.

It is important to *always practice safe sex*, whether or not pregnancy is a concern. It is still possible to get a sexually transmitted disease (STD) even if you are infertile.

Physical activity and recreation

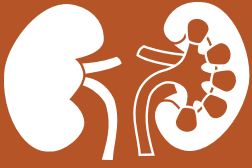
Taking part in pleasant leisure activities and maintaining a well-balanced lifestyle can go a long way toward helping you stay healthy. It is important (and fun!) to take part in social activities, sports and recreational events, and other pastimes that you, your family and friends enjoy. You may need to make a few adjustments, but they will be well worth it. Yes, kidney disease is a part of your life, but it should not consume your life.

Exercise, sports and physical activity

Exercise is vitally important to both your physical and mental health. Staying physically active will give you more energy. With more energy, you’ll feel like doing more things, which will make you happier and speed your return to a more usual lifestyle. Before you begin (or resume) physical activities, talk to your healthcare team about finding a suitable exercise program, sport or other physical activity program that is right for you. Everyone has different interests and physical capabilities, and these may change over time.



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Living well with kidney failure

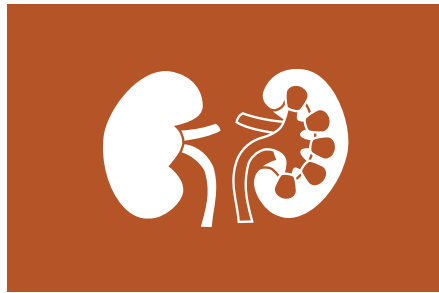
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How much exercise is needed?

The amount of exercise you need depends on your overall health, age and physical capabilities. The recommended level of activity is 150 minutes of moderate intensity exercise per week or roughly 30 minutes, five times per week. This can be activities like walking, cycling or swimming. This amount of exercise is the guideline recommended for the prevention and treatment of hypertension (high blood pressure) and the majority of people with kidney failure have hypertension. However, some people, such as the elderly, those with multiple other medical problems, or some people receiving dialysis, may not be able to follow such a vigorous exercise program. For these individuals walking for 15 minutes at least three times a week may be more suitable. There are also simple movements and gentle but effective exercises that can be done while sitting down. *The important thing is that you regularly do a sufficient amount of physical activity that you enjoy and that is suitable for your situation.* Your physiotherapist or other members of your healthcare team can give you suggestions about the safest ways for you to do this.



Living well with kidney failure



Whatever your situation, there are benefits to be enjoyed from regular exercise:**

- Improved physical functioning
- Better blood pressure control
- Improved muscle strength
- Lower level of blood fats (cholesterol and triglycerides)
- Better sleep
- Better weight control
- Reduced risk of heart disease
- Development of stronger bones and/or prevention of thinning bones - a problem that dialysis and transplant patients often have
- Reduced stress and depression
- Meeting people
- Having fun

**Adapted with permission from the National Kidney Foundation, Inc., USA.

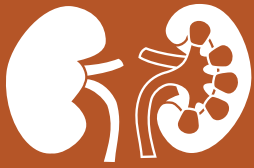
Travel

Whether you enjoy taking a cruise, spending a week at a resort, camping, or just a weekend away visiting family or friends, travel is still an option for you. The first step is to check with your doctor to make sure you are in stable health. Then you can proceed to make the necessary arrangements.

Make sure you have enough medications with you for the length of the trip (plus some extra in case there are travel delays). Be sure to carry a *list* of your medications with you. It is also a good idea, especially if you are travelling by air where security measures have increased, to carry a letter from your doctor stating you need to travel with these medications (and syringes, if you use them). Keep medications in their original containers or boxes with the pharmacy label so that security personnel can verify what is in the containers. Carry your medication with you just in case your luggage is misplaced or delayed.

NOTES:





Living well with kidney failure

It may be difficult to get travel insurance if you've had a transplant. Or you might be approved for a policy that does not cover any incidents related to the transplant, but does cover other medical costs. In some cases you may be able to get insurance that does cover your transplant, depending, for example, on how stable your condition and your medications have been over a period of time before travelling.

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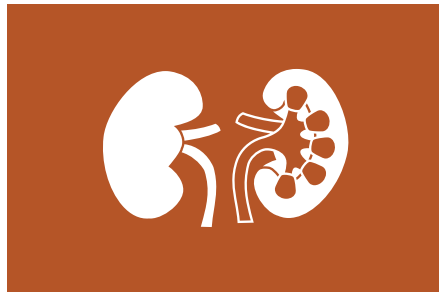


Travelling with a kidney transplant

Here are some tips to help make your travels successful:

- Some of the medications you take to stop your kidney from rejecting make your skin very sensitive to the sun. If you are travelling to a hot and sunny location, be sure to wear sunscreen (SPF 45) and protective clothing. Drink enough liquids so you stay well hydrated.
- If you are travelling to a location where diarrhea is a common concern among travellers, this can be a serious concern for you. Be sure that you discuss safe treatments with your doctor and take a supply of recommended medications just in case.
- The medications you take weaken your immune system, which may put you at greater risk for certain viruses and other diseases. Learn about your travel destination in advance to see if there are any increased risks for hepatitis, West Nile virus or other problems due to the quality of the local water (including ice, or foods that have been washed in the local water supply).

Living well with kidney failure



Travelling on peritoneal dialysis

Travelling on peritoneal dialysis is relatively easy. That’s one of the convenient things about this form of dialysis. Exchanges can be performed almost anywhere that is clean.

You will need to arrange transportation for your supplies, including dressings and your cyclor, if needed. Supplies can be carried with you as carry-on luggage or shipped ahead as cargo. Do *not* pack your supplies with your checked luggage because the storage areas on some airplanes can get too cold for dialysis solutions and they may freeze. Be sure to tell this to the shipping company if you are sending your supplies ahead as air cargo.

If you are travelling outside of Canada, make sure to have the necessary customs documents with you.

Some companies that provide dialysis supplies will arrange to deliver them to your destination at no cost to you. Others may charge you for shipping. Be sure to make your arrangements for supplies at least six weeks before you plan to travel. Your peritoneal dialysis unit can help you with your travel questions.

Travelling on hemodialysis

The procedures and techniques in the units you visit may be different from what you’re used to. Once you’ve travelled and visited other dialysis units, you may have greater confidence planning future travel. With improved methods of dialysis, people are able to travel all over the world.

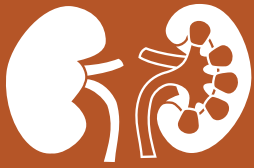
In fact, having the extra contact with a renal unit often makes the holiday special. You’ll get interesting tips while dialyzing in a visiting unit - tips on local transportation, hotels and restaurants, sight-seeing, and local attractions. This often leads to experiences that you would not otherwise have enjoyed.

Remember, though, that dialysis units are very busy places, and may have limited space and staff, so it is necessary to make your arrangements with other units several months in advance. Your hemodialysis unit can help you with your travel questions.



NOTES:

Ask your local Kidney Foundation office for information about travelling on dialysis.



Living well with kidney failure



Hemodialysis within Canada

In Canada, a reciprocal agreement among the provinces/territories allows you to be dialyzed anywhere in Canada, if space permits. Your province/territory is billed directly for the service. A directory of the dialysis centres that accept visitors (i.e. travelling patients) is available from your renal unit, local Kidney Foundation office or online at cihi.ca/corr.

In some places, private dialysis clinics have opened. However, not all provinces/territories will reimburse all the costs for dialyzing at private clinics. Some clinics also add a surcharge over and above the amount your province/territory does cover. Make sure you find out the exact costs before you leave your home unit. Check with your provincial/territorial health plan to find out what your province/territory will pay for. It is important to submit itemized costs to your provincial/territorial health plan for partial or full reimbursement. If you have any questions about dialyzing outside of your home province/territory, talk to your kidney social worker.

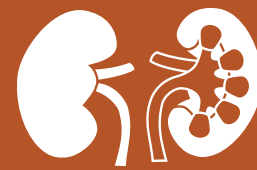
Hemodialysis outside Canada

In the United States, most units request payment four to six weeks ahead. Your province/territory may pay back some of these costs. Most provinces/territories have a limit for reimbursement for dialysis. Since many U.S. units charge considerably more than the limit, you may have to pay an additional amount for each treatment. Blood work, medications, and even just talking to a doctor may result in an extra charge. A few units require that your potassium level be tested before treatment and some units require that you be tested for HIV at an additional charge. Check these costs before you arrange your trip. Make sure to have all costs itemized separately on your invoice as this will provide more detailed information for your provincial/territorial health plan and may increase the reimbursement that you might receive.

In Europe or other countries, the cost of hemodialysis may be about the same as in the U.S., or more. Find out all of the costs in advance so you don't have any unpleasant surprises.

NOTES:

Living well with kidney failure



Interest-free travel loans may be available from The Kidney Foundation to help pay for dialysis until you're reimbursed. Check with your local Branch for details. Your renal program or Kidney Foundation office can also give you directories listing hemodialysis units virtually anywhere you want to go.

Making travel arrangements

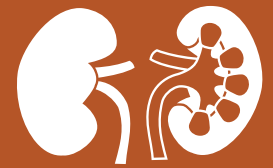
Although there are more hemodialysis units now than ever before, most units run on a very tight schedule due to limited staff and space. To ensure you get on their schedule, make your arrangements four to six months ahead. If possible, plan your vacation around one dialysis unit rather than two or three different ones - the arrangements will be easier to make. Your own dialysis unit may be able to advise you about making these arrangements, but it is *your* responsibility to actually make them. Because of the technical information required, the other unit may want to talk directly to your unit's nursing/medical staff before you finalize your arrangements.

Scheduling is very important. You cannot just skip a treatment as this would increase the chances that something would go wrong on your holiday. Therefore, if you cannot dialyze on some days because of planned tours, weddings or special events, let the unit you are visiting know so your dialysis appointment can be rescheduled. Some units may allow you to choose your schedule.

NOTES:



Living well with kidney failure



There are also resorts around the world for people on dialysis. They have complete hemodialysis units, are staffed with qualified medical and nursing personnel, and can cater to your special dietary needs. When signing up for cruises or resorts, always indicate any special needs you have.

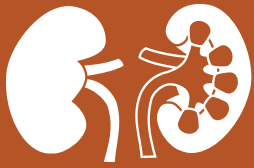
Unexpected events and emergencies

You never know what unexpected events may occur during your travels, so it's always best to be prepared. There may be unplanned travel problems such as plane delays that cause a major disruption to your schedule, local weather problems that make ground travel difficult, blackouts or other emergencies. You should try to arrange a back-up plan that you can rely on if you need to.

Be sure to carry along your latest dialysis and medical information, plus a current letter from your doctor outlining your medical condition, dialysis information, medications and contact telephone numbers.

In the case of an emergency when you have to return home immediately, explain the situation to the airline. They can usually get you a seat on the next flight, even if it's full. It's always a good idea to have a major credit card so you can buy a direct flight home if you have to.





Living well with kidney failure

See **Chapter Seven:**

Practical matters: Work, money and insurance for more insurance tips, including travel insurance.

Travel insurance

It is wise to obtain travel insurance in case of an accident or illness. However, there are a lot of variations in the policies provided by different travel insurance companies. There are often limitations and exclusions relating to pre-existing medical conditions, age, and travel inside and outside Canada. It is recommended that you carefully compare the different policies. Your social worker may have some information.

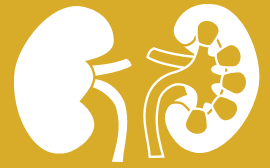


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Summary

- Living well with kidney failure may seem an impossible task, especially when you are first starting treatment and are getting used to new routines – but it is possible and there are many people who can help support you.
- A diagnosis of kidney failure is very upsetting and can lead to all kinds of emotions, depression and anxiety, and worries about coping. Help is available to deal with these feelings and challenges.
- It's quite common to have problems relating to sexuality and fertility when you have kidney failure. Don't be shy to talk about these difficulties because there are often things that can be done to help. Feel free to talk to your healthcare team.
- It's important to take part in pleasant leisure activities such as recreational events, exercise and gentle sports, and pastimes that you like. These activities may help lift your spirits and will help keep you strong.
- Travel is a possibility with a kidney transplant, while on peritoneal dialysis and even hemodialysis, as long as suitable preparations are made well in advance of travelling.

Glossary



Advance care planning A process in which you decide what you would like to happen to you, or not happen to you, if you become unable to make decisions about your healthcare treatment or if you are unable to communicate your wishes.

Anemia Medical condition in which the number of red blood cells (the blood count) is reduced.

Anti-rejection medications Medications given after an organ transplant to lower the body's immune system so that the transplanted organ is not rejected.

Antibody A protein produced in the body to fight an invasion by foreign material (antigen).

Artery Blood vessel taking blood from the heart to other parts of the body.

Automated or continuous cycler peritoneal dialysis (APD, CCPD) Form of continuous peritoneal dialysis in which a machine called an automatic cycler performs regular exchanges throughout the night.

Cadaveric transplant Type of kidney transplant in which a kidney is donated from someone who has died suddenly. Also called *deceased donor transplant* or *non-living donor transplant*.

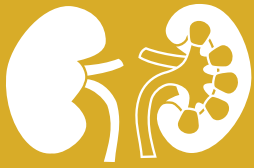
Calcium Mineral that is important for bone growth and body function.

Catheter Hollow tube used to transport fluids to or from the body.

Central venous catheter Two soft tubes joined together to provide quick access to the bloodstream are inserted into a large vein. Often temporary.

Cholesterol A type of fat found in most body tissues.

NOTES:



Glossary

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CKD-MBD *Chronic kidney disease - mineral and bone disorder* is the disordered balance of minerals (phosphate and calcium), parathyroid hormone and activated vitamin D often associated with chronic kidney disease. May lead to abnormalities in bone structure and calcification (hardening) of blood vessels and soft tissue.

Conservative care A treatment option that aims to provide physical and emotional comfort care, instead of extended life. Also known as *non-dialysis supportive care*.

Continuous ambulatory peritoneal dialysis (CAPD) Form of peritoneal dialysis in which dialysis fluid is exchanged at regular intervals throughout the 24-hour day.

Creatinine Waste product of muscle activity.

Cross match Blood test to measure the compatibility of a blood transfusion, or of a transplant donor and recipient.

Cytotoxic antibody Substance in the blood (antibody) designed to kill the antigen; usually means that the body would reject a transplanted kidney.

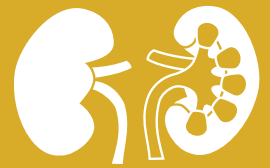
Deceased donor transplant Type of kidney transplant in which a kidney is donated from someone who has died suddenly. Also called *non-living donor transplant* or *cadaveric transplant*.

Dependent dialysis Hemodialysis done in a hospital or clinic is considered “dependent” because you must travel to a treatment centre for your treatments.

Dialysate, dialysis fluid Special fluid used in dialysis into which wastes are passed. Also called *bath*.

Dialysis From Greek, meaning “to separate or dissolve.” A treatment for kidney failure that removes wastes and water from the blood.

Glossary



Dialyzer The part of an artificial kidney machine which acts like a filter to remove wastes from the blood.

Dry weight The body weight achieved when extra fluid is removed during dialysis.

Edema Swelling of the body tissues (usually ankles or lungs) due to sodium and water retention.

End-of-life care The special physical, emotional and spiritual care that is given to people at the end of their life. Also called *palliative care* or *comfort care*.

Erythropoietin (EPO) Hormone that stimulates the bone marrow to produce red blood cells. The hormone is naturally produced by the kidneys, and is also available as a family of injectable medications.

Exchange One complete cycle of peritoneal dialysis, consisting of inflow, equilibration (also called *dwelling*), and outflow.

Emergency diet In an emergency (such as a power failure or weather-related event) when you cannot do dialysis or get to your dialysis clinic, you must follow the emergency diet (provided by your clinic staff) to help slow the build-up of waste products in the body until you can do your next dialysis treatment.

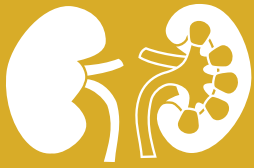
Fistula Commonly used method of providing access to the bloodstream in which a vein and an artery in the arm are joined together. Also called *arterio-venous fistula*.

Graft A vein and an artery in the arm are joined with a piece of special tubing. The graft provides access to the bloodstream for dialysis. Also called *arterio-venous graft*.

Hemodialysis Treatment for kidney failure in which the blood passes through a dialyzer to remove wastes and water.

Hemoglobin The protein in red blood cells that carries oxygen.

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Glossary

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Home nocturnal hemodialysis Method of carrying out hemodialysis at home while you sleep.

Hypertension High blood pressure. May be either a cause or a result of kidney disease.

Immunosuppressants Medications that suppress (decrease) the body's immune system and help prevent rejection of a transplanted kidney.

Incompatible pair When blood tests show that a potential organ donor and recipient do not match, they are called an incompatible pair.

Independent dialysis Peritoneal dialysis and hemodialysis done at home are considered "independent" because you have more flexibility about scheduling these treatments at home.

Jugular vein Blood vessel located in the side of the neck sometimes used to provide access for hemodialysis.

Kidney transplant A treatment option for kidney disease in which a healthy organ from a donor is transplanted into the body.

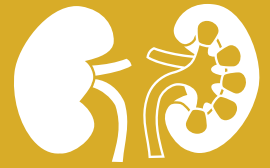
Live donor transplant Type of kidney transplant in which a kidney is donated by a live donor, often a blood relative.

Membrane Porous material that is used to filter wastes from the blood.

Non-dialysis supportive care A treatment option that aims to provide physical and emotional comfort care, instead of extended life. Also known as *conservative care*.

Non-living donor transplant Type of kidney transplant in which a kidney is donated from someone who has died suddenly. Also called *deceased donor transplant* or *cadaveric transplant*.

Glossary



Palliative care The special physical, emotional and spiritual care that is given to people at the end of their life. Also called *end-of-life care* or *comfort care*.

Peritoneal cavity Abdominal cavity (tummy) that contains the intestines and other internal organs.

Peritoneal dialysis Treatment for kidney failure in which dialysis fluid is introduced into the peritoneal cavity to remove wastes and water from the blood.

Phosphate binder Medication that binds with some of the phosphate when the food is in the stomach and intestine causing the phosphate to be passed in the stool instead of letting it get into the blood.

Phosphorus (phosphate) Mineral in many nutritious foods. The kidneys regulate it in the body fluids. At normal levels, keeps bones strong and healthy. At high levels, causes itching, painful joints, and bone disease.

Platelets Cells in the blood that are involved in blood clotting.

Potassium Mineral in the body fluids regulated by the kidneys. At normal levels, helps nerves and muscles work well. At high levels, may stop the heart.

Pre-emptive transplant A transplant performed *before* the recipient needs to go on dialysis.

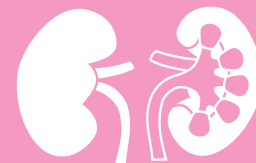
Protein Substance obtained from food that builds, repairs and maintains body tissues. High sources of protein are mainly from animal foods.

Rejection Process in which the body recognizes that a transplanted organ is not its own and mobilizes the immune system to fight against it.

Subclavian vein Blood vessel located underneath the collarbone sometimes used to provide access for hemodialysis.

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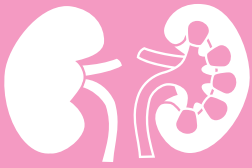
Medications



This chart lists some medications used in treating various aspects of kidney disease and kidney failure, including anti-rejection medications for transplant recipients. This handbook does not discuss all of these medications.

NOTES:

GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
ACEBUTOLOL	Sectral®	Beta-blocker/blood pressure
ACETAMINOPHEN	Tylenol®	Analgesic/pain or fever
ALFACALCIDOL	One-Alpha®	Active vitamin D/bones/mineral metabolism
ALUMINUM HYDROXIDE		Phosphate binder/bones/mineral metabolism
AMILORIDE		Diuretic or water pill/fluid build-up
AMLODIPINE	Norvasc®	Calcium channel blocker/blood pressure
ANTITHYMOCYTE GLOBULIN	Atgam®, Thymoglobulin®	Anti-rejection
ATENOLOL	Tenormin®	Beta-blocker/blood pressure
ATORVASTATIN	Lipitor®	Statin/cholesterol
AZATHIOPRINE	Imuran®	Anti-rejection
BASILIXIMAB	Simulect®	Anti-rejection
BENAZEPRIL	Lotensin®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
BISOPROLOL		Beta-blocker/blood pressure
CALCITRIOL	Calcijex®, Rocaltrol®	Active vitamin D/bones/mineral metabolism
CALCIUM ACETATE		Phosphate binder/bones/mineral metabolism
CALCIUM CARBONATE	Calsan®, Tums®	Phosphate binder/bones/mineral metabolism
CALCIUM POLYSTYRENE SULFONATE	Resonium Calcium®	Exchange resin/hyperkalemia (or high potassium)

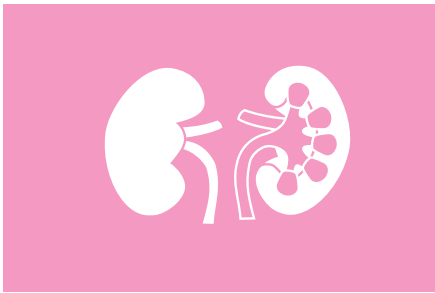


Medications

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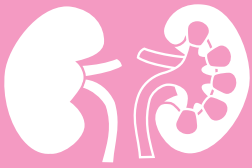
GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
CANDESARTAN	Atacand®	Angiotensin receptor blocker (ARB)/ blood pressure
CAPTOPRIL	Capoten®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
CARVEDILOL	Coreg®	Beta-blocker/blood pressure
CHLORTHALIDONE		Diuretic or water pill/fluid build-up
CINACALCET	Sensipar®	Calcimimetic/bones/mineral metabolism
CYCLOSPORINE	Neoral®, Sandimmune®	Anti-rejection
DARBEPOETIN ALFA	Aranesp®	EPO/anemia
DILTIAZEM	Tiazac®, Cardizem®	Calcium channel blocker/blood pressure
DIPHENHYDRAMINE	Benadryl®	Antihistamine/rash or itching
ENALAPRIL	Vasotec®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
EPOETIN ALFA	Epex®	EPO/anemia
EZETIMIBE	Ezetrol®	Cholesterol absorption inhibitor/cholesterol
FELODIPINE	Plendil®	Calcium channel blocker/blood pressure
FENOFIBRATE	Lipidil®	Fibrate/cholesterol
FERROUS GLUCONATE		Iron/anemia
FERROUS SULPHATE		Iron/anemia
FERROUS FUMARATE		Iron/anemia
FERUMOXYTOL (INTRAVENOUS)	Feraheme®	Iron/anemia
FLUVASTATIN	Lescol®	Statin/cholesterol

Medications



GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
FOSINOPRIL	Monopril®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
FUROSEMIDE	Lasix®	Diuretic or water pill/fluid build-up
GEMFIBROZIL	Lopid®	Fibrate/cholesterol
HYDROCHLOROTHIAZIDE		Diuretic or water pill/fluid build-up
HYDROXYZINE	Atarax®	Antihistamine/rash or itching
IBUPROFEN	Advil®	Analgesic/pain or fever
INDAPAMIDE	Lozide®	Diuretic or water pill/fluid build-up
IRBESARTAN	Avapro®	Angiotensin receptor blocker (ARB)/ blood pressure
IRON DEXTRAN (INTRAVENOUS)	Dexiron®, Infufer®	Iron/anemia
IRON SUCROSE (INTRAVENOUS)	Venofer®	Iron/anemia
LABETALOL	Trandate®	Beta-blocker/blood pressure
LANTHANUM	Fosrenol®	Phosphate binder/bones/mineral metabolism
LISINOPRIL	Prinivil®, Zestril®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
LOSARTAN	Cozaar®	Angiotensin receptor blocker (ARB)/ blood pressure
LOVASTATIN	Mevacor®	Statin/cholesterol
METOLAZONE	Zaroxolyn®	Diuretic or water pill/fluid build-up
METOPROLOL	Lopresor®	Beta-blocker/blood pressure
MYCOPHENOLATE	CellCept®	Anti-rejection
NADOLOL		Beta-blocker/blood pressure

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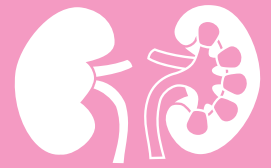


Medications

NOTES:

GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
NAPROXEN	Aleve®, Naprosyn®	Analgesic/pain or fever
NIFEDIPINE	Adalat XL®	Calcium channel blocker/blood pressure
OLMESARTAN	Olmotec®	Angiotensin receptor blocker (ARB)/ blood pressure
PERINDOPRIL	Coversyl®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
PINDOLOL		Beta-blocker/blood pressure
PRAVASTATIN	Pravachol®	Statin/cholesterol
PREDNISONE		Steroid/anti-rejection
PROPRANOLOL	Inderal®	Beta-blocker/blood pressure
QUINAPRIL	Accupril®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
RAMIPRIL	Altace®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
ROSUVASTATIN	Crestor®	Statin/cholesterol
SEVELAMER	Renagel®	Phosphate binder/bones/mineral metabolism
SIMVASTATIN	Zocor®	Statin/cholesterol
SIROLIMUS	Rapamune®	Anti-rejection
SODIUM BICARBONATE		Alkalinizing agent/acidosis
SODIUM FERRIC GLUCONATE	Ferrlecit®	Iron/anemia
SODIUM POLYSTYRENE SULFONATE	Kayexalate®	Exchange resin/hyperkalemia (or high potassium)
SOTALOL		Beta-blocker/blood pressure

Medications



GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
SPIRONOLACTONE	Aldactone®	Diuretic or water pill/fluid build-up
TACROLIMUS	Prograf®, Advagraf®	Anti-rejection
TELMISARTAN	Micardis®	Angiotensin receptor blocker (ARB)/ blood pressure
TRANDOLAPRIL	Mavik®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
TRIAMTERENE		Diuretic or water pill/fluid build-up
VALSARTAN	Diovan®	Angiotensin receptor blocker (ARB)/ blood pressure
VERAPAMIL	Isoptin SR®	Calcium channel blocker/blood pressure

NOTES:



Your feedback is important

NOTES:

We would like to know how helpful you found this handbook. Any feedback we receive is confidential and will be used to help us continue improving this handbook and other Kidney Foundation resources.

You can fill out an online evaluation at **www.kidney.ca/handbooks/evaluation**.

Or you can write us a note and mail it to:

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Thanks in advance for your comments.

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Our Vision

The Kidney Foundation of Canada is committed to achieving excellent kidney health, optimal quality of life, and a cure for kidney disease.

Our Mission

The Kidney Foundation of Canada is the national volunteer organization committed to eliminating the burden of kidney disease through:

- Funding and stimulating innovative research for better treatments and a cure;
- Providing education and support to prevent kidney disease in those at risk and empower those with kidney disease to optimize their health status;
- Advocating for improved access to high quality health care;
- Increasing public awareness and commitment to advancing kidney health and organ donation.

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