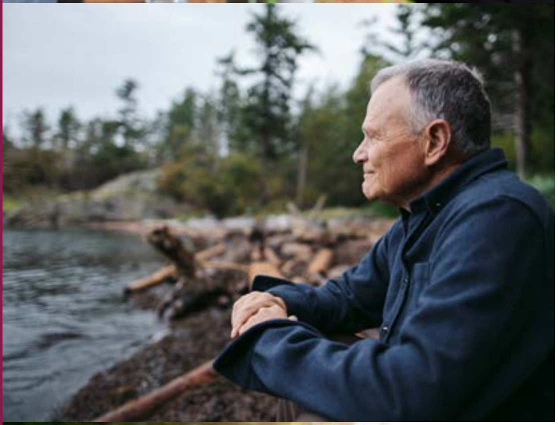

Living with Kidney Failure

6th Edition

kidney
FOUNDATION
™

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 at kidneycommunitykitchen.ca. The Kidney Connect social network for people living with kidney disease is available at kidneyconnect.ca.

Model(s) are a depiction of people
with kidney disease.

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kidney.ca

Living with Kidney Failure

My Personal Information

Name

Address

Phone Number(s)

Email Address

Personal Health Number

Primary Care Provider/Family Physician

Kidney Doctor

Kidney Nurse

Kidney Dietitian

Kidney Pharmacist

Kidney Social Worker

Transplant Kidney Doctor

Transplant Coordinator

Dialysis Unit

Substitute Decision Maker & Phone Number

Thank You

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AstraZeneca Canada Inc.
Innovative Medicines Canada
Janssen Inc.
Otsuka Canada Pharmaceutical Inc.
Sanofi Genzyme

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Table of Contents

Introduction

What is this handbook about?

Every year thousands of people in Canada are told that their kidneys are working very poorly. Some have known that they have chronic kidney disease and have been expecting this possibility. For others, this news comes as a complete shock. In either case The Kidney Foundation of Canada (KFOC) hopes that the information in *Living with Kidney Failure* will help you and your family understand the possible treatment options: dialysis, transplant and conservative kidney management.

This handbook covers other important topics including: advance care planning; advice for dealing with practical matters such as work, money and insurance; and, tips for living well with kidney failure. The information and suggestions in this book are general – you should always seek the advice of healthcare professionals for an assessment and treatment plan that meets your individual needs.

This handbook is produced by The Kidney Foundation of Canada and is provided free-of-charge to any person living in Canada who has been diagnosed with kidney disease. Others may obtain a copy of the handbook, for a small fee, by contacting their local Kidney Foundation office. Contact information and an electronic version of this handbook are available on The Kidney Foundation's website at kidney.ca.

Hints on how to use this handbook

Being told that your kidneys are failing can be overwhelming and may raise a lot of questions about your future: *"Can I keep working or going to school? Will I be able to start a family? Do I have to do dialysis? Will I be able to get a transplant and if so, how long will I have to wait? What should I do to feel my best?"*

Research has shown that people have better health outcomes when they are involved in seeking answers to many of their questions for themselves, by understanding their disease(s) and by participating in decision-making about their treatment and care. This handbook will help you explore some of the questions you may have about treatment. It will also help you have conversations with your healthcare team, family and friends about your treatment choices, so that you can live well with kidney failure.

This handbook and other information about kidney disease are available online at kidney.ca.

This material is available in accessible formats upon request by contacting info@kidney.ca or calling 1-800-361-7494.

- While the focus of this handbook is on adults living with kidney failure, most of the information can also be used to help the pediatric population and their families.
- Each chapter includes helpful tips and/or suggestions for people living with kidney failure. It also has highlights, photos, icons and a summary of key points so you can more easily find the information you want.
- Whenever a new or important word or term is introduced, it is shown in ***bold italic type*** the first time it appears in the book. You will find the definitions of these words and terms in the glossary.
- Sometimes italics are used to emphasize certain words or phrases. These words and phrases do not appear in the glossary.
- When medications are mentioned, the generic (common) name of the medication is used because there are often several brands available. There is also a chart at the end of the handbook that gives examples of brand names for various medications.
- Wherever you see a QR code, use your smartphone to scan the code to open the website.

Please use this handbook as a resource in whichever way works best for you. Read it all the way through or skip to the chapters that you find most relevant. Mark up the margins with your own notes or use it as a reference and re-read sections as your situation changes. We also encourage you to share this resource with family, friends, colleagues, or anyone around you who would like to learn more about kidney failure in order to help and support you.

NOTES:

Acknowledgements

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The Kidney Foundation of Canada would like to thank all those people across Canada who generously gave their time and effort to make this handbook possible. Without their encouragement, ideas and support, it would not have been possible.

The Foundation would especially like to acknowledge the healthcare professionals, people with lived experience and others from across the country for their tremendous assistance.

Chapter 1

Exploring your treatment options

“I didn’t expect my kidneys to fail me but I wouldn’t change it. The people I have met, the opportunities to share my story and give back to my community overshadow those harder days.” - Kate

Chapter 1

Exploring your treatment options

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 may discuss additional treatment choices with you. 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; this can be stressful and lead to initial treatments that may not be optimal for you.

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 the 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.

There are three main treatment options: dialysis, a ***kidney transplant*** and ***conservative kidney management***. This chapter will help you consider your options and the 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 case.

Chapter 1

Exploring your treatment options

NOTE:

This information is intended to help you discuss treatment options with your healthcare team. It is not meant to suggest any particular type of medical treatment.

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***, flows through the catheter into the ***peritoneal cavity*** and “cleans” the blood; the PD fluid is then drained along with the toxins. Draining PD fluid filled with toxins and filling with “clean”fluid is called an “***exchange***”. PD fluid exchanges are done every day or every night, although there is always fluid in the abdomen to remove toxins.

Peritoneal dialysis usually requires about one to two weeks of training before doing it on your own. You will also receive on-going support from the dialysis clinic. With peritoneal dialysis, dialysate fluid in bags is delivered to your home and most (if not all) costs are covered by your provincial/territorial healthcare plan. You will need to ensure that you’re home to receive your supplies and that you have space in your home to store them where they won’t freeze or be exposed to excessive heat or humidity – usually a closet about the size of a double bed.

With PD, you’ll have a permanent catheter in your abdomen, but you’ll have more flexibility, independence and control over your own treatment. People who want to continue working, attending school, or those who need or wish to travel, often choose peritoneal dialysis. People who live far from a hemodialysis unit (see below) and would prefer to spend their time at home, rather than travelling to and from treatment, might also choose PD.

Hemodialysis

Hemodialysis pumps your blood through a dialysis machine to remove waste and excess fluid, and then returns the ‘cleaned’ blood back into your body. To do hemodialysis, access to large veins is needed. This access can be in the form of a ***fistula*** or ***graft***, usually in your arm, and is surgically put in place. Sometimes, in order to start dialysis on short notice, a catheter or line is inserted in the large ***vein*** of your neck for temporary access. A fistula or graft must be created weeks to months before it is needed, but there is less chance of infection than with a catheter. Hemodialysis can be done at home or at a dialysis centre.

Hemodialysis at home

Instead of travelling to a clinic or hospital and having a healthcare provider connect you to a machine, you and/or a caregiver learn how to use the dialysis machine at home. You’ll need to complete training, which can take three to six weeks, depending on the location where you’re trained. After that, you will be able to dialyze at home (often at night while you sleep).

Generally, people feel and do better with independent (home) hemodialysis than with hemodialysis in a hospital or clinic. That’s because home hemodialysis can be done more frequently, on your own schedule, and with fewer dietary and fluid restrictions. For example, many patients choose to start hemodialysis before going to bed and receive gentle hemodialysis while they are sleeping. This provides very good removal of toxins and fluid while freeing up the day for other activities. You also have much more flexibility in when you want to do hemodialysis than at a dialysis centre.

You are in charge of your own day-to-day care with the benefit of on-going support from your dialysis clinic. You’ll need to make sure you have space in your home to store your dialysis supplies and to set up a comfortable, permanent place in your home for your dialysis machine and water system. You may need to install special plumbing connections and electrical outlets for your dialysis machine. The costs of these modifications may be covered by provincial/territorial medical insurance. However, this option may increase your home energy, water and/or garbage disposal costs because you are dialyzing at home. Please check with your local dialysis program to find out what expenses are covered.

Hemodialysis at a hospital or clinic

Some people are not able to do dialysis (either PD or hemodialysis) at home and instead go to a hospital or clinic where a trained nurse or technician can connect them to the dialysis machine. In-centre dialysis means you have to travel at least three times per week, sometimes at a great distance, for treatment and you will have to cover transportation costs yourself. The time spent on in-centre hemodialysis is typically four hours, not including preparing and coming off the treatment.

You'll also have to plan your week and your activities around your hemodialysis schedule. In addition, you'll have a daily fluid limit and a restricted diet in order to help your body manage fluid and waste build-up between treatments.

There are factors that make having hemodialysis in a clinic a better choice in certain situations. For example, if you are physically or cognitively unable to do dialysis at home, if you don't have appropriate housing and/or if you lack the support needed to do your treatment at home.

See **Chapter Two: Dialysis** for more information about dialysis options.

Kidney transplant

A kidney transplant is generally considered the best treatment for most people with kidney failure. However, not everyone is a candidate for a transplant. You may not be eligible, for example, if you have other serious health issues in addition to kidney disease, are severely obese, and/or if you are currently abusing drugs or alcohol. Even if you are eligible for a transplant, a kidney donor may not be immediately available. Most people start dialysis while they wait for a kidney donor.

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.

See **Chapter Four: Transplant** for more information about kidney transplantation.

Conservative kidney management

Performing dialysis can be a burden for some people, and may lead to a decreased quality of life. Conservative kidney management (CKM) is an active intervention plan that maximizes physical, mental, emotional and spiritual health within the limits imposed by their chronic illness(es). Conservative kidney care does not include dialysis or a transplant. It offers you time to spend doing what matters most to you. If you choose conservative kidney management your healthcare team will develop a personalized plan to help slow the kidneys' decline and manage any symptoms you may have.

See **Chapter Five: Conservative kidney management** for more information about this option.

Which treatment is best for you?

Now that you have a basic understanding of your treatment options, you might wonder which treatment is best for you. The following questions can help you consider your options. The first chart looks at dialysis, and the questions below the chart focus on transplant and conservative kidney management. You can use your answers as a way to communicate your thoughts and concerns about treatment with your healthcare team.

What's important to me?

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

NOTES:

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.			
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.			
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.			
My thoughts:				

(Adapted with permission from Kidney Health Australia)

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.			
My thoughts:				
Starting a family	More frequent dialysis is needed when you are pregnant.			
My thoughts:				
Diet and fluid restrictions	In-centre hemodialysis has more diet and fluid restrictions than peritoneal dialysis or home hemodialysis.			
My thoughts:				
Side effects	Home hemodialysis and peritoneal dialysis may mean fewer overall side effects than in-centre hemodialysis (blood pressure, heart issues).			
My thoughts:				

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.			
My thoughts:				
Quality of life	Chosing 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.			
My thoughts:				
Anything else?				
My thoughts:				

(Adapted with permission from Kidney Health Australia)

Other considerations

These are questions related to transplant and conservative kidney management, and general questions about all treatment options. You may not have all the answers right now, but they are here for your consideration.

1. Are you a candidate for a transplant?

Yes No

If yes, do you have a potential living donor(s)?
(See Chapter 4: Transplant for more information about living donors.)

Yes No

2. Do you have other medical conditions? (high blood pressure, diabetes, heart disease, etc.)

Yes No

3. Do you feel that the burden and discomfort of dialysis outweigh the benefits?

Yes No

4. Have you done your advance care planning?

Yes No

5. Do you understand the options available to you?

Yes No

6. What is important to you?

7. Which option would you like to explore in more detail?

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) ______________________________

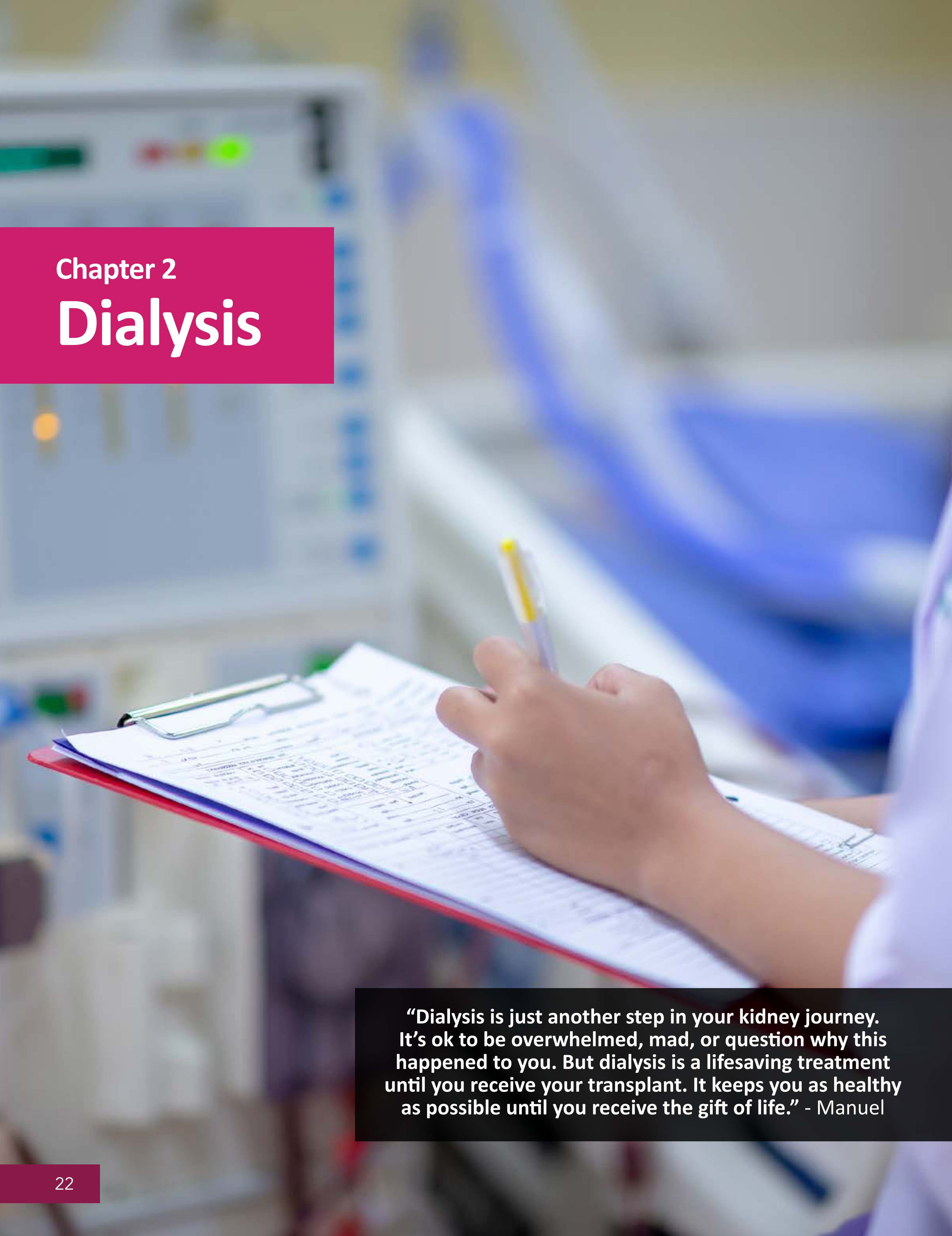
f) ______________________________

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 there is a shift in your life situation. 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. This means that the disease will run its course until the end of life. Your health care team can connect you with the resources you need to support you through this process.

Summary

- There are three treatment options: dialysis (either peritoneal dialysis or hemodialysis), a kidney transplant and conservative kidney management.
- There are advantages and limitations to consider for each option that will be expanded on in the next chapters.
- 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.



Chapter 2

Dialysis

"Dialysis is just another step in your kidney journey. It's ok to be overwhelmed, mad, or question why this happened to you. But dialysis is a lifesaving treatment until you receive your transplant. It keeps you as healthy as possible until you receive the gift of life." - Manuel

Chapter 2

Dialysis

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 conservative kidney management, 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.

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 are interested in. Many people find that their fears about home-based dialysis melt away once they find out more about it and their questions are answered. 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.

Chapter 2

Dialysis

Types of dialysis

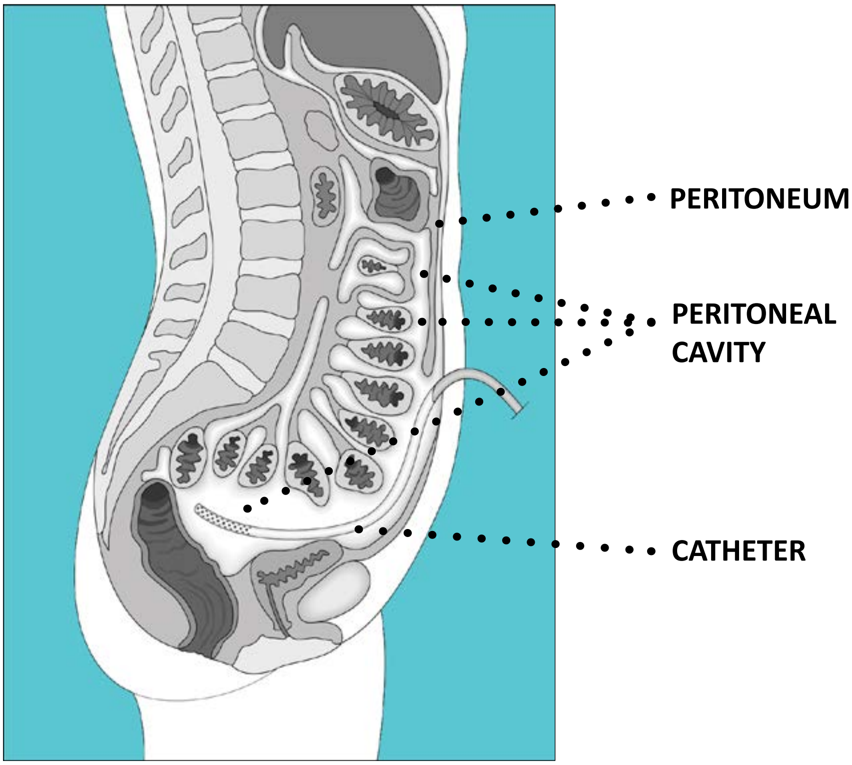
	Peritoneal dialysis	Hemodialysis
Independent (generally done at home)	Continuous ambulatory peritoneal dialysis (CAPD) Automated or continuous cycler peritoneal dialysis (APD, CCPD)	Home hemodialysis
Dependent (done in a hospital, clinic or dialysis centre)	None	In-centre hemodialysis at a hospital, clinic or dialysis centre

See **Chapter One: Exploring your treatment options** for an overview of the available options.

Peritoneal dialysis

What is peritoneal dialysis?

Peritoneal dialysis removes waste products and excess water from your body by using the ***peritoneal cavity*** on the inside of your abdomen to clean your blood.



Peritoneal Cavity and Catheter

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.

NOTES:

How is access to the peritoneal cavity established?

Dialysis fluid enters the peritoneal cavity through a tube called a catheter. The catheter is inserted in your abdomen, usually below and to one side of your belly button. 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 at the hospital bedside using local anesthetic, in the X-ray department, 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 by draining the "older" fluid, and then instilling "clean" dialysis fluid; draining old fluid and instilling clean fluid is called an "exchange". There are two types of peritoneal dialysis:

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

Continuous ambulatory peritoneal dialysis (CAPD)

In CAPD, you carry about 1.5 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, at 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. 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 cycler peritoneal dialysis (APD, CCPD)

In APD (which is sometimes known as CCPD), a machine called an automatic cycler 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 cycler for the night. While this option 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 APD (also known as CCPD) will be made with your healthcare team. Some people do better with one type of dialysis and others do better with another. A special test called a PET (Peritoneal Equilibration Test), along with other measures of how well dialysis is working for you, will help your healthcare team decide which method is best for you.

You will be responsible for ordering your own supplies and someone must be home to accept delivery. You will also need to store your supplies in a relatively large space – usually a closet about the size of a double bed, where they won't freeze or be exposed to excessive heat or humidity. You won't have to pay for these supplies yourself because they are covered by your provincial/territorial medical insurance. You may also be able to claim a tax deduction for the space in your home used for storing your PD supplies.

For more information on tax deductions related to dialysis done at home (both PD and HD), please see the Tax Tips document at kidney.ca or contact your local Kidney Foundation office.

"After crash starting dialysis in 1979, I have done almost every treatment modality offered including two kidney transplants. I am currently doing home hemodialysis, which allows me to have control of my treatment with less travel."
- Peggy

Chapter 2

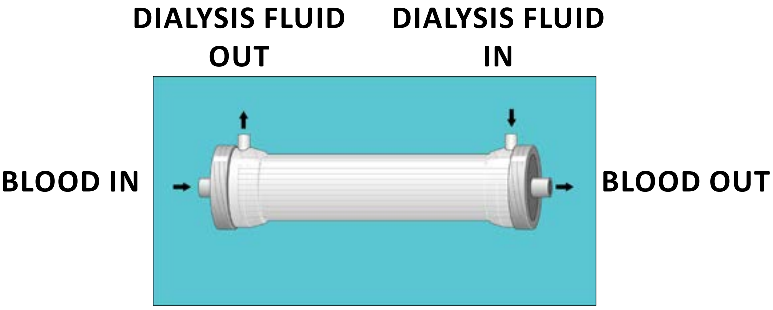
Dialysis

Hemodialysis

Hemodialysis means “cleaning the blood” and that’s exactly what this treatment does. Blood is withdrawn from the body by a machine and passed through an artificial kidney. It is called an artificial kidney because it cleans the blood, although not as efficiently as a healthy kidney. The cleaned blood is then returned to your body.

How do hemodialysis machines work?

There are several different kinds of dialysis machines, but they work in almost the same way. A ***dialyzer*** (artificial kidney) is attached to the machine. The dialyzer has two spaces: a space for blood and a space for dialysis fluid. ***Dialysis fluid*** is a special liquid which helps remove waste products from the blood. A very thin artificial ***membrane*** separates the two spaces in the dialyzer from each other. Blood passes on one side of the membrane and the dialysis fluid passes on the other side. Waste products and water pass from the blood through the membrane into the dialysis fluid and are removed from the body. Freshly cleaned blood is constantly returned to the body. Only a small amount of blood is out of the body at one time – about one cup. You have five to six litres of blood in your body, equivalent to about 20 cups.



DIALYZER

HEMODIALYSIS MACHINE

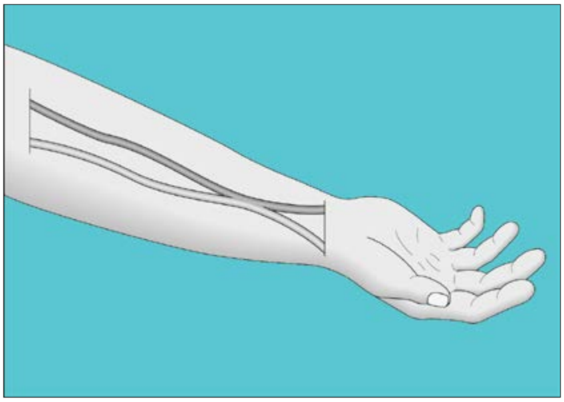
How is excess water removed from the body?

One of the functions of normal kidneys is to remove excess salt and 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)



FISTULA

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.

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.

GRAFT

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.

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.

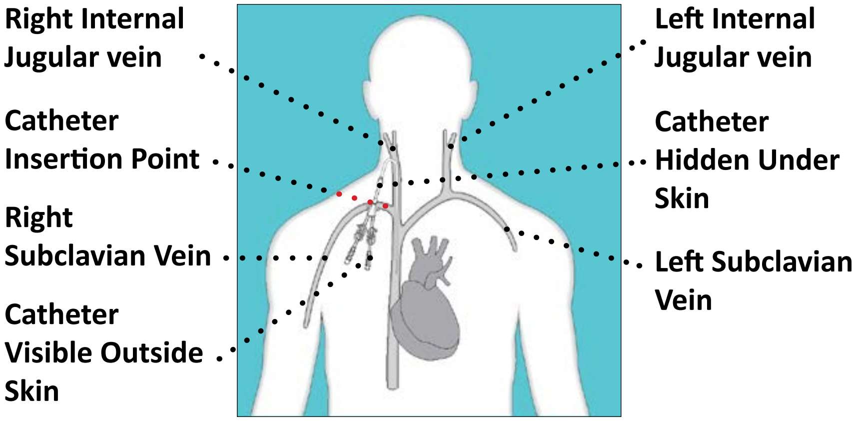
To care for your fistula or graft, avoid…

- 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

NOTES:

Central venous catheter

A central venous catheter may also be called a central venous “line”. It is two soft tubes joined together side-by-side. One end of the catheter is inserted into a large vein, with the other end sticking out through the skin. The most commonly used vein is the ***jugular vein*** at the side of the neck. The catheter is inserted using a local anesthetic to numb the skin. It is then covered with a dressing. The catheter is left in place until a permanent access site (fistula, graft, or peritoneal dialysis catheter) is ready.



CENTRAL VENOUS CATHETER

A central venous catheter is normally only used when a fistula or graft cannot be created, usually because the veins in the arms and legs are too small. When access to the bloodstream is needed quickly, a catheter is used temporarily until a better permanent access site is ready.

Care of central venous catheters

The major short-term risks of central venous catheters are clotting and infection. To try to prevent clotting, the dialysis nurse will fill the catheter with a solution at the end of each dialysis treatment. To try to prevent an infection in your catheter, many things will be done. Special dressings may be placed on the skin and caps on the lines will be used. You must not get it wet (while swimming or taking a bath). You must not let anyone use the catheter unless they have first spoken directly with your dialysis team. If you do get an infection, you might get fevers or chills, or just not be yourself. If this happens, you need to tell your dialysis team right away. An infection might be treated with a cream or antibiotics. Sometimes the catheter needs to be removed and replaced to help treat the infection.

NOTES:

Does hemodialysis hurt?

Inserting the needles causes pain, but only for a brief time. While most people tolerate this without difficulty, for a few it can be difficult. Sometimes prescription anesthetic creams and/or training in relaxation techniques can help. Occasionally nausea, muscle cramps or dizziness can occur with hemodialysis. Some symptoms may be related to taking in too much salt which results in large fluid gains, but there may be other reasons. If these symptoms occur, let your dialysis team know. Often the symptoms can be improved with changes to your dialysis prescription, diet and medications.

Independent (home) hemodialysis

Home hemodialysis gives you the opportunity to manage your dialysis care in your own home instead of travelling to a clinic or hospital for treatment. Most people who do home hemodialysis find that they have a more flexible schedule and better health results because they can dialyze more often or for longer periods of time.

The length of the training program varies from region to region and can take up to six weeks. You will be taught everything you need to know to do the hemodialysis yourself, and in most cases, a partner is taught at the same time. In some centres, you can’t do home hemodialysis if you don’t have a support person or partner.

One type of home dialysis is ***home nocturnal hemodialysis***. With this method, you carry out dialysis four to six nights a week for six to eight hours while you sleep at home. Home nocturnal hemodialysis greatly improves the removal of waste products from the body. It has also been found to improve well-being, allow you a more liberal diet and reduce the need for medications. It also frees up the daytime for other activities.

To do home hemodialysis, you have to set up a comfortable permanent place in your home for you, your dialysis machine and your water system. Your home training team will help you determine what is required. You may need to install special plumbing connections and electrical outlets.

The hospital or dialysis centre provides the dialysis machine and arranges the necessary modifications to your home. However, you may claim on your income tax return any costs that the dialysis centre does not cover to make changes to your home to accommodate your dialysis. You may also claim a portion of the cost of keeping the dialysis machine in your home (for things like utilities, insurance, heating, maintenance and repairs). Your home hemodialysis program will help you order your supplies. You won’t have to pay for the supplies yourself since they are covered by your provincial/territorial medical insurance.

How much hemodialysis is best?

Twelve hours of hemodialysis each week (for example, three treatments of four hours) is usually sufficient to clean the blood well enough to control your symptoms. Some patients may require more dialysis, and some less. It will also help to balance various substances in your body. However, it does not come close to the function that normal kidneys perform. Most people find that PD or home hemodialysis will allow them to dialyze more frequently than dialysis provided in a hospital or clinic, giving them better health outcomes, more energy and fewer dietary restrictions.

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.

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.

NOTE

Some centres offer hemodialysis overnight at the hospital, although this option is not available everywhere.

Potential complications and issues with dialysis

There are a number of potential complications for people with kidney failure on dialysis, which may also be experienced by patients with end-stage kidney disease who are not on dialysis. Fortunately, there are often effective methods of treating them. Below we discuss the most common complications and how they are treated. Remember, these are possible complications – they are not necessarily ones that you will experience.

Anemia

A condition commonly caused by chronic kidney disease is ***anemia***, which is a reduction in the number of red blood cells in the blood. Patients may have a reduction in the iron needed to make red blood cells for several reasons: from eating less iron-rich food, by losing small amounts of blood from frequent blood tests, and from blood lost in the hemodialysis tubing after each session. Over time, this can lead to anemia. Also, the kidneys make a hormone called ***EPO (erythropoietin)*** when the body senses a reduction in red blood cells. EPO tells your bones to make more red blood cells. As kidney disease progresses, your body is not able to make enough EPO in response to low red blood cells. When anemia is mild, there may not be any negative effects on the body. However, as anemia becomes more severe, it may lead to low energy, tiredness, shortness of breath and sometimes, increased sensitivity to cold.

The only real way to know if you have anemia is to have a blood test to check your red blood cells and, specifically, your ***hemoglobin***. The hemoglobin value is a measure of the total red blood cell content of blood. Testing will help you know if your hemoglobin levels are within your target range.

My target ranges

My hemoglobin target range is ______ to ______.

My iron targets: ______.

Transferrin Saturation (iron readily available in blood): ______.

Ferritin (long-term iron stores): ______.

Treatment options for anemia:

- Dietary changes (increading iron-rich foods)
- Prescription medications (eryhropoietin [EPO], iron)
- Blood tranfusions

EPO

To tell your bone marrow to make more red blood cells, you may be prescribed a medication called EPO – it acts like your body's natural EPO hormone. It's given by injection one to three times per week. The EPO dose may be changed often in order to keep your hemoglobin in the target range. However, pushing the hemoglobin level too high for a long time with EPO can be dangerous, as there are a number of medical risks, including stroke. Your kidney healthcare team will make sure to adjust the EPO to keep it at the right level for you.

Some common EPO medications used in Canada are:

- Epoetin alfa (Eprex®)
- Darbepoetin alfa (Aranesp®)

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.

NOTES:

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. These glands release parathyroid hormone (PTH) when they sense a drop in calcium levels in your blood. PTH raises calcium levels in the blood by removing calcium from bone. When calcium levels in the blood return to normal, the parathyroid glands stop releasing PTH.

High phosphate and low activated vitamin D levels (commonly found in people with chronic kidney disease) also stimulate the parathyroid gland. If high phosphate levels go untreated for a long time, the parathyroid glands become overactive leading to high PTH levels that remove more calcium from bone than needed. This may affect the health of your bones. High phosphate and calcium levels in the blood may also lead to calcification (hardening) of blood vessels and other soft tissues, which can lead to serious health problems.

You can decrease the risk of mineral and bone disorder with proper food choices and medications. If your phosphate level is too high, you will develop severe itching and weak bones. To reverse this, you should reduce the amount of high phosphate food in your diet as directed by your kidney dietitian.

My target ranges

My phosphorus target is: ______.

My calcium target range is: ______ to ______.

My parathyroid hormone (PTH) target range is: ______ to ______.

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.

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.

NOTE:

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 49 for a more complete list of ingredients to avoid.

Too much salt and water - fluid overload

An important function of healthy kidneys is to remove excess salt and water (fluid) from the body. With advanced kidney disease, the kidneys may not produce as much urine as before, so 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. Excess fluid is sometimes seen as swelling in the ankles and around the eyes. Sometimes, fluid stays in the lungs causing coughing and shortness of breath.

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

NOTES:

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 salt 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 (salt and water) 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 may 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.

My target ranges

My target blood pressure is: ______.

My target dry weight: ______.

My target weight gain between dialysis runs is: ______.

Be sure to ask when the medication should be taken; for example, it is usually not taken before dialysis treatments. Most people should follow a low sodium diet to help manage high blood pressure.

See **Chapter Three: Diet and dialysis** for more information on how to manage your phosphate levels, and the role of diet and medications.

NOTES:

Low blood pressure

Low blood pressure can be a side-effect of hemodialysis. When too much fluid is removed from the blood during hemodialysis, it can cause your blood pressure to drop, which can make you feel dizzy, nauseous and/or can give you painful muscle cramps. You can try to avoid this issue by knowing your dry weight and your fluid removal goal at each treatment, and by preventing too much fluid intake (or build-up) between hemodialysis runs so that less fluid is removed in a treatment. Your healthcare team will also be able to help you during treatment if you experience low blood pressure.

Nerve changes

Some people with kidney disease experience changes in nerve function, usually in the legs and feet and/or arms and hands. Your doctor can provide you with advice for managing these symptoms.

Symptoms of nerve changes:

- Restless legs
- Burning sensation
- Numbness
- Tingling

Skin changes

People with kidney disease, particularly those on dialysis, often have skin problems. The most common is itchiness, which can be annoying and is often difficult to treat. There are many reasons for itchy skin in people with kidney failure:

- High levels of phosphate
- Poor kidney functions (for those not on dialysis) or not enough dialysis
- Dry skin
- Infections (like scabies)
- Other possible reasons that doctors and researchers do not yet understand

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.

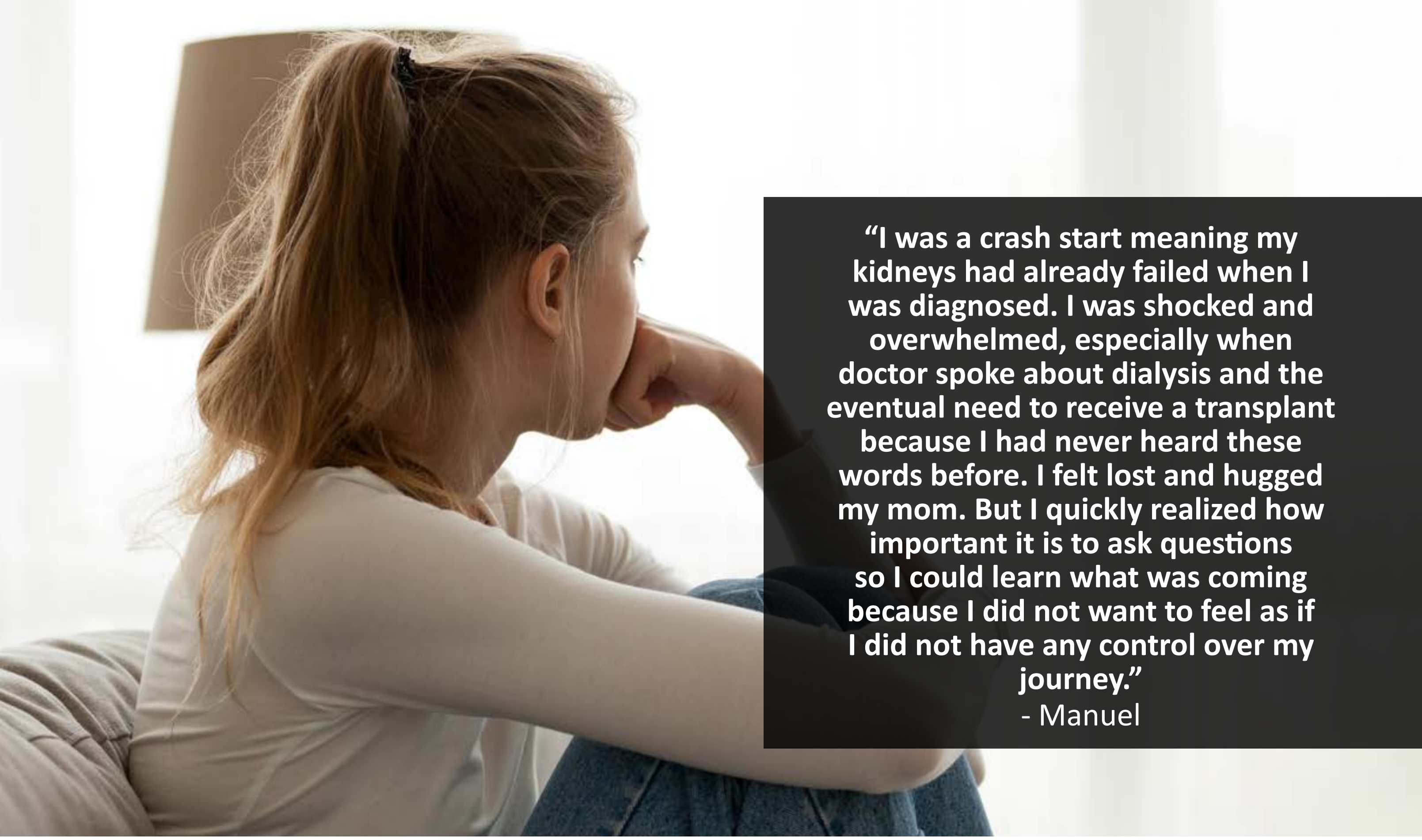
A number of strategies can be used, alone or in combination, to treat itching. A first step is to control the phosphate in your diet, take phosphate-binding medications if needed, and get the right amount of dialysis. If these don't work, your doctor may prescribe special creams, medications or ultraviolet 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 as they can make the itching worse.
- Wear soft cotton fabrics – avoid wool and rough polyesters.
- Use as little laundry detergent as possible, as 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 as the chemicals that produce the scent can irritate the skin.

NOTES:



> **"I was a crash start meaning my kidneys had already failed when I was diagnosed. I was shocked and overwhelmed, especially when doctor spoke about dialysis and the eventual need to receive a transplant because I had never heard these words before. I felt lost and hugged my mom. But I quickly realized how important it is to ask questions so I could learn what was coming because I did not want to feel as if I did not have any control over my journey."**
>
> - Manuel

Overcoming an emergency start on dialysis

The ideal way to start dialysis is to have seen your kidney healthcare team for at least a year, to have learned about treatment choices, to have made early decisions and then to have followed them through. This means that when you start dialysis:

- **you are on the method of your choice**
- **you are receiving dialysis as an outpatient**
- **you already have a PD catheter, an AV fistula or an AV graft, as needed**

Unfortunately, some people start dialysis without prior planning, as a hospitalized inpatient and/or with a central venous catheter. This is often called a "crash start", or an "emergency start". There are many reasons why this happens, some of which are unavoidable. Regardless of the reason, there are ways to lessen the impact of an emergency start on dialysis. Here are some of them.

Chapter 2

Dialysis

Education

Start (or complete) your education about how the kidneys work, both healthy and diseased. Learn about kidney failure treatment options. Even if you start on hospital-based hemodialysis, you should work with your healthcare team to determine which treatment option is best for you and your ongoing therapy. Find out if you are a candidate for transplantation. If you're not, perhaps you are a candidate to do dialysis at home (either peritoneal dialysis or home hemodialysis), which has many advantages over hospital-based dialysis for suitable patients.

Get the best vascular access for dialysis

If you started hemodialysis with a central venous catheter, find out why and whether an AV fistula or AV graft is possible. While not everyone is eligible, a fistula or graft is usually better than a central venous catheter for long-term dialysis. Try to get your most appropriate vascular access in place as soon as possible.

Diet and medications

Remember that dialysis alone does not do everything that normal kidneys do. That is why diet and medications are also required. Even the combination of dialysis, diet and medications does not work as well as healthy kidneys. Learn why you need to follow a certain diet and why you need each of your medications. Some medications will be stopped when dialysis starts, while others may need a change in dose or the timing of the dose. Other medications may be added. Make sure a doctor and pharmacist carefully review your medications.

Dry weight and high blood pressure

Learn about the concept of dry weight and work with your team to limit your fluid weight gain between treatments. If you have high blood pressure or swelling, then slowly but surely reducing dietary sodium intake and removing more fluid on dialysis can lead to better blood pressure control, fewer blood pressure pills and less swelling.

Medication and your targets

Make sure you are on the right medications. Most facilities do blood work every four to six weeks so you can understand how well your medications are working. Ask to review it, learn about targets and work with your team to achieve them.

Take control

A diagnosis of end-stage kidney disease (ESKD) can come as a shock for many people, since there aren't any symptoms until the disease is quite advanced. This shock is often accompanied by a feeling of grief for previous good health, a sense of loss of control, and isolation from family and friends who may struggle to understand what you are going through. Try to stay positive, optimistic and take control of your own care as much as possible. Speak with your healthcare team if you are feeling anxious or depressed. Support is available to help you manage your emotions during this difficult time.

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.

NOTES:

How to cope in an emergency situation (power failure, weather related, etc.)

In an emergency, you may have to evacuate from your home with little warning, you may have to miss a dialysis session or you may not be able to do dialysis at all. Many dialysis programs have information on Emergency Preparedness – ask them to give you their handouts.

Here are some valuable tips to help you prepare:

- Unless you are injured, stay where you are. Listen to the radio for instructions from local officials. (Keep a battery-operated radio and extra batteries on hand.)
- Continue dialysis if you can. If you are unable to do dialysis, you will need to start the ***emergency diet*** provided by your clinic staff. This diet is designed to slow the build-up of waste products in the body.
- If you need to be evacuated, bring your medications, medical information, and identification with you so any caregiver will understand your needs.
- Keep your fistula, graft or catheter area clean to avoid infections.

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.

Summary

- Peritoneal dialysis cleans your blood inside your abdomen (peritoneal cavity) and is generally performed at home.
- Hemodialysis cleans your blood in a machine and can be done at the hospital, clinic, dialysis centre or at home.
- Potential complications and issues that may arise with dialysis include anemia, mineral and bone problems, fluid overload, high or low blood pressure, and nerve and skin changes.
- Sometimes dialysis must be started on an emergency basis and this can create special challenges; there are ways to minimize these challenges.
- Emergency situations may arise (such as weather-related disasters or extended power failures) which may prevent you from doing dialysis; there are precautions you can take in advance and emergency procedures you can follow.

NOTES:

Chapter 3

Diet and dialysis

“When you’re on dialysis and limited to what food you can eat, try to focus on what you CAN have and be glad for that. I sometimes didn’t even look at the list of high potassium foods, instead focusing on the low potassium list.” - Jan

Chapter 3

Diet and dialysis

Eating the right foods when you're on dialysis can be challenging, but you can still enjoy good food. In this chapter we explain the changes you may need to make in your diet to 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.

How is healthy eating different on dialysis?

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 ***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
- Lentils, legumes

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'll also have access to the meal planner tool.

Phosphorus (phosphate)

Phosphorus is a mineral that keeps your bones strong and healthy but tends to build up in people with reduced kidney function. Almost all foods have phosphorus, but some foods have much more than others. Most people on dialysis will likely need to limit their phosphorus intake to reduce phosphate build-up in the blood. Dialysis removes only a small amount of phosphate from the blood. Too much phosphorus in the blood may lead to weak bones, itching, and even calcification of the soft tissues of the body. You cannot avoid all phosphorus in your diet but you can reduce how much high phosphorus food you eat. *You should avoid all foods with phosphate additives because they are the most easily absorbed.*

Too much phosphorus may cause:

- Itching
- Joint pain
- Hardening of blood vessel walls
- Weak bones

NOTE:

Phosphates from natural sources (meat, dairy, legumes, grains) are less easily absorbed into the blood than phosphate food additives. *Speak to your dialysis team about the phosphate target that's right for you.*

Read the labels

Check the ingredient list for words that include “phosphate” or “phosphoric” such as:

- Hexametaphosphate
- Monocalcium phosphate
- Phosphoric acid
- Sodium acid pyrophosphate
- Sodium aluminum phosphate
- Sodium phosphate
- Sodium tripolyphosphate

If your phosphate levels are high, limit foods high in phosphorus by avoiding foods with phosphate additives, including:

- ‘Seasoned’ meats
- Soft drinks (colas, dark sodas and some iced teas)
- Fast food
- Processed meats and cheeses
- Limit dairy products (milk, cheese, yogurt, ice cream)
- Limit nuts and seeds

Milk substitutes

Milk substitutes (including oat, rice and almond beverages without added phosphate) can often be used to replace cow’s milk but speak with a dietitian first to see if these products are right for you.

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 for best results.

See **Chapter Two: Dialysis**, the section called “Chronic kidney disease – mineral and bone disorder (CKD-MBD)” for more information about phosphorus.

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. Constipation can also contribute to high levels of potassium. Your dialysis team will help you determine the right amount of potassium for you.

My target ranges

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.

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 and vegetables. Dietitians used to suggest that people with limited kidney function avoid whole grains, such as whole wheat bread. But guidelines around whole grains have changed. Recent studies suggest the potassium in whole grains is not absorbed by the body as much as previously thought. That means you can keep eating whole grain bread, pasta and rice unless advised otherwise by your healthcare team.

NOTES:

Here are some tips to help you reduce potassium in your diet:

- 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. There are new ways to remove potassium from foods like potatoes. See instructions at kidneycommunitykitchen.ca.
- Processing makes potassium easier to absorb. Choose whole foods more often and limit juices and other ultra processed foods.
- Limit milk and dairy products to ½ cup per day.

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 fact sheets and information about potassium and kidney disease.

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. A high fiber diet and regular bowel movements can also help your body eliminate some potassium in your stool.

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. of 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.

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 2000-2300mg 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.

NOTES:

Read the labels
Choose products with less than 10% of the Daily Value for sodium. Check the list of ingredients for salty items and for words that include “sodium” such as:

- Monosodium glutamate (MSG)
- Sodium benzoate
- Sodium bicarbonate
- Sodium phosphate
- Sodium saccharin

Limiting fluids

In addition to limiting sodium intake, some people need to limit their fluid intake. If you must limit your fluid intake, a dietitian can help you work your fluid allowance into your daily eating plan.

NOTES:

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, which are extra calories. *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.

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. You may need to decrease your insulin, or other hypoglycemic agent. Speak with your diabetes team about how to do this safely. 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.

NOTES:

Chapter 3

Diet and dialysis

How a dietitian can help you

Making changes to the foods you eat can be difficult and sometimes stressful for you and your family. It often requires that you change your eating habits including what you eat, how much you eat, how often you eat out and where you eat out. A registered dietitian specializing in kidney nutrition can help you. You should also speak with a dietitian if you:

- Are losing or gaining weight
- Have difficulty making shopping or cooking decisions that fit with your diet
- Have more than one diet and need help putting them together; for example, if you also have diabetes
- Are in the pre-dialysis stage or are receiving conservative kidney management

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 conservative kidney management.
- 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.
- Another good resource is the Kidney Community Kitchen at kidneycommunitykitchen.ca.

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.

Chapter 4

Kidney transplant

"I went from receiving dialysis three times a week in hospital to having the time and energy to finish school. Because of my transplant, I've had the opportunity to build a career, travel the world, get married and start a family."- Manuel

Chapter 4

Kidney transplant

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 transplants:

- 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"

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. You should also have a flu shot and keep other vaccines up-to-date as needed. Don't forget to repeat your transplant blood work and tests as directed, so that your transplant file is kept up-to-date.

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.

NOTES:

Chapter 4

Kidney transplant

Before being considered for a kidney transplant, whether living or deceased donor, all potential recipients (person receiving the kidney) 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.

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.

Live donor transplant

A ***live donor transplant*** is when a kidney from a living donor is transplanted into your body. Live donor transplants tend to last a little longer than transplants from deceased donors. This is usually because a live donor kidney is healthier and there is often a better genetic match because extensive testing is done beforehand. In addition, the transplant can be planned for the best time for both the donor and the recipient. It may even be possible to receive a transplant before needing to go on dialysis: this is called a ***pre-emptive transplant***.

Compatibility is a key factor in determining whether your body will accept or reject a donated kidney. Therefore, the most suitable donors are often members of your immediate family, such as your sibling, child, or parent. If a member of your immediate family is not available, you can also seek out other living donors who may be compatible, regardless of whether they are related to you or not. In any type of transplant, the blood group of the donor must be compatible with the blood group of the recipient. If the donor's blood group is compatible with the recipient's, a second blood test called ***tissue typing*** is done. This test will determine if the kidney donor and the intended recipient are a 'match' (they have the genetic similarities to ensure the greatest chance of a successful 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 someone else on the waiting list who is a match. In turn, the original 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 Kidney Paired Donation program is available on the Canadian Blood Services web site at organsandtissues.ca.

Living kidney donors

People who donate a kidney can live a normal life with one kidney and it can be a very rewarding experience. However, this is a big decision for most people. Donating a kidney involves personal sacrifice. A donor faces the usual risks of surgery and is unable to resume normal daily activities for an average of four weeks after the surgery, although this varies from person to person. The transplant team will provide advice and follow-up on the amount of recovery time needed.

Some transplant centres are able to offer minimally invasive laparoscopic surgery (also known as keyhole surgery) for kidney donors. With this less invasive procedure, the surgical scar is smaller, there is less pain after the operation and recovery is quicker for the donor.

Living organ donor expense reimbursement

Living organ donor expense reimbursement is designed to reimburse (pay back) living organ donors and potential living organ donors for their eligible expenses related to the assessment, surgery and recovery phases of the organ donation process. For more information contact your local Kidney Foundation of Canada office to find out if there is a reimbursement program offered in your province/territory.

Tips for talking about living organ donation

It can be very difficult to ask someone to consider donating a kidney to you. You might worry that the donor's health will be affected or that you are being a burden to your friends and family. A good way to start exploring this option is by educating yourself about living donation and transplant so that you will be prepared when you start sharing your story with people and explaining the options available to you. Tell as many people as you can (it's easiest to start with your family and closest friends) about your failing kidneys, how a transplant will help you, and how most healthy people can donate a kidney. Focus on educating people about your situation and the options available rather than asking them to donate to you. Ask your kidney social worker or members of your healthcare team for more tips on talking to people about living organ donation. Perhaps a friend or family member can help out and raise awareness of kidney donation on your behalf.

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 provide 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.

NOTES:

Chapter 4

Kidney transplant

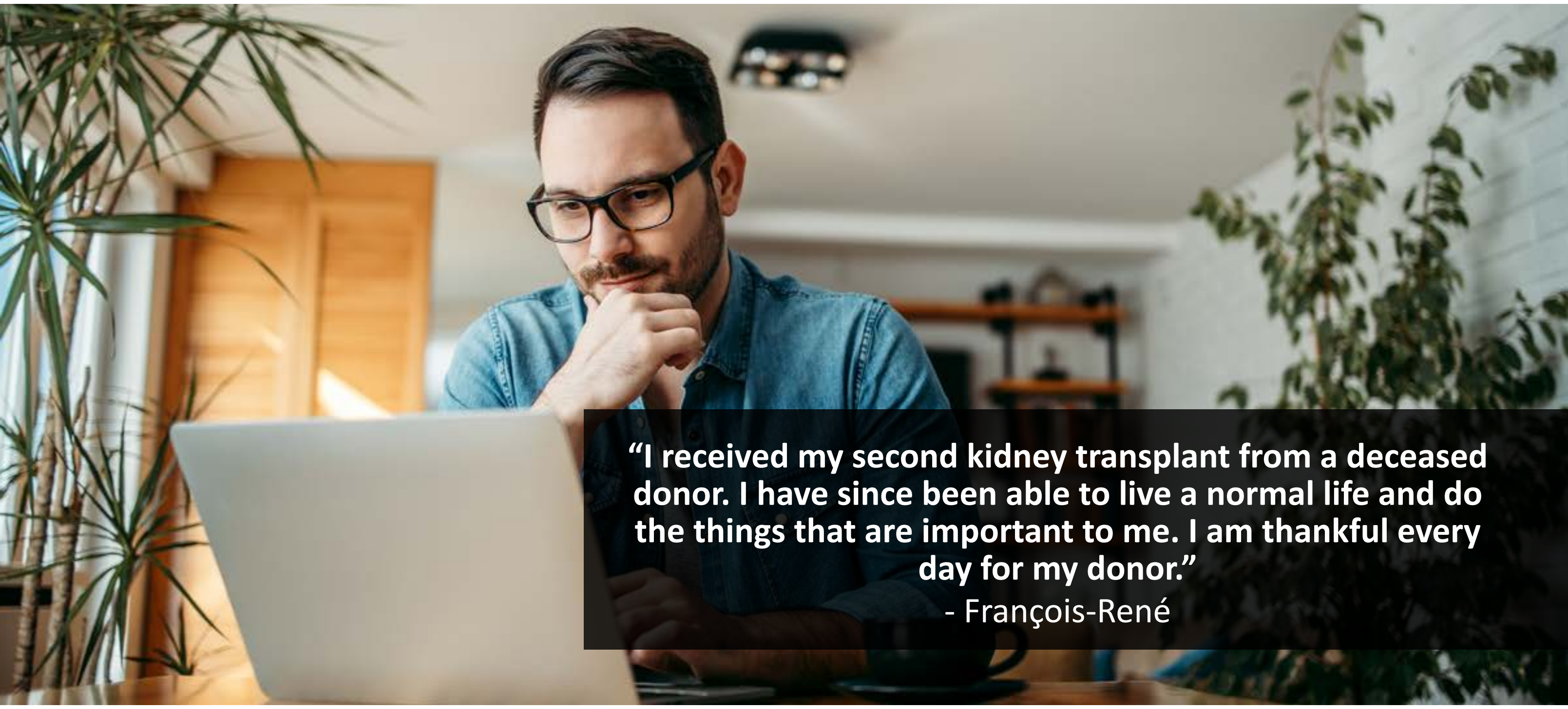
Deceased donor transplant

A transplant from a deceased donor is also called a ***non-living*** or ***cadaveric transplant*** (although this last term isn't used much anymore). 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, but in most places in Canada it is several years.

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.

Before any transplant, some of your blood and some of the donor's cells are mixed together to see if your blood will damage or kill the donor's cells. This is called a ***cross match*** and is done to make sure there are no substances in your blood, called ***cytotoxic antibodies***, that may cause your body to reject the transplanted kidney. While you are on the transplant waiting list, a sample of your blood is periodically collected to determine the level of cytotoxic antibodies. These levels can change over time and affect your ability to receive a transplant.



"I received my second kidney transplant from a deceased donor. I have since been able to live a normal life and do the things that are important to me. I am thankful every day for my donor."

- François-René

Chapter 4

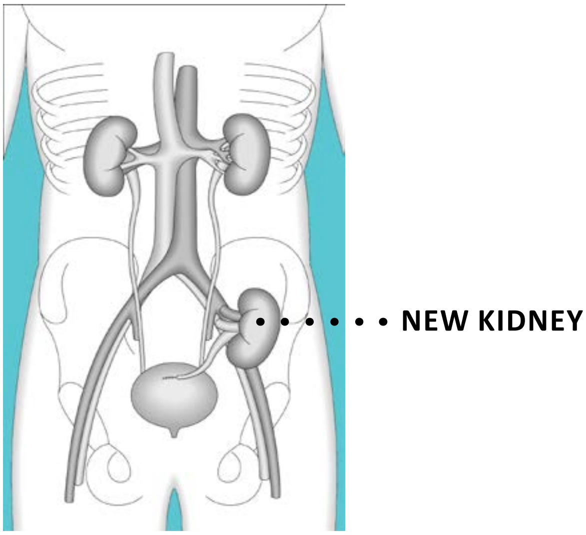
Kidney transplant

What is involved in transplant surgery?

The transplant operation usually takes two to four hours. The new kidney and ureter are placed in the lower abdomen near the groin and are attached to your blood vessels and bladder. A catheter is placed in the bladder for a few days to drain the urine made by the new kidney.

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.



LOCATION OF TRANSPLANTED KIDNEY

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.

NOTES:

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.

Signs of rejection

- Decrease in urine output
- Increased ankle swelling
- Pain over the transplant area
- Fever
- General feeling of being unwell
- Increase in ***creatinine*** level

It is hard to say how long a transplanted kidney will last. Many factors influence its long-term functioning. Some kidneys have lasted as long as 25 years or more. On average, about half of transplanted kidneys are still working 10 years later. If the transplanted kidney stops working, you will need to go back on dialysis. The transplanted kidney is often not removed. You may be considered for another kidney transplant, depending on your personal situation.

IMPORTANT

If you experience any of the signs of rejection, tell your doctor immediately.

Chapter 4

Kidney transplant

“My transplant team and mentor encouraged me to use the dosettes to put my weekly meds in, and this has been an excellent tool for me to make sure I am taking the best care of my new kidney.” - Jan

Anti-rejection medications

Why anti-rejection medications are needed

After an organ transplant, many types of medication are given to lower the body’s immune system so that the transplanted organ is not rejected. These medications are called anti-rejection medications, ***immunosuppressants*** or transplant medications.

After an organ transplant, you’ll need to keep taking your anti-rejection medications for as long as the transplanted kidney is working. You should not miss any doses because it puts you at risk for rejection of your transplant.

NOTE

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

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.

NOTES:

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 laboratory to get your levels checked before or after visits to the transplant clinic.

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.

NOTES:

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 is important for your transplant team to know if you are having any side effects from the anti-rejection medications.

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 antivirus medications to prevent serious viral infections.
- Wash your hands often and thoroughly with regular soap and water.
- Avoid being around people who are sick.

On the next page 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 in the chart. 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

	Azathioprine	Cyclosporine	Mycophenolate	Prednisone	Sirolimus	Tacrolimus
Increased risk of high blood sugar or diabetes*				X		X
Low blood cell count	X		X		X	
Increased appetite and weight gain**	X		X		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 your dietitian to discuss the foods you can and should eat after the transplant.

NOTES:

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.

Important

Here are come 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 is 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.

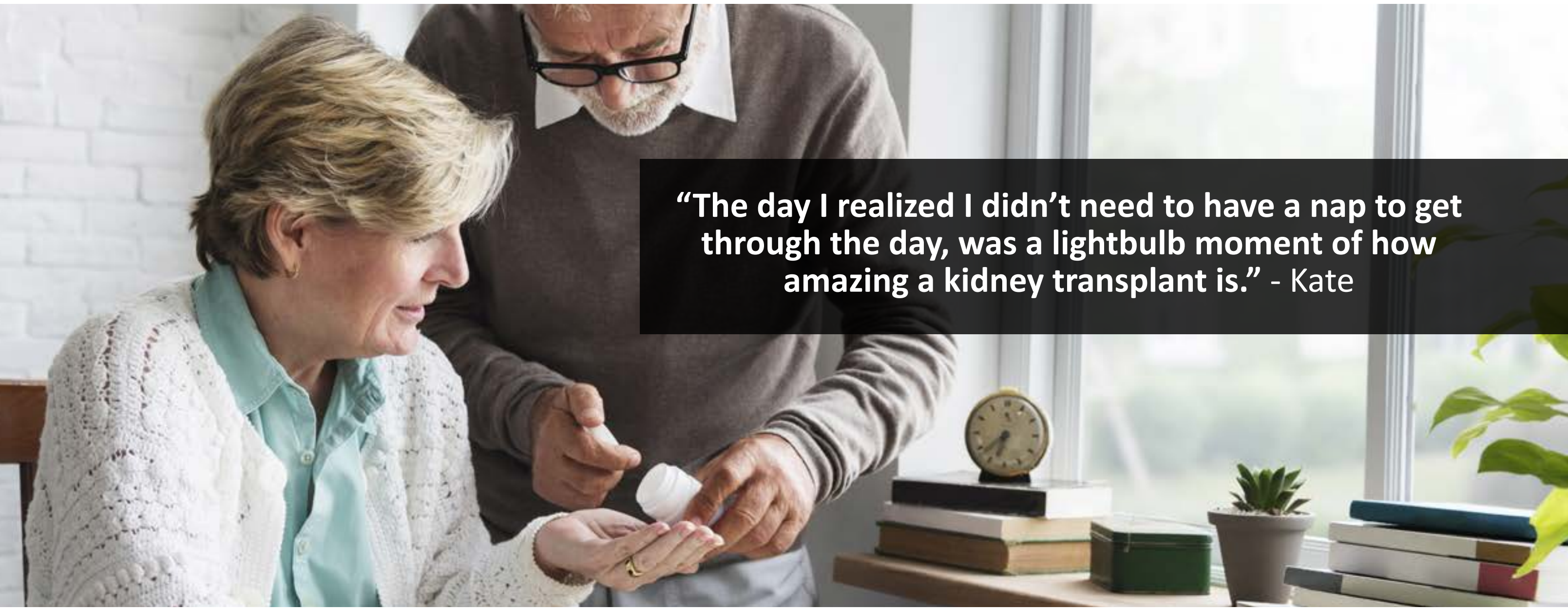
When any doctor or pharmacist prescribes a medication or other treatment for you, always make sure they have considered your transplanted kidney and the other medications you are taking.

NOTE

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.

Chapter 4

Kidney transplant



“The day I realized I didn’t need to have a nap to get through the day, was a lightbulb moment of how amazing a kidney transplant is.” - Kate

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.

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.

TRAVEL TIP

If you travel after your transplant, bring an extra supply of medications in case your travel plans change. Always keep your medications in the original containers with labels that come from the pharmacy. Carry your medications with you in your carry-on bag. You may also consider keeping another set of the same medications in your check-in luggage, as a back-up in case you lose your carry-on.

See **Chapter Eight: Living well with kidney failure** for more information about travel-related topics.

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.

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.

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.

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.

FOOD SAFETY

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

General recommendations for good health after a transplant

- Wear a Medical ID bracelet that identifies you as the recipient of a kidney transplant. If you feel you cannot afford one, speak to your social worker about the Medic Alert assistance program.
- 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.

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.
- 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.

Chapter 5

Conservative kidney management

Chapter 5

Conservative kidney management

Conservative kidney management is an active treatment choice in which kidney disease is managed with medication and diet, with no plans for a transplant or dialysis. It involves treating the symptoms of kidney disease, preventing and managing problems, protecting the remaining kidney function, and supportive medical and psychosocial care. This type of kidney care is for patients with end-stage kidney disease who would prefer not to include dialysis as part of their treatment plan.

If you choose conservative kidney management either because you decide not to start dialysis or because you've decided to stop, you will receive high quality medical care. The goal of conservative kidney management 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.

Why do people choose conservative kidney management?

Some people choose this type of care because they have other life-threatening medical conditions, are not candidates for a transplant, and/or feel the burden and discomfort of dialysis outweigh the potential benefits. They decide that conservative kidney management is a reasonable choice for them because they will receive supportive physical and emotional care right up until the end 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. Your healthcare team can help you rule out depression and other issues that may be influencing how you feel. 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.

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.

NOTES:

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 your health and quality of 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. Choosing not to go on dialysis is a personal decision based on what is most important to you.

Dialysis trial

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. Your healthcare team may be able to provide an estimate as to how much time you have left if you decide to stop dialysis. However, each person is unique, and it is difficult to predict when death will occur.

If you choose conservative kidney management

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 if that is what you wish. 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 sodium you take in to avoid fluid build up and breathing difficulties. Medication is always available to help manage any pain you may have. Machines like respirators will not be used.

If you have done advance care planning, you might want to review your wishes. If you have not, read **Chapter Six: Advance care planning**. It provides a more complete list of questions for you to think about.

Questions to ask yourself

- Have I looked at other options before considering conservative kidney management?
- If I choose conservative kidney management, 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, and further information. 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 depression.

Regardless of your treatment choice, it is the quality of your life 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.

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. 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.

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 conservative kidney management, and later for end-of-life care. In particular, your social worker will have details about local resources.

NOTE

Choosing conservative kidney management 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.

Summary

- Conservative kidney management 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.
- Specialized physical, emotional and spiritual care is provided to patients towards the end of their lives.
- 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.

Chapter 6

Advance care planning

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Advance care planning

Regardless of your 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.

Increasingly, advance care planning is becoming part of routine healthcare.

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.

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 own wishes.

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 would want.

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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Some facts about advance care planning

- 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 participate in a process of advance care planning.
- You will want to review your wishes 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.
- You can change your mind about any of your wishes at any time.

Questions to think about while doing your advance care planning

Advance Care Planning 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, even if leads to a poorer quality of life. Other people may not want treatments that would prolong their life if death is imminent, 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.

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Advance care planning

No one likes to think of a time when serious illness or injury may happen, or a time when we may not be able to communicate for ourselves. But if the unexpected happens, knowing your wishes and feelings may help your loved ones make decisions on your behalf during a difficult time. While it is impossible to anticipate every eventuality, there are some vital questions you can ask yourself:

- What are my hopes, values and beliefs?
- What is my understanding of end-of-life care and specific medical procedures?
- Would I want, or not want, certain medical interventions (for example, resuscitation, feeding tubes or dialysis) if I am unlikely to survive or live independently?
- Why would I want, or not want, these procedures?
- What is important to me? Communicating with my family and friends? Mobility? Independence?
- What if I can't return home; do I have a plan?
- Do I have any fears about dying (e.g., I will be in pain, or not be able to breathe)? Is there someone I can speak with about these fears, such as my doctor?
- 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 comfort care or sometimes ***palliative 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 their 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.

Here are some questions about end-of-life care to think about:

- 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?

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 is often better to have these discussions while you are 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.

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 plan once it is finished.
- While you are working on your advance care planning, it is sometimes helpful to discuss your questions with your doctor. That way, you can make sure you are working with accurate information about possible treatments, etc. Most people will also consult with their spouse, partner or a close family member while they're working through this process. You don't have to do this planning alone, but you can make all your own decisions.
- 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 your kidney healthcare team and/or others involved in your care (i.e., home care) are aware of your wishes.
- You should review and re-evaluate your wishes 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 for Property:** 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. In some jurisdictions, the person holding *Power of Attorney* for Property is also responsible for personal care.
- **Power of Attorney for Personal Care:** This document is similar to a regular *Power of Attorney* but in this case, one in which you identify a Substitute Decision Maker who you authorize to make personal and healthcare decisions for you, if you are unable to make these decisions yourself or to communicate them. A *Power of Attorney for Personal Care* is part of advance care planning. Depending on your province/territory, it may be called an advance directive, personal directive, or proxy.
- 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 websites, bank machines/ATMs, etc.
- 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

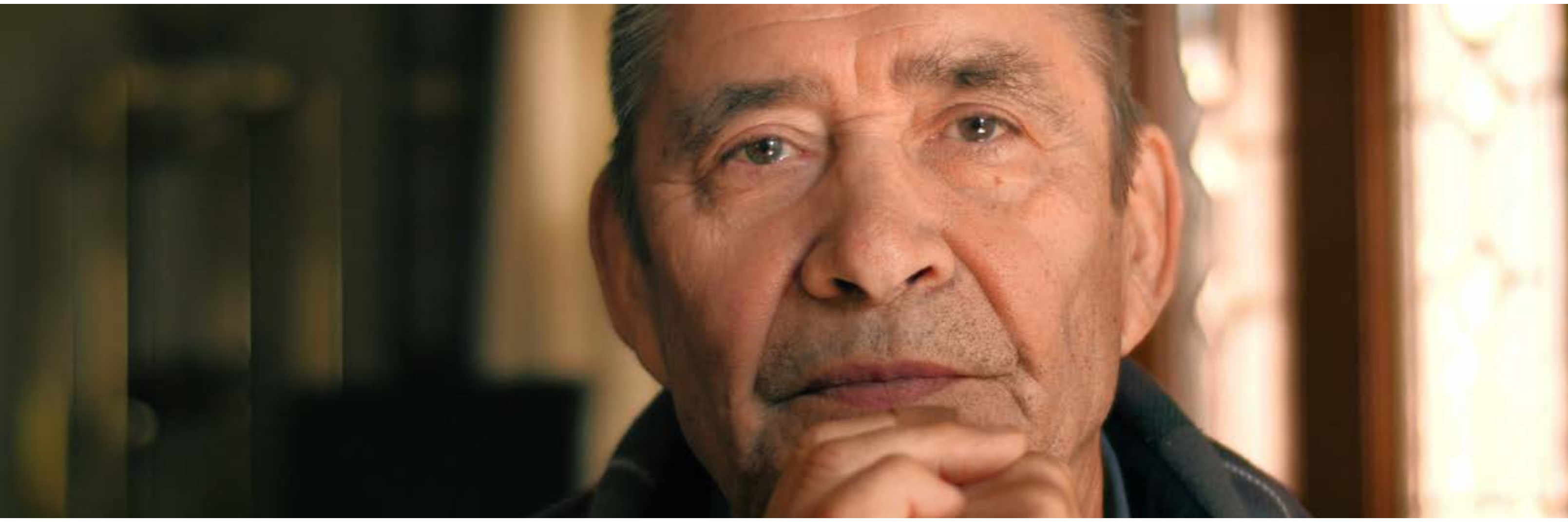
There are specific national and provincial organizations that specialize in advance care planning such as advancecareplanning.ca and you can find them by searching online. You can also get information from your social worker or your local Kidney Foundation office. This information may include brochures,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

What if I am considering Medical Assistance in Dying (MAID)?

Medical assistance in dying refers to a doctor or nurse practitioner helping an eligible person to voluntarily end their life. The person must meet certain criteria to be eligible for this option. You do not need to stop dialysis to have medical assistance in dying and you can have help to decide about other services such as end-of-life care. If you are thinking about medical assistance in dying, talk about it with your doctor or healthcare team.

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.



Chapter 6

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 are unable to make decisions about your healthcare treatment or if you are 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.

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Chapter 7

Work, money and insurance

Chapter 7

Work, money and insurance

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.

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 and working

The type of treatment you're receiving may affect your ability to continue working. Some types of treatment, such as home dialysis, 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.

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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.

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.

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 prescription 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.

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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.

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 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.

NOTES:

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. Your social worker will be able to help you determine which program you may be eligible for and will also be able to help you with the paperwork needed.

NOTE

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

Resources for caregivers

Employment Insurance (EI) provides three types of caregiving benefits. The first is Compassionate Care Benefits. It is for 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.

The second is Family Caregiver Benefits for Adults. It allows people to be away from work temporarily to care for a critically ill or injured family member who is over 18. You may qualify for this benefit if you are assisting a family member with training for home dialysis, or if you need to be home to care for a loved one for an extended period of time.

The third benefit is called the Family Caregiver Benefits for Children. This program allows people to be away from work to care of a critically ill or injured person under 18. More information is available at servicecanada.gc.ca.

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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 social worker, your local Kidney Foundation office or the website at kidney.ca.

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 website at cra-arc.gc.ca or your local tax services office, or by calling the CRA.

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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, for 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.

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 another 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.

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 website at cra.gc.ca or speak to your financial advisor.

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.*

NOTE

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

NOTES:

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:
    1. Do you have experience helping people with kidney disease or other chronic illnesses?
    2. 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, the agent can more easily check with another.

Travel insurance

- Make sure you understand all the exclusions and limitations of any policy. For example, most insurance policies have restrictions with respect to pre-existing conditions. They may 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 (usually 3 to 6 months). 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.

NOTE

Keep in mind that most travel insurance policies will **not** cover the cost of hemodialysis sessions outside of Canada. This is because dialysis is an ongoing medical treatment related to a pre-existing condition (kidney disease).

NOTES:

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.

Life insurance

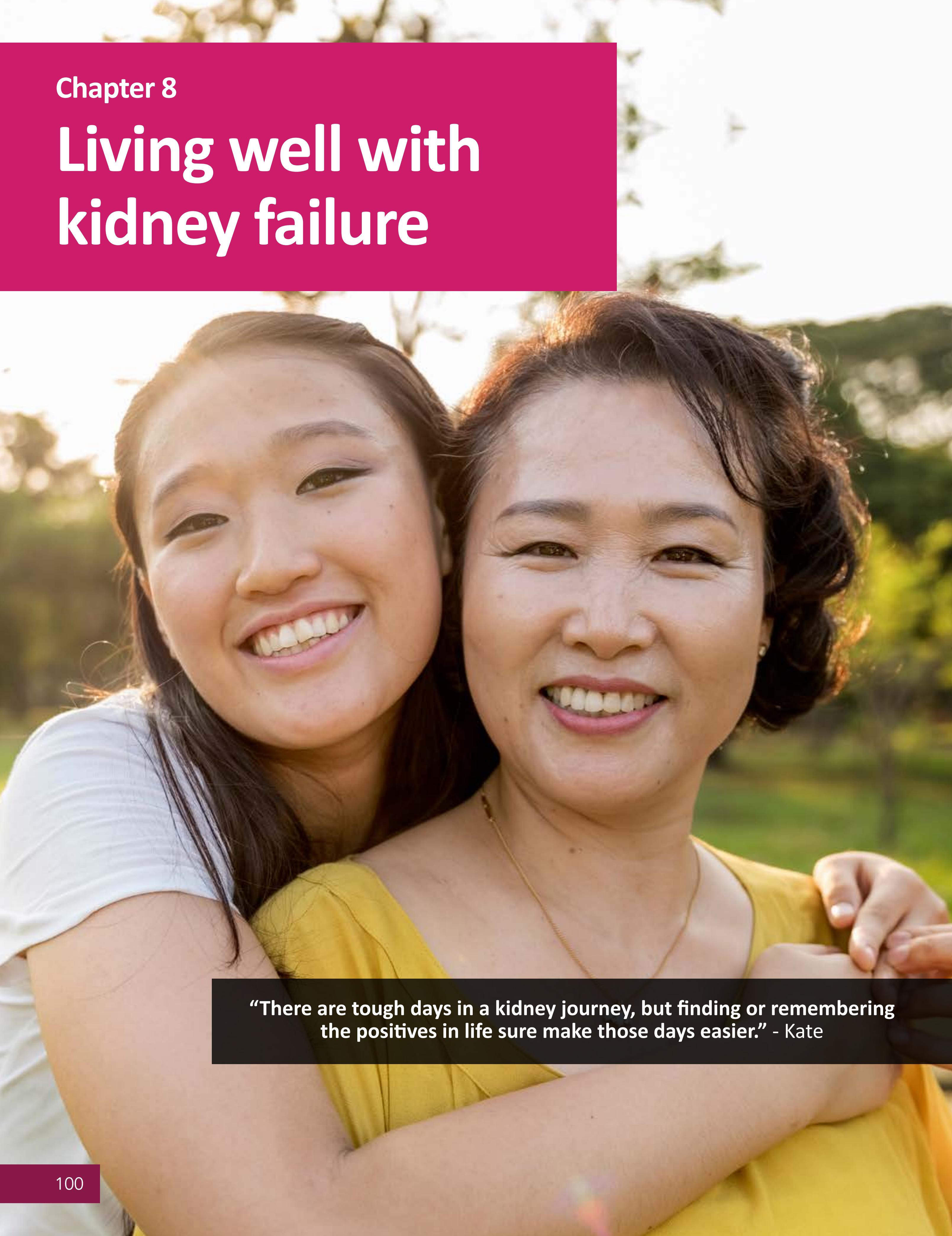
- If you belong to a workplace life insurance plan, you may be able to take your group life insurance with you, even if you switch employers.
- Do not apply and then wait and see if you are declined – it will go on record. A better option is to have your insurance agent or broker explore coverage options 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 are 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 the loss of company insurance benefits and sometimes people may feel a loss of self-esteem.
- If you are 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.

Chapter 8

Living well with kidney failure



“There are tough days in a kidney journey, but finding or remembering the positives in life sure make those days easier.” - Kate

Chapter 8

Living well with kidney failure

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 are going to discuss several aspects of emotional and physical well-being. We will also look at sexuality and fertility, the importance of getting enough physical activity, 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.

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.

NOTES:

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.

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.

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.

Dealing with depression and anxiety

Many people are shocked to find out their kidneys have failed. The thought of having regular dialysis - perhaps while waiting for a kidney transplant, perhaps for years ahead - may lead to feelings of anxiety and depression.

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. Family and friends may not know how best to offer support, which can lead to feelings of loneliness for kidney patients.

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 is a good idea to speak to healthcare team members. Depression can be effectively treated. Your social worker is there to help make this transition as smooth as possible.

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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.
- 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

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.

It is important to recognize that you may be more prone to being irritable, and you'll need to find ways to help lessen the tension so you don't take out your frustrations on those you love and others.

What should I tell my children?*

Children can often sense when something isn't right. Therefore, it is important to discuss your illness and treatment openly with your children at a level they can understand. By explaining things to your children in a clear, age-appropriate way, you can help prevent them from developing fears and wrong ideas about what is going on. For example, sometimes children blame themselves for their parent's illness or they may dwell on 'terrible' things they have done or said. This can cause problems in the future.

Often, children may begin to behave differently after the parent is diagnosed with kidney failure. Sometimes they begin to act like "little adults" or "perfect angels". Other times, they begin to misbehave and have problems in school. These are ways children cope with a parent's illness and their fears about that illness.

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

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.

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.

See **Chapter Seven: Work, money and insurance** for more information about employment-related issues.

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 best and would be a good person to answer this question.

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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.

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.

The first step is a medical examination to determine if the problem is physical. This may be followed by a referral to a social worker, psychologist, psychiatrist, specialist nurse or sexologist to look at non-medical factors. Frequently, many people feel better just knowing they are not alone. It's reassuring to hear that other people have similar problems and that these problems can be solved.

Counselling and education often follow the assessment. Learning how to speak more openly with your partner and express your personal needs more clearly can often reduce anxiety and improve your sexuality. Doctors may also prescribe medications, lubrications or special devices that can help with dryness or impotency. Asking for help is the first step to solving the problem.

What can I do for myself?

There are lots of things you can do to change how you feel about yourself. Taking extra care with personal grooming is one. A different hairstyle or some new clothes may improve the way you view yourself. When you feel good about how you look, you feel better overall.

Thinking of sexual intercourse as the only real sex act may cause you unnecessary distress if you have limited desire or energy. Sexuality doesn't have to include intercourse. There are many forms of sexual expression that don't require as much energy and are enjoyable. Simply hugging, kissing and caressing can make you feel better and improve your outlook.

If you're a little shy, books can be a good source of self-help information. Bookstores and libraries often have whole sections covering every imaginable aspect of sexuality. Browse through them – you may find a book that will help you with your concerns.

Most importantly, don't ignore the problem. If you're not satisfied with your sexuality, try to talk about it. A positive attitude is important to physical health.

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Frequently asked questions

Here are answers to some frequently asked questions about chronic kidney disease as it relates to sexuality and childbirth.

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.

Because of the uncertainty about whether you are able to become pregnant or not and if you want to use birth control measures, all forms of birth control are safe. Please discuss with your family doctor or kidney healthcare team which form of birth control may be best for you.

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 when you feel ready to do so. After a transplant, you may have more energy for intercourse because your uremia and anemia will have resolved. 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 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. If you do not wish to become pregnant, please discuss the most appropriate form of birth control for your particular circumstance with your transplant team.

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

Vaccines

Flu vaccine: It is recommended that all people with chronic kidney disease (CKD) and end-stage kidney disease (ESKD) receive a flu vaccine once a year in the fall unless your healthcare team advises otherwise.

Pneumococcal (pneumonia) vaccine: It is recommended that all people with CKD and ESKD receive the pneumococcal vaccine to prevent severe forms of pneumonia. This is given once and then repeated in five years.

Hepatitis B: You may need to be vaccinated against Hepatitis B – a virus that can cause liver damage – if there is a plan for hemodialysis and/or a kidney transplant in the future. Hepatitis B can be spread through blood and the hemodialysis procedure involves cleaning your blood.

Covid-19 Vaccine: It is recommended that everyone diagnosed with CKD and ESKD receive the recommended doses of the Covid-19 vaccine. Kidney disease is a risk factor for more severe complications of Covid-19, such as hospitalization and death.

TIP: Check with your healthcare team about these vaccinations to help ensure your health and safety. There are some special considerations for kidney transplant recipients.

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 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.

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.

If you feel up to it, you may want to consider adding long walks to your weekly routine, or bike rides and swimming. Not only are they fun to do, but these activities will help you better manage your blood pressure. The 150 minutes per week 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.

There are some people - such as the elderly, those with multiple other medical problems, or some people receiving dialysis – who 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.

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“Your mental health is just as important as your physical health. You are not alone. Your family, friends, health care providers, and organizations such as The Kidney Foundation are there to support you.” - Manuel

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 spending 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.

Travelling with a kidney transplant

Here are some tips to help make your travels successful:

- Some of the anti-rejection medications you take can 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). Ensure that you get the appropriate vaccinations for your destination.

NOTE

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 is over a period of time before travelling.

Travelling while receiving peritoneal dialysis

Travelling while 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. 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.

You will need to arrange transportation for your supplies, including dressings and your cycler, 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.

NOTE

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

Travelling while receiving hemodialysis

If you are travelling while on hemodialysis, this will involve booking dialysis sessions at a healthcare centre at, or near your travel destination. 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 to many places around 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 different 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. You may also be responsible for covering the cost, or part of the cost, of dialysis sessions on your trip. Your hemodialysis unit can help you with your travel questions.

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.

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.

NOTES:

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.

It is a good idea to check with your doctor or members of your healthcare team before finalizing any travel arrangements. Both your home dialysis unit and the unit you will be visiting need to do a lot of work to help you have your vacation. They will really appreciate it if you are courteous and flexible in your dealings with them.

Tips for travelling on hemodialysis

- Confirm your hemodialysis schedule a few days before your trip.
- Contact each unit again a day or two before you arrive.
- Give each unit a phone number where you can be reached in case the unit has an emergency and needs to reschedule your treatment.
- Arrive at the unit on time. Schedules are very tight and delays will affect the people who regularly dialyze there.
- Respect the rules for each unit; for example, some units ask that there be no visitors.
- If you are uncomfortable with certain techniques, discuss this right away with the nurse. Most units will do everything they can to make you feel comfortable.

Cruises and resorts

A few companies offer cruises especially for people on hemodialysis. They have fully-equipped hemodialysis units on board, staffed with qualified medical and nursing personnel. Even though these cruises are usually expensive, they offer a unique chance to travel. The point of departure is usually an American city, although many Alaskan cruises leave from Vancouver. Cruises are also available in the Mediterranean, Baltic Sea, Southeast Asia and other areas.

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 is 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 is full. It is always a good idea to have a major credit card so you can buy a direct flight home if you have to.

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 be able to provide guidance in this area.

See **Chapter Seven: Work, money and insurance** for more insurance tips, including travel insurance.

Chapter 8

Living well with kidney failure

"I am so thankful for the invention of dialysis treatment, for kidney donors, for the healthcare professionals, for having a strong will and for the support of family and friends. While on my kidney journey, I have been and continue to have a productive and very fulfilling life!"

- Peggy

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 enjoy. 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 on hemodialysis, as long as suitable preparations are made well in advance of travelling.

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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.

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

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

Cholesterol
A type of fat found in most body tissues.

CKD-MBD *Chronic kidney disease - mineral and bone disorder*
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 Kidney Management
An active treatment choice in which kidney disease is managed with medication and diet, with no plans for a transplant or dialysis.

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.

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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.

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 the ankles or lungs) due to sodium and water retention.

NOTES:

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

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Hemoglobin
The protein in red blood cells that carries oxygen.

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 who may be related or un-related to the recipient.

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Membrane
Porous material used to filter wastes from the blood.

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.*

Palliative care
Supportive care and symptom management provided to patients and their families from time of diagnosis with a life-limiting illness through to end-of-life 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 foods. The kidneys regulate it in 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.

NOTES:

Glossary

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.

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.

Substitute decision-maker

A person you know well and trust, whom you appoint to make healthcare decisions on your behalf in the event you become unable to; this person is usually appointed as part of your advance care planning process.

Target weight

The body weight that is “targeted” after extra fluid is removed during dialysis. When all of the body’s extra fluid is gone, this is the dry weight.

Tissue typing

Laboratory test to determine the genetic makeup of a person. Used to ensure compatibility of a kidney before transplant.

Ultrafiltration

Process in which blood entering a dialyzer is placed under pressure to remove excess water.

Vein

Blood vessel returning blood to the heart.

Medications

This chart lists some medications used in treating various aspects of kidney disease and kidney failure. This handbook does not discuss all the medications that can be used for kidney disease. If you have questions about specific medications, please ask your primary care provider and/or kidney doctor.

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

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Medications

GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
CALCIUM POLYSTYRENE SULFONATE	Resonium Calcium®	Exchange resin/hyperkalemia (or high potassium)
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	Eprex®	EPO/anemia
EZETIMIBE	Ezetrol®	Cholesterol absorption inhibitor/cholesterol
FELODIPINE	Plendil®	Calcium channel blocker/blood pressure
FERROUS GLUCONATE		Iron/anemia
FERROUS SULPHATE		Iron/anemia
FERROUS FUMARATE		Iron/anemia

NOTES:

GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
FERUMOXYTOL (INTRAVENOUS)	Feraheme®	Iron/anemia
FLUVASTATIN	Lescol®	Statin/cholesterol
FOSINOPRIL	Monopril®	Angiotensin-converting enzyme (ACE) inhibitor/blood pressure
FUROSEMIDE	Lasix®	Diuretic or water pill/fluid build-up
HYDROCHLOROTHIAZIDE		Diuretic or water pill/fluid build-up
HYDROXYZINE	Atarax®	Antihistamine/rash or itching
IBUPROFEN	Advil®	Analgesic/pain or fever **often not recommended for people with kidney disease or transplant. Check with your kidney healthcare team before taking these over-the-counter medications.*
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

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Medications

GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
METOLAZONE	Zaroxolyn®	Diuretic or water pill/fluid build-up
METOPROLOL	Lopresor®	Beta-blocker/blood pressure
MYCOPHENOLATE	CellCept®	Anti-rejection
NADOLOL		Beta-blocker/blood pressure
NAPROXEN	Aleve®, Naprosyn®	Analgesic/pain or fever **often not recommended for people with kidney disease or transplant. Check with your kidney healthcare team before taking these over-the-counter medications.*
NIFEDIPINE	Adalat XL®	Calcium channel blocker/blood pressure
OLMESARTAN	Olmetec®	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

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Medications

GENERIC NAME	SOME COMMON BRAND NAMES	TYPE/USE OF MEDICATION
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
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

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Medications

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Feedback page

Your feedback is important.

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 kidney.ca/kidneyfailurehandbook/evaluation.

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

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Thank you in advance for your comments.

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kidney.ca

Our Vision

Excellent kidney health, optimal quality of life for those affected by kidney disease, and a cure.

Our Mission

The Kidney Foundation of Canada is the leading charity committed to eliminating the burden of kidney disease through:

- Funding and stimulating innovative research for better prevention, 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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