

Hemodialysis Education Handbook

LAUNCH



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Introduction

What is this hand book about?

Members of your healthcare team at London Health Sciences Centre have written this book for you. The Kidney Foundation of Canada has an excellent education resource, Living with Kidney Disease, Book Two, which provides new dialysis patients with a wealth of information including Treatment Options, Dialysis, Dietary and Nutritional supports, Transplantation, Palliative Care and Advanced Care Planning and ways to live well with kidney disease. The purpose of this education handbook is to provide specific education resources for patients on dialysis within the Renal Care Program at LHSC. The education materials will align with the chapters of the Living with Kidney Disease Book 2 and will guide your decisions throughout your journey with kidney disease. The colours of each chapter in this handbook will be similar to those of the chapters outlined in the Living with Kidney Disease Book 2.

At the end of each chapter a series of questions are provided for you. These will help you decide whether you have enough information to make an informed decision about each chapter or topic. This will also provide you with an opportunity to make notes for future reference or identify additional questions you may need answered. Please use this handbook in a way that works best for you. We encourage you to share this material with family, friends and those who are close to you. You are welcome to have these people involved in any or all of the discussions you make with your renal team.

Chapter 1

Options

Dialysis patients may or may not have had the time or opportunity to learn about their options prior to starting dialysis. This resource will allow you to further discuss your options with your renal team. We will work together to ensure you have all of the required resources to make the best decisions regarding your life with renal disease. As you have started dialysis; this may have been planned or more urgent than you anticipated, now is an ideal time to think about your values and understanding your kidney disease/dialysis and what it means to your quality of life. You are welcome to attend our monthly chronic kidney disease classes at the Kidney Care Centre at Westmount Mall, London Ontario. The information at the classes will help you better understand your kidney disease and options. If you wish to attend please contact your renal team for future dates and times of the classes.

The LHSC Renal Care Program Dialysis Nurse Case Manager is available to provide further education resources that will assist you with future decisions about your options such as type of dialysis and transplantation. You may contact the Nurse Case Manager at 519-685-8500 ext. 75606.

Chapter 2

Home Hemodialysis

Many people can learn to do home hemodialysis (HHD), with a few weeks of training. Our program will allow home HD without a partner. This is because doing longer and/or more frequent HD treatments gets rid of most of the symptoms (like muscle cramps, headaches, nausea, etc.) that occur during standard in-center HD.

You do not have to buy the machine; the center supplies it and trains the patient and a partner to do the treatments. With home HD, the center has someone on call 24 hours a day to answer questions.

It is possible to do home HD three times a week for a few hours, just the way it is done in-center. But this type of home HD is much less common now. Having a 2-day gap in HD treatments is hard on the heart. In fact, two large studies have shown that sudden death from heart failure is twice as likely on the day after the 2-day dialysis “weekend.” So, at a minimum, most people who do HD at home do it every other day.

These days, home HD is most often done as short daily treatments (5 to 7 times per week for 2+ hours a day) or overnight treatments (at night for 8 hours or so during sleep, 3 to 6 nights per week, so days are free).



Reasons You Should Consider Home Hemodialysis

- You can control your own schedule at home, so it is much easier to keep your job, care for children or an aging spouse or parents, etc.
- You are less likely to get an infection at home than in the hospital.
- You can do more dialysis at home, so you feel much better have more energy, and fewer symptoms.
- This makes it easier to plan ahead and know that you'll be able to do what you want to.
- When you get more dialysis, you have fewer diet and fluid restrictions. In fact, you may not have any diet or fluid restrictions —and you may not have to take (and pay for) as many medications.
- With more HD, your blood pressure is likely to be normal, which can protect your heart from left ventricular hypertrophy (a type of enlargement that is the leading cause of death in people on dialysis).
- With more HD, your blood chemistry levels are closer to normal all the time, which may help prevent long-term problems like neuropathy (nerve damage), amyloidosis (build-up of a waxy protein in the joints, tendons, and bones), and bone disease.
- When you do your own dialysis, you gain vital knowledge about how to care for yourself that will build your self-esteem and win you the respect of medical staff.

Patients who choose home hemodialysis like the freedom of choosing their own schedules and being in charge of their treatments:

“My wife has assisted my dialysis treatments at home for the past one and a half years. As a result of being able to determine the time of my hemo sessions, I have been able to work full time despite hemodialysis. When I feel that I need it, I have dialyzed more often or for longer periods of time.

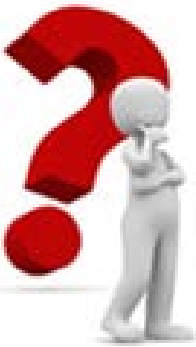
During the past one and a half years, I have felt great!” –James

There's No Place

Like Home



London Health Science Centre's renal program hires a plumber to make the appropriate connection changes to your home or apartment's plumbing to accommodate the hemodialysis machine.



Questions?

- Has anyone from your renal team talked to you about home hemodialysis?
- Do you feel you have enough information to make an informed decision whether or not to do home hemodialysis?
- Would you be interested in visiting the home hemodialysis unit at the Kidney Care Center at Westmount Mall?
- Can you tell me any barriers you may have that would not allow you to do dialysis at home?

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Peritoneal Dialysis

What is Peritoneal Dialysis?

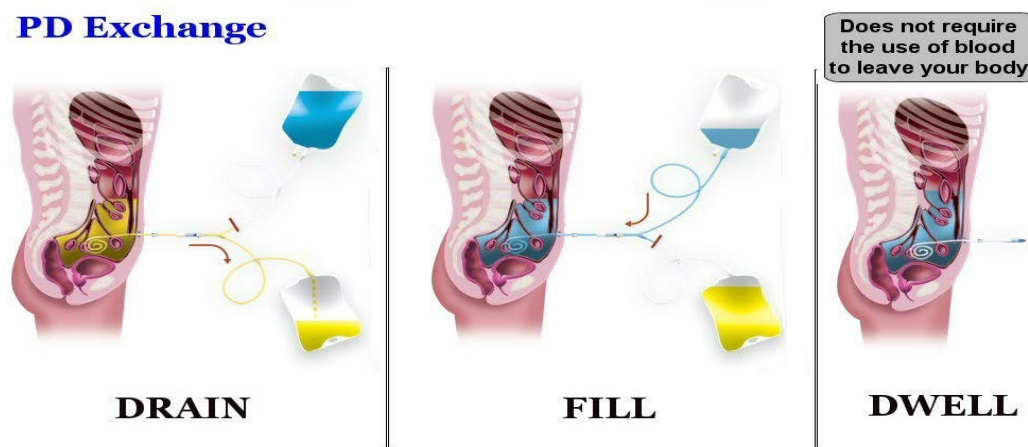
Peritoneal dialysis is a type of dialysis that works inside your body. Peritoneal dialysis uses your body's own peritoneum to filter your blood. Everyone has a peritoneum. It is like a thin stretchy “bag” which holds your stomach, intestines, liver and other organs in place.

Your peritoneum has a good blood supply. The thin stretchy sac has a lot of blood vessels around it. With peritoneal dialysis, waste products and extra water are cleaned out of the bloodstream through the peritoneum.

How does Peritoneal Dialysis work?

In peritoneal dialysis, special fluid called dialysate flows inside your body and into your peritoneum through a catheter. This catheter is a small tube, about the size of a pencil, made of soft flexible rubber. The tube is surgically inserted through your skin near your belly button. The other end of the catheter is inside your peritoneum, in what is called the peritoneal cavity. This catheter is used to drain dialysate into and out of your peritoneum. The dialysate inside your peritoneum works 24 hours a day, 7 days a week to remove the waste products and extra fluid from your blood. Dialysis is the next best thing to having your healthy kidneys working to clean your blood. To do peritoneal dialysis, you will need to do “exchanges” every day. An exchange consists of draining the old dialysate fluid out of your peritoneum and replacing it with new fluid. In other words, you are “exchanging” the old fluid for new fresh fluid. It is not painful, and you will have plenty of training to learn how to do exchanges yourself.

PD Exchange



How does Peritoneal Dialysis clean the blood?

Peritoneal dialysis uses your body's own peritoneum to filter, or clean, your blood. Your peritoneum has a good blood supply. The thin stretchy sac has a lot of blood vessels around it. During peritoneal dialysis, waste products and extra water are cleaned out of the bloodstream through the peritoneum. Your blood is constantly moving throughout your body. All your bodies' blood supply passes through the vessels around the peritoneum over and over throughout the day. So, as time passes, eventually all of your blood gets cleaned.

Why do waste products and extra water go into the dialysis solution?

The dialysis solution put in your peritoneum is made with millions of tiny chemical substances. These are the same substances, called "electrolytes" and "minerals," that are found normally in your blood. Electrolytes and minerals are things like sodium, potassium, and calcium. There are electrolytes and waste products naturally in the blood, and electrolytes put in the solution. They are separated by the peritoneum, which acts as a filter.

These electrolytes float through the tiny holes in the peritoneal membrane from one side to the other. They always float from the-side that is crowded with electrolytes to the side that is less filled up. The blood has too many substances, because your kidneys are not filtering the blood, and it needs to be "cleaned". For example, there is more sodium in the blood than in the new solution. So, the tiny sodium pieces will slowly float over into the dialysis solution. This natural process is called diffusion, and you won't even feel it happening inside you at all. Eventually there will be equal amounts of sodium in the blood and the solution on each side of the membrane. This takes about four hours. That is when you drain out the solution, put fresh solution with less electrolytes into the peritoneum, and the process of electrolytes moving across to the solution begins again.

This process of substances moving from the more crowded side (the blood) to the less filled side (the solution) happens with each of the different types of electrolytes in the blood all at the same time. The process of diffusion stops after a while when the two sides of the membrane become equally crowded. That is why you have to put in new solution every four to six hours.

Water in the blood moves into the solution in a similar way. There is more water in the blood so it floats through the tiny holes in the membrane over into the dialysis solution. There is sugar, in the solution to make even more water move into the solution than naturally happens. Sugar has a special way of attracting, or "pulling",

DIALYSIS

water from one place to another. If you put sugar on cut-up strawberries or a potato cut in half, it will pull extra water out of them, too. Using sugar to pull off water is called osmosis, and it is a very natural process. The water that moves into the solution is called ultrafiltration.

The more sugar used in the bag of dialysate, the more water that is pulled from the blood. That is why you use a 4.25% (the highest strength) bag if you have extra fluid in your body. This process will happen inside you without feeling it at all. After about 4 to 6 hours, water stops moving out of the blood, and may even start going back into the blood. This “back-filtration” (water going back into the blood) is not good, because then your body is still left with too much water in it. That is why you need to change the solution after 4 to 6 hours (8 hours overnight).



Concentrations of sugar (glucose) in your dialysis fluid will determine how much fluid comes off your body. The higher the glucose, the more fluid can be removed from your body. If you are diabetic, we will need to work closely to maintain good blood sugar readings.

DIALYSIS



Cycler



Twin Bag

What Kinds of Peritoneal Dialysis are there?

There are two types of Peritoneal Dialysis:

1. CAPD (Twin Bag)
2. APD (also called CCPD, or cycler)

Both types of peritoneal dialysis allow for continuous dialysis. The fluid is always in your peritoneum, so it is always cleaning your blood, the way your kidneys would if they could. Because PD is a continuous form of dialysis, you can usually eat and drink most of the same things you did before your kidneys failed.

Your doctor and nurse can help you decide which type of peritoneal dialysis is best for you. This is done by doing simple tests on the fluid approximately 6 weeks after you are finished training. This is called a PET test.

Type 1 - CAPD stands for Continuous Ambulatory Peritoneal Dialysis. This is the type of peritoneal dialysis where you do exchanges four times a day, seven days a week.

An exchange consists of several steps. What are these steps? (hint see page 6.)

1. **Drain.** This means letting the dialysate fluid which is inside your peritoneum drain out through your catheter. The fluid has been in your peritoneal cavity, cleaning your blood, for about 4 to 6 hours. To let this fluid out of your body, you attach a long thin tube and open a clamp. The fluid, which is now filled with waste products and extra water, drains by gravity into an empty bag which you put on a clean surface below you. Draining normally takes about 20 minutes. You can be reading, watching TV, or resting while you are draining.
2. **Fill.** This means letting new fresh fluid fill up your peritoneum. First, you will attach a new bag of dialysate, and hang it higher than your head. You can use a hook on a wall, or an IV pole. Then you open a clamp on another long thin tube and the fluid runs through the catheter and into your peritoneum. This also works by gravity, and takes about 10 minutes. Your nurse will show you exactly how to do this. After you have filled, you just go on with your normal daily activities.
3. **Dwell:** This means letting the fluid stay inside your body, inside your peritoneum, continuously cleaning your blood. It is during this dwell time that the dialysis is working. You will have fluid dwelling in your peritoneum for about 4 to 6 hours (overnight - 8 hours) before you do another exchange and put fresh solution into your peritoneum. You may notice the fluid inside you a little bit at first. After you've been doing PD for a few days you probably won't even notice it anymore.

What does CAPD stand for?

- C** Continuous: Dialysis fluid is always inside your peritoneum cleaning the blood. This happens continuously, except for the short time while you drain solution in and out.
- A** Ambulatory: This means that between exchanges you are able to move around and go about your normal activities. That means that you are ambulatory.
- P** Peritoneal: This type of dialysis uses your body's own peritoneum to clean the blood.
- D** Dialysis: Dialysis is the process of removing waste products from the blood.

Type 2 - A.P.D.

APD stands for Automated Peritoneal Dialysis. This form of Peritoneal Dialysis uses a machine to perform your exchanges every night while you sleep. (This therapy is sometimes called C.C.P.D. which stands for Continuous Cycling Peritoneal Dialysis.) After you set it up, the machine will automatically warm the solution, fill your peritoneum with the right amount of solution, allow the solution to dwell in your peritoneum for the correct amount of time, and then drain your peritoneum. This all happens while you are sleeping. You will usually have several cycles of drain, fill, and dwell through the night.

Your nurse or doctor will program your cycler to give you exactly the kind of treatment you need. You can also learn how to make changes in your treatment schedule by programming the machine at your house.

On APD, you will get all the exchanges you need during the night. Before you get up in the morning, some patients will have the cycler fill them with an amount of solution they will keep in their peritoneum all day. This is called the “daytime dwell”.

How does a cycler work?

The machine you will use is called a cycler because it automatically “cycles” fluid in and out of your peritoneum. On APD, you only have to set up the machine once before bedtime, connect the tubing set to your transfer set, and the machine does all your exchanges while you sleep. Then, when you wake up, all you do is disconnect from the tubing set. Some people may need to do an exchange during the day if required, but your doctor will decide this.

Setting up the cycler involves loading the machine with solution bags (usually 2 or 3 bags), and a disposable cycler set. This special cycler set has tubes that carry the solution from each of the bags, and to and from your peritoneum.

First, you set up the cycler with bags of Dianeal and cycler tubing.

Next, you attach all of the Dianeal bags to the cycler tubing. You need to be careful not to contaminate the sterile outlet ports on the bags or the end of the cycler set tubing. The cycler primes the tubing automatically and tells you when it is ready.

After some practice, most people can set up their cyclers in about 20 minutes. If you have problems with your vision, or have a difficult time doing your own exchanges, your nurse can teach someone in your family to set up the cycler at night for you.

More and more patients are choosing APD because it's easy to do and gives you daytime freedom from doing exchanges. Your doctor can determine if APD will work for you.

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Travelling with Peritoneal Dialysis

The portability of Peritoneal Dialysis (PD) makes travelling easier than with other forms of dialysis. It is possible to carry your own supplies for short trips and have them pre-delivered for longer trips.

Plan your trip with your clinic and PD supplier in advance. Some of the preparations you need to consider before you travel include:

- The type of dialysis you will use when you are away (APD or CAPD – many people who use APD switch over to CAPD for travel)
- The electricity current at destination if using APD (discuss with dialysis technologist if different from North American voltage)
- The amount of required supplies you need while you are away, including how much you would need in transit
- The cost of delivering your supplies to your destination, if any
- Medical documents, including medication list, for Customs as well as in case of emergencies
- Knowing where the closest hospital is to your destination
- Finding out if a close hospital has a Nephrology (kidney) department familiar with PD
- Medications. Check with your clinic if you are to bring extra medications such as antibiotics, heparin, ESAs Such as Eprex™ or Aranesp™
- The need for vaccinations and medical insurance

Getting Ready for Peritoneal Dialysis (PD)

If you have expressed interest in PD the following document will outline your process. Here is some important information to assist you in preparing to start Peritoneal Dialysis (PD).



The Road to Peritoneal Dialysis:

1. PD Unit Assessment/ Interview at the Kidney Care Center at Westmount Mall. Once you have chosen PD contact your Nephrologist/ Nurse Practitioner or your Nurse Case Manager.
2. Once you decide PD is an option for you will receive a consultation appointment with Dr. Jain (PD nephrologist). At this appointment you will find out if you are a candidate for either a percutaneous or a surgical PD catheter insertion.



3.

Candidate for Percutaneous PD catheter insertion (Dr. Jain)
Done in X-ray

Candidate for Surgical PD catheter insertion (Surgeon)
Done in the operating room

4. A plan will be made with you to start peritoneal dialysis

1) PD Unit Assessment/ Interview

- We encourage you to ask a family member or friend to attend PD appointments with you! We welcome questions!
- A PD Nurse will orientate you to the PD unit and share with you what a PD lifestyle will look like. You will be shown a PD machine, PD catheter and supplies.
- The PD nurse will talk with you to complete a short interview. This will to help identify any challenges you may encounter, as well as supports you may benefit from.
- You will meet our Social Worker who will discuss community supports that are available to you.
- Our goal is to help support you toward a successful PD experience!
- We encourage you to discuss this with your family/friends and significant others to determine if PD is the right dialysis choice for you.
- Contact your Nephrologist, Nurse Practitioner or Nurse Case Manager once you have made a decision.

2) PD Consultation appointment with Nephrologist (Dr. Jain)

- The purpose of this appointment is to determine if you are a candidate for PD catheter placement one of two ways: percutaneously or surgically. Dr. Jain will review your PD unit assessment/interview, perform a short physical exam, and review your health history to determine which method of insertion is best for you.--A percutaneous insertion is done in the Radiology/X-Ray department where you will receive sedation through an intravenous/IV. A surgical insertion is done in the Operating room and requires a general anesthetic.
- You will meet a Dialysis Access Nurse Case Manager who will talk to you about the PD insertion procedure and make the arrangements for your PD catheter insertion whenever you are ready to start dialysis. You will receive written information outlining what to expect regarding your PD insertion.
- If you are a candidate for a percutaneous PD insertion, you will be asked to a sign consent form. Dr. Jain will discuss timing of the PD insertion with you.
- Alternatively, if you are a candidate for a surgical PD insertion, you will be referred to a surgeon. Note: If you are not on dialysis yet, you will be referred to the surgeon 3-4 months before your nephrologist feels you need to start dialysis. If you are already on hemodialysis the referral to the surgeon will be sent right

away. You will be contacted with a consultation appointment to see the surgeon. You will receive a date for surgery when you see the surgeon.

- Your nephrologist may have asked you to attend this appointment even though you may not need to start dialysis yet. Your plan for dialysis will be kept in your file for reference for when the time comes that you need to start dialysis.
- Having a dialysis plan in place before you need to start dialysis is optimal and proactive!

3) If you agree to proceed with PD a future plan will then be made with you to have your PD catheter inserted and to start peritoneal dialysis.



Questions?

- Have you had a discussion regarding peritoneal dialysis with your Nephrologist, Nurse Practitioner, Nurse or anyone in the renal team?
- Do you feel you have enough information/education to make an informed decision about peritoneal dialysis?
- Have you ever met our peritoneal dialysis team at the KCC at Westmount Mall?
- What barriers do you foresee that may prevent you from proceeding with peritoneal dialysis?

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Choosing the Best Vascular Access

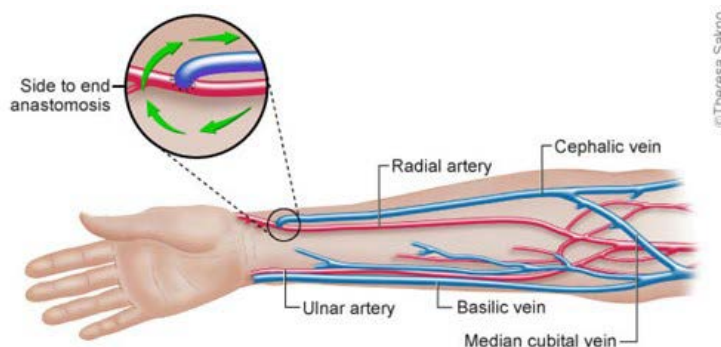
Everyone is encouraged to speak to your Nephrologist, Nurse Practitioner, Vascular Access Case Manager, and dialysis nurses about the best access for you. Once you have agreed to talk to a surgeon about your options a referral will be sent to our Vascular Surgeons (at Victoria Hospital). The following information will help outline your journey before and after your vascular access is created.

What is an AV Fistula or Vascular Access?

A vascular access is needed to continuously take blood to the hemodialysis machine to be cleaned and returned to the body. An arteriovenous or AV fistula is the preferred choice for vascular access when feasible.

Fistula

The AV fistula is created by a surgeon who connects a vein to an artery in your arm. This vein becomes bigger and stronger, allowing blood to flow from the body to the dialysis machine. To perform hemodialysis, two dialysis needles will be inserted into this big vein which is the AV fistula. Your vascular access team will assess the size and suitability of your veins and arteries to make a well-functioning AV fistula.



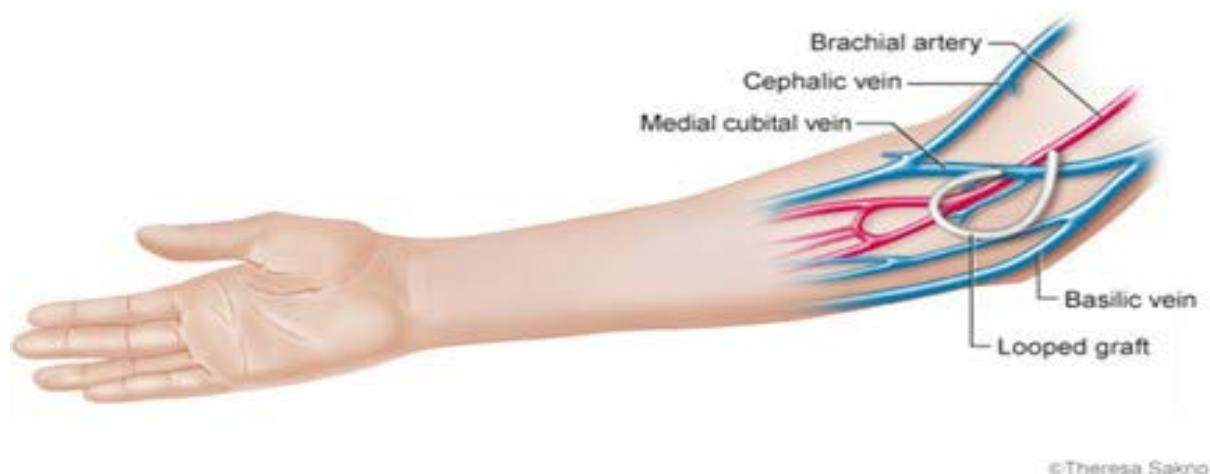
An AV Fistula

- Sits under your skin either in your lower or upper arm
- Can be created in either your right or left arm
- Usually take 8-12 weeks to develop
- May not develop enough to be used for dialysis
- May require procedure(s) to help them keep it working
- Is usually created several months before starting dialysis

- Uses your vein and your artery - no synthetic tubing needed
- Is associated with a lower risk of infection compared to AV grafts and catheters

Graft

An arteriovenous or AV graft is made when the veins are not suitable for an AV fistula. The AV graft is a form of vascular access which is created by inserting a synthetic tube to connect a vein to an artery. Two dialysis needles are inserted into the AV graft for each hemodialysis treatment. Your vascular access team will assess the size and suitability of your veins and arteries to make a well-functioning AV graft.

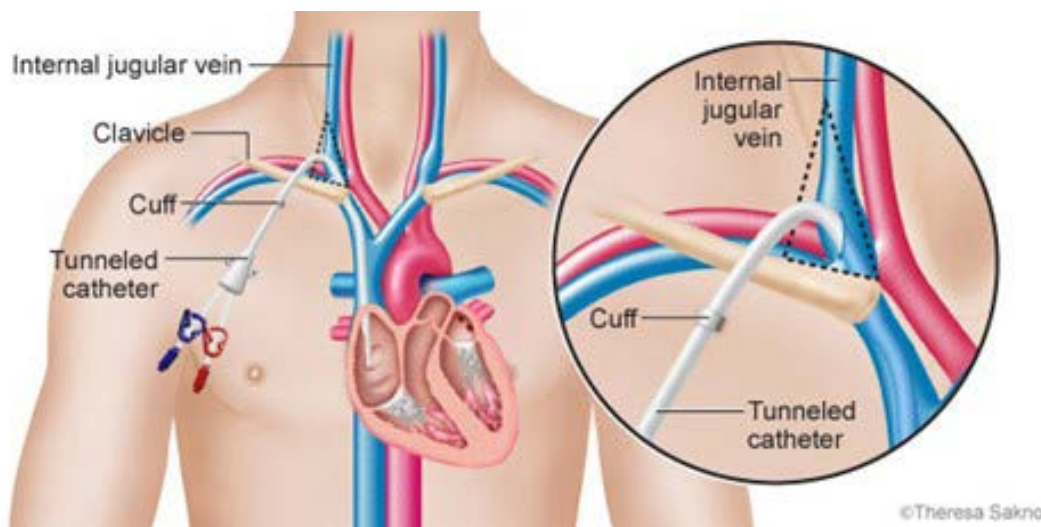


An AV Graft

- Is made of synthetic material; one end is attached to a vein, the other to an artery
- Sits under your skin either in your lower or upper arm
- Can be created in either right or left arm, or in the leg
- Can be ready for use in days to weeks depending on the type of AV graft you have
- Is an option for patients who do not have veins for AV fistulas
- Is associated with a lower risk of infection compared to catheters, but with a higher risk of infection compared to AV fistulas
- Has a risk of clotting
- May require procedure(s) to keep it working

Catheter

A catheter is a flexible, hollow tube inserted into a vein in the neck, chest, or groin that rests in the heart and allows blood to flow from the body to the dialysis machine. A dressing is used to cover the area where the catheter exits the skin.



A Catheter

- Is used when hemodialysis is required urgently, for temporary use or while waiting for an AV fistula or an AV graft to be made
- Is used in patients who do not have veins or arteries suitable for an AV fistula or AV graft
- Is associated with a higher risk of infection compared to AV fistulas or AV grafts
- Requires frequent interventions (i.e. insertion of a new catheter) to improve blood flow
- Has a higher risk of narrowing or clotting of veins
- Patients with catheters cannot go swimming or submerge in tub



Questions?

- Have you met with our vascular access team?
- Do you feel you have enough education or resources to feel confident making a decision about a vascular access?
- Do you know who to ask for more information about vascular access?

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Getting Ready for Access Placement

Here is some important information to assist you in preparing for your access placement.



The Road to Surgery:

Clinic consult appointment → pre-admit → surgery post op care

Consult appointment with vascular surgery:

- You will be contacted by the access team with an appointment date to see the surgeon, this is strictly a consultation
- There, you will meet with a nurse who will take your history and talk to you about different access options available
- You may have an ultrasound of your arm veins done while you are in clinic
- The surgeon will discuss the best access options for you

A few weeks before surgery:

- You will be contacted by the surgeon's office with your Pre Admit appointment date. This is generally two weeks prior to your surgery. They will also call you about your surgery date. If either of these fall on a dialysis day, please let your dialysis unit know.

What to expect during your pre admission appointment:

- Bring all of your medications with you. They will give you instructions regarding which medications to take on the day of surgery
- You will have an ECG done
- You will be seen by either one or both an anesthetist and a medicine doctor who will declare you fit to have surgery
- You may have blood work taken or if you are on dialysis, the dialysis unit will take your blood work closer to your surgery date

What to expect the day of surgery:

- You must have NOTHING TO EAT OR DRINK AFTER MIDNIGHT

- You will be asked to shower using a Chlorhexadine Gluconate 4% wash
- You will be asked to arrive 3 hours before your scheduled surgery time. This is to ensure that you are prepped for surgery
- The nurse may:
 - Take your vital signs: including your temperature, blood pressure, pulse and your breathing rate
 - Take blood work for tests
 - Start an IV: a small tube is placed in your vein for giving medication or liquids
 - Use a pulse Oximeter: a little clip is connected to your finger, ear or toe, this machine measures the oxygen in your blood

After Surgery:

- In most cases, you will go home the same day as your surgery
- The site will have a bandage to keep the area clean and prevent infection
- You may remove this bandage in 24-48 hours, please follow your discharge instructions. Cleanse the incision area with warm water, dry thoroughly and reapply light gauze or a large Band-Aid.
 - Note: Dissolvable stitches are most often used. Non dissolvable stitches or staples (if used) will be taken out in the dialysis unit or at the follow up appointment with the surgeon, depending on your surgeon's preference
- Avoid bathing and soaking the incision line for 1 week. You may shower and reapply the bandage following your shower
- Avoid heavy lifting or straining on the operative arm for 1 week
- After the surgery the nurse will use a stethoscope or their fingers to check the flow in the new access
- Prior to discharge, the nurse will show you how to check the fistula/graft for a thrill or buzz
- At 2-3 weeks after surgery you may start exercising your affected arm if the incision is well healed. Before you leave the hospital, you will be given a squeeze ball and instructions on proper exercises to perform at home
- You may be given a prescription for pain medication

- You may put ice in a plastic bag, cover it with a towel and place it over the incision for 15-20 mins. 20 mins on 20 mins off. Treatment with ice is most useful if started right after surgery and used for 24-48 hours to reduce swelling.
 - For any other questions or concerns contact: 519-685-8500 extension 55762



Call your Doctor/Nurse Practitioner if you notice any of these ANYTIME!...

- Your incision is swollen and red or you see any pus. These could be signs of infection
- You develop a high temperature
- Your stitches come apart
- Your bandage becomes soaked with blood
- You no longer feel the 'buzzing in your arm'
- The fingers or toes below the fistula or graft turn blue, go pale, or feel cold

How Do I Care For My AV Fistula?

- Keep all dressings dry after your AV fistula has been made.
- Check for the vibration or thrill over your AV fistula at least once a day.
- Avoid wearing anything tight over your AV fistula.
- Avoid resting anything heavy on your AV fistula.
- Do not allow blood to be drawn, blood pressure taken or intravenous lines to be placed in the arm that your AV fistula was made.
- There is no restriction to most usual activity once the surgical site has healed.
- Elevate your arm if you develop any swelling in the same arm as your AV fistula and notify your vascular access team.

Once We Are Using My Fistula What Do I Need To Do Before Hemodialysis Treatment?

- Wash your AV fistula arm with soap and water.
- Wash your hands when you arrive in the dialysis unit.
- Talk to your dialysis nurse about learning to needle yourself.
- Encourage your dialysis nurse to rotate your needle sites at every dialysis treatment.

What Do I Need To Do After Hemodialysis Treatments?

- Wear gloves when holding your needle sites.
- Do not scratch or remove scabs.
- If your AV fistula starts to bleed after dialysis, apply gentle pressure using a clean towel/gauze. If the bleeding continues, keep applying pressure and go to the nearest Emergency Department.
- Contact your dialysis team if you do not feel a thrill over your AV fistula or if your AV fistula is red, oozing fluid or painful.

AGAIN IT IS VERY IMPORTANT TO: Inform your dialysis nurse of any numbness, tingling, weakness, discolouration, coolness or pain in your arm or hand (on the same sides as your AV fistula). The colour and temperature of your fingers should be the same in both hands.

Chapter 3

Nutrition and Dialysis

What are the keys to healthy eating on dialysis?

1. Eat the amount of protein recommended on your meal plan.
2. Avoid foods high in phosphorus and potassium.
3. Avoid salt and salty foods. They will make you thirsty and make it more difficult to limit your fluid intake.

With a few changes in your usual diet, you can have a wide variety of healthy and tasty meals whether dining at home or in restaurants. The dietitian will help you individualize your meal plan.

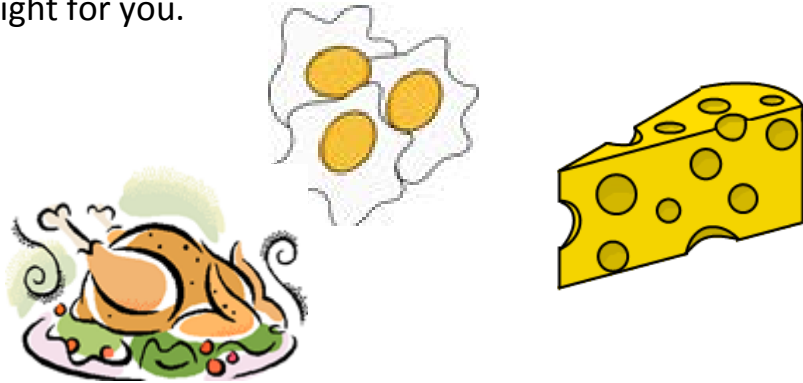
Why do I need to eat plenty of protein?

Protein is needed for growth, repair and fighting off disease and to replace protein lost during dialysis.

You will need to eat more high protein foods than you did before you started dialysis. The dietitian will set up a nutrition plan just for you. Your meal plan will tell you how much protein is right for you.

Foods high in protein are:

- Meat
- fish
- poultry
- eggs
- cottage cheese
- hard cheese
- peanut butter



Refer to your Nutrition and Dialysis poster for individualized meal plan.

Why may I need to restrict certain foods?

Some waste products are not removed very well during dialysis. These include:

- phosphorus
- potassium
- sodium

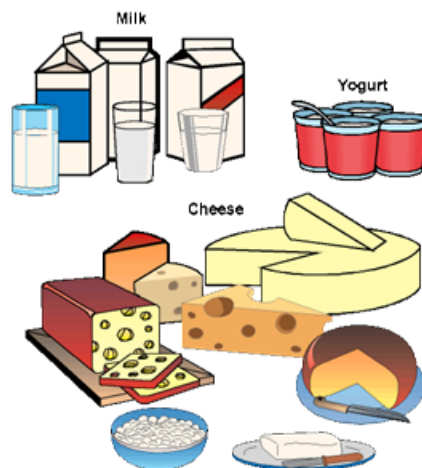
Phosphorus, potassium and sodium come from the food you eat. Making the right food choices helps to control these waste products so they won't build up in your body and make you unhealthy.

Phosphorus:

Over a period of time, extra phosphorus can make your bones brittle. When the phosphorus in your blood is very high, calcium is removed from your bones and teeth. High phosphorus in your blood can also cause your skin to feel extremely itchy.

How can I control my phosphorus level?

1. Take your phosphate binders with your food. Phosphate binders are medications, which help to prevent the absorption of phosphorus from your food. The phosphorus stays in your intestinal tract and is excreted in your stools rather than being absorbed into your blood stream. Phosphate binders include Calcium Carbonate, or Tums, Renagel, Basaljel and Lanthanum Carbonate or Fosrenol.
2. You may need to limit food rich in phosphorus. Refer to your dialysis diet information.



Potassium:

Potassium is needed to keep nerves and muscles working well but too much can be very dangerous. High potassium can cause muscle weakness.

Your heart is a large muscle. High potassium may cause your heart muscle to become weak and to beat irregularly.

High potassium foods may need to be avoided. The dietitian will give you a Nutrition and Dialysis poster with an individualized meal plan.

Sodium (Salt):

Salt holds water in your body. Healthy kidneys regulate how much sodium your body needs to balance water in your body. Because your kidneys cannot do this anymore, it is possible that you can eat too much salt.



Too much sodium can cause your body to hold too much water. This causes fluid weight gain, high blood pressure, swelling in the legs and ankles and difficulty breathing.

If you are having problems with fluid overload, you may need to avoid foods that are high in sodium.

Remember that eating foods high in sodium will make you thirsty. When you are thirsty, it is difficult to limit your fluid intake.

Questions: ?

- Who can help me if I'm not sure if I am eating the right things?
- How can I tell if I am drinking too much fluid?
- What steps can I take to manage my fluid intake?



NOTES: _____

Your food choices make a difference...

Food Group	Daily Total
Meat and Alternatives	
Fruits and Vegetables	
Grains and Starches	
Milk and Alternatives	
Fluids	
Other Foods	

Your dietitian will help you better understand your daily totals

Your nutrition needs are unique to you. The medications you take are prescribed to meet your special needs and your dialysis prescription is tailored to meet your own needs. Your dialysis diet should be designed especially for you to keep you healthy. One diet does not suit everyone. Your dietitian will work with you to develop a personalized nutrition plan that meets your dialysis needs and takes into consideration your food preferences and your living situation. She will help you put together your diets for other conditions, like diabetes, with your diet for dialysis.

Over time, you may have other questions that your dietitian can help you with. Here are some examples:

- Why is my potassium too high?
- Why is my potassium so low?
- What do I need to know to keep my phosphorus within the target range?
- How can I keep my blood sugars from going too high?
- What should I do if my blood sugars go low?
- How can I lose weight while I am waiting for a transplant?
- Can I still eat in restaurants?

Fluid Control

Why do I need to control my fluids?

Healthy kidneys balance the amount of fluid in your body by removing extra water from your blood. When a person drinks large amounts of fluid, healthy kidneys remove extra water by producing more urine. When a person on dialysis drinks fluid, the fluid stays in your body until dialysis removes it. Dialysis will comfortably remove 2 litres of fluid.

How much can I drink?



It is very important that you drink the right amount of fluid. Drinking too much or too little fluid will make you feel sick. If you no longer produce urine, drink 600 mL or 2 ½ cups of fluid per day, at the most. If you do produce urine, drink 600 mL of fluid plus whatever volume of urine you are able to put out each day. Your dietitian or nurse will help you determine the amount you can safely drink.

Fluid Weight Gains:

The amount of weight you gain between dialysis treatments shows how much fluid you have taken in.

1 litre (34 oz.) of fluid = 1 kilogram (2 pound) weight gain

Every litre of fluid you drink results in a weight gain of 1 kilogram between dialysis. The amount of weight you gain between dialysis is from the fluid you drink not the food you eat.

Why do I sometimes feel unwell on dialysis?

If you drink too much fluid, you will need to remove a lot of fluid in a short time on dialysis. This may cause cramps and frequent drops in blood pressure, making your dialysis treatment uncomfortable. Controlling your fluid intake will help to prevent this.



What does "target weight" mean?

Target weight is your weight with no EXTRA fluid in your body. You are not short of breath, your blood pressure is normal, and you have no swelling. This is your weight at the end of dialysis when all the EXTRA fluid has been removed from your body. It is sometimes called "ideal" weight or "dry weight".

Your target weight is the same weight you would be if your kidneys were working and were removing extra fluid.

Can this dry weight change?



This weight may need to be adjusted occasionally if the amount of fat or muscle in your body changes. If you are eating well and you gain body muscle or fat, your target weight will need to go up. If you aren't eating well and you lose body fat or muscle, your target weight will need to go down.

Your blood pressure and how you feel will help the doctor or nurse practitioner make these decisions.

How can I tell if I have too much fluid?

The term fluid overload means too much fluid in your body.

Signs of Extra Fluid:

- gaining more than 2 kg (4 ½ pounds) between dialysis
- puffy skin or swelling around your eyes, ankles, fingers
- shortness of breath
- high blood pressure

Too much fluid in your lungs can be very dangerous. If you are feeling short of breath and can't get enough air, you need to seek medical attention. Extra fluid causes your heart to work harder. This may damage your heart.

How can I tell if I have too little fluid?

Sometimes you may have too little fluid in your body. You may be dehydrated. This could happen if you are sick with the flu. You will lose fluid if you are vomiting and also if you have diarrhea. You may also become dehydrated if you still have a large urine output.

Signs of dehydration:

- you feel dizzy
- your blood pressure is low
- you have a cold sweat

You need to drink more fluid. Sometimes a salty broth works best. Water, apple juice, cranberry juice, ginger ale, popsicles and Jell-O will also give you fluid. You should also lie down. If you continue to feel unwell you should seek medical attention.

Some helpful hints for controlling your fluids:

- Avoid salt and salty foods. They make you thirsty.
- Avoid high blood sugars (if you are diabetic) the best you can.
- Drink only when you are thirsty, not from habit or to be sociable.
- Rinse your mouth with cold water but do not swallow it.
- Use hard candies, chewing gum or lemon wedges to stimulate saliva and keep your mouth moist.
- Try putting lemon juice in your ice cubes or water. The sour taste will quench your thirst.
- Ice may quench your thirst better than water, but needs to be included in your total fluid for the day. Measure the water you use to make the ice cubes.
- Use a small cup or glass. Learn to sip fluids slowly.
- Try to eat well-balanced meals; you will have less desire for excess fluids.
- Try to keep yourself as active as possible. When you are idle you may become preoccupied with a desire for liquid.
- Take your medication with meals or soft foods like applesauce. Save your fluid for something you enjoy.
- Brush your teeth often.
- Eat vegetables and fruit ice cold between meals. Frozen grapes are very refreshing.
- Keep your mouth fresh by rinsing it with mouthwash.

Chapter 4

Renal Transplantation at LHSC

Have you ever wanted to know if you can have a kidney transplant?

Transplantation is the ideal choice of therapy for most patients with chronic renal failure. **Successful transplantation offers patients a survival advantage and better quality of life without the need for dialysis.** As well as feeling better, most recipients enjoy greater freedom, including work and travel.

The transplant process, however, can be a difficult time for both the patient and the patient's family. Every person considering transplantation approaches the issue as an individual with his or her own fears, hopes and expectations. We are here to help you decide if transplantation is the right choice for you. We hope that this booklet will help you feel more comfortable and knowledgeable about transplant as an option for kidney disease.

Everyone undergoing a transplant assessment must first complete certain medical tests. **Completing these tests often take a number of months (approximately 3-6 months).** Once your transplant investigations have been completed your package is then sent for to the transplant coordinators to review. Once everything is reviewed and complete you will be notified with appointments with the transplant team. Because you have already completed this series of tests to determine your suitability for a kidney transplant, the next step is assessment. Your assessment is done on an outpatient basis over the course of two days. You will meet the following team members during your visit:

- Nephrologist (a doctor who specializes in kidney disease)
- Transplant Surgeon (a doctor who performs the transplant surgery)
- Transplant Recipient Coordinator (a nurse who explains the transplant process to you, and is also your contact person during the assessment and waiting period)
- Social Worker (the social worker provides you and your family members with emotional and practical support throughout the transplant process)
- Anaesthetist (a physician who will administer your anaesthetic during surgery)

Transplant Assessment

Your assessment will be done over a two-day period, as it is not possible to schedule all of your appointments in one day. If you need a dialysis treatment during this time, arrangements will be made. If you use peritoneal dialysis, please bring enough supplies with you for your visit to London.

The transplant assessment can be stressful. It is recommended that a family member or close friend attend these appointments with you. You will receive a lot of new information about transplantation during your assessment appointments. It is also a good practice to write down any questions you have so they can be answered.

Once you have completed your transplant assessment, you will return home. If any further additional tests are required, they can usually be done at your own center of care. The transplant recipient coordinator will request any necessary tests with your local physician or dialysis/clinic nurse. There will be a waiting period between the time of your assessment and your acceptance to the list. It may take several months to determine your suitability for a transplant. **The entire process from when you start your transplant work up tests, have your assessment with the transplant team and list as a potential transplant patient often takes 6-12 months.** Once you have been accepted, you will receive a letter from the transplant coordinator, stating you are on the list. Arrangements will be made at that time to provide you with a pager. **Although you may have been accepted for a kidney transplant, the average waiting time on dialysis for a deceased donor transplant for LHSC is approximately 2.5 years.**

Types of Kidney Transplant Options:

Living Donor

Patients can receive a new kidney from either a living donor or by placing their name on the waiting list for a deceased donor. We recommend that patients receive a kidney transplant from a living donor, if possible, for the following reasons:

- shorter waiting time for transplant
- dialysis can sometimes be avoided altogether
- better patient and transplant survival
- shorter hospital stay

- less likelihood of needing short-term dialysis after the transplant

Family members, spouses, and close friends can be considered for living kidney donation. Potential donors must be healthy and their blood type must be compatible with the recipient. If your potential living donor is not compatible, the two of you may want to consider participating in the Living Donor Paired Exchange Registry, which is designed to match unsuitable recipient-donor pairs with other pairs who do not match.

There are numerous medical tests that the potential donor needs to complete in order to be assessed and approved for living donation. We recommend that anyone interested in finding out more about living kidney donation contact our living donor coordinator at 519-685-8500 ext. 33552 or visit

www.lhsc.on.ca/livingkidneydonation (see attached document). Please remember that a family member or friend's decision to donate is voluntary and must be free from any pressure.

Deceased Donor Transplant

If you do not have a living donor, your name can be placed on the waiting list for a deceased donor transplant. Over the past decade, waiting times have become longer for patients on the transplant list. The average waiting time for a deceased donor transplant is 2 to 3 years. Some patients wait much longer as a result of several factors, including their blood type. Your renal transplant team will discuss the various options for deceased donor transplantation during your assessment.

Drug coverage for Transplant

To be on the transplant waiting list, you must have proof of adequate drug coverage. You will need to take anti-rejection medication for as long as you have your transplant kidney, and these drugs are expensive. You may have drug coverage through a private drug plan or you may be eligible for some assistance through the provincial Trillium Program.

If you are a senior citizen or receive General Welfare Assistance, Family Benefits Assistance, Mother's Allowance and have a drug card, you need not apply to the Trillium Program.

The Trillium Program helps Ontario residents who must spend a large part of their income on medication. This program is also available to those with insurance plans that do not provide 100% coverage of drug costs. Owing to the high cost of anti-rejection drugs, we require that all patients have Trillium approval or full drug

coverage through an insurance policy before being placed on the active transplant list.

If you do not have drug coverage, apply to the Trillium Program immediately. This has benefits for both you and your family. Please remember that you cannot be on the transplant list without proof of adequate drug coverage. If you need assistance with the application process, please contact your dialysis social worker or call the telephone helpline that is provided on the application form.

Trillium application forms can be obtained from your pharmacy. The application asks for information about your family, your drug costs and your previous year's income. There is no fee to apply. Please complete this form and mail as soon as possible. We recommend you keep a copy for your own records. This application form must be renewed every year.

Staying healthy

While waiting for your transplant, you should try to remain as healthy as possible. All patients are asked to stop smoking and to maintain a healthy lifestyle in preparation for the transplant. Attend all your routine health care visits, eat a balanced diet appropriate for kidney patients, and continue to engage in physical activity. Healthy individuals recover faster and have fewer complications after surgery. Although your dialysis unit/renal clinic is responsible for keeping the transplant team updated on your condition, we welcome your enquiries or health status updates.

Contraindications for Renal Transplantation

The absolute contraindications are active infection, malignancy, substance abuse (this is case by case) and Non-adherence. Cardiac issues will be reviewed and suitability for transplant may need to be decided upon (case by case) by a cardiologist.

Smoking and Body Mass Index (BMI) Evaluation

Smoking

Smoking is not an absolute contraindication to transplant except in conditions of peripheral vascular disease (PVD), coronary artery disease CAD, or Pulmonary disease in which smoking is linked to increased mortality and can affect survival of the transplant. The patient must quit >3months before activation can take place. It is the expectation that the referring center keep us aware of any recidivism in patients that are active on our list. Our program recommends that all patients be

enrolled in a smoking cessation program; however, this will not be a barrier to referral or assessment unless the patient has the above conditions associated with increased mortality. For patients being referred for Pancreas or kidney Pancreas transplant, smoking remains an absolute contraindication due to greater risk of thrombosis of the graft.

Body Mass Index (BMI)

BMI (we realize there is a difference between BMI and fat distribution)- Patients with a BMI >40 need to be assessed by surgery to determine surgical risk prior to initiating a referral workup as there is a very high risk of wound complications. Those patients with a BMI 35-40 will be assessed on a case by case basis and they too may not be listed based on their fat distribution.

Potential Complications with Renal Transplantation

Delayed graft function (“sleepy kidney”)

It is important to remember that not all transplanted kidneys function immediately. Some kidneys are slow to start. In this case, you may need to continue with dialysis treatments until your kidney “wakes up”. Sleepy kidneys sometimes last several weeks or more.

Rejection

Rejection is an attempt by your immune system to attack your transplanted kidney and to destroy it. Rejection can occur any time, but the risk is greatest during the first 6 months after your transplant. It is not uncommon for transplant patients to experience a rejection episode. Most rejection episodes are successfully treated. It is important to treat the rejection episode as soon as possible. The longer treatment is withheld, the more likely permanent damage will be done.

Infection

Anti-rejection medication interferes with your natural immunity making you more prone to infections after your transplant. There are different types of infections:

- Viral (CMV, EBV, Herpes simplex (cold sores), Herpes zoster (shingles) or chickenpox)
- BK Polyoma Virus: this is becoming an important cause of kidney transplant failure and, at present, there are few treatment options
- Fungal (candida)

- Bacterial (signs of bacterial infection include fever, cough, sore throat, burning sensation when voiding, redness, swelling or drainage around an incision)
- Pneumocystis Carinii Pneumonia (PCP): A type of pneumonia that immune-suppressed patients are more prone to get. You will be given medication to prevent this.

Cancer

There is a slightly increased risk of cancer associated with the use of any immunosuppressive drug. It is very important to have yearly health check-ups with your family doctor. It is recommended that women have a pap smear and mammogram every 2 years, and a stool sample for occult blood testing should be done for women older than 40 years. Men over 40 years old should have yearly prostate check-ups and stool for occult blood. Skin cancer is the more common type of cancer seen in transplant patients. Report any new moles or any skin changes to your physician. Always wear sunscreen when you are out in the sun. Another type of cancer is a blood cancer called PTLN, Post-Transplant Lymphoproliferative Disorder. Report any unusual lumps or bumps, unexplained weight loss or night sweats to your doctor.

Diabetes

Glucose, a simple sugar, is the main source of energy in the body's cells. Diabetes occurs if sugar accumulates in your body because either your body is not using it properly or your body is not producing enough insulin. Some of your prescribed drugs (prednisone, Advagraf) can cause diabetes or make diabetes worse. Early signs and symptoms include tiredness, unusual thirst, weight loss, excessive production of urine, blurred vision and confusion. Monitoring blood sugar after your transplant is done to detect high levels. If you were taking insulin, after the transplant you may require higher doses. If you were taking pills or watching your diet to control your blood sugar before transplant, you may need to take insulin after transplant. If your blood sugar goes high immediately after your transplant, it may return to normal as your dose of medication is decreased. If your blood sugar remains high when you are ready to go home, you will be taught how to check your blood sugar, how to give yourself insulin, and how to change your diet to help control your blood sugar.

Answers to further questions can be directed to your Nephrologist, Health Care Provider or most importantly the Transplant Team themselves.

Contact information

London Health Sciences Centre 519-685-8500

Outpatient Pharmacy (UH) 519-663-3231

Nephrology Outpatient Clinic 519-685-8500 ext. 33346

Surgical Outpatient Clinic 519-685-8500 ext. 33188

Multi-Organ Transplant Unit 519-663-3015

Renal Transplant Coordinator 519-665-8500 ext. 33851

(Sault Ste. Marie, Windsor, PD London, South Street, CKD Clinic at University Hospital)

Renal Transplant Coordinator 519-685-8500 ext. 32331

(Sudbury, London satellites, Adam Linton Dialysis Unit, CKD Clinic at Victoria Hospital)

Social Worker 519-685-8500 ext. 32411

Living Donor Program 519-685-8500 ext. 33552

Multi-Organ Transplant Program website: www.lhsc.on.ca/transplant

Email: motslhsc@lhsc.on.ca

Provincial resource (patient hub) for transplant information:

www.renalnetwork.on.ca/TransplantPatientHub



Questions?

- Has anyone from your renal/kidney team discussed a renal transplant with you?
- Are you interested in knowing more about renal transplant?
- Do you feel you have enough education materials or resources to make a decision on whether you would like to be considered for renal transplant?
- Do you have anyone who may donate a kidney to you?

NOTES: _____

Chapter 5

Non-Dialysis Supportive Care

Dialysis and Supportive Care

No one person will have the same journey with kidney disease. As your kidney function changes, you will need to make decisions about your care wishes. Some people choose to not start dialysis and allow a natural death with palliative care support. We continue to provide support should this treatment choice, called conservative care, be in line with your wishes. Some people wish to have a trial of dialysis to see if it provides an improvement in their quality of life and should this not be the case, they may decide to withdraw from treatment.

Individuals who begin renal replacement therapy will find that there are times when their treatments go smoothly and times when adjustments need to be made to their treatment plans. Many things can influence your health and the success of your treatments. There may be a time when you may question whether you want to continue dialysis as your quality of life is no longer in line with your wishes.

Palliative Care or Supportive Care

Advanced chronic kidney disease (CKD) is a complex, life-limiting disorder for which there is no cure. Every year, thousands of Ontarians with CKD are treated with dialysis, as either a life-saving bridge to kidney transplantation or as long-term maintenance. For some individuals, however— particularly those who are elderly, are frail or have multiple medical conditions, the benefits of dialysis may be minimal, burdening patients with disability, significant adverse effects and diminished quality of life in exchange for poor survival rates.

A palliative approach to care is a holistic, person-centred approach to caring for patients with a life-limiting illness and their families. It can occur alongside chosen treatment (like dialysis), with a focus on preventing and easing suffering and promoting quality of life. Treatment goals are based not solely on the patient's physical condition but also personal goals, preferences and prognosis.

DIALYSIS AND SUPPORTIVE CARE

Why is Palliative Care Important?

While dialysis prolongs life for most CKD patients, the quality and quantity of life varies from patient to patient. Many individuals with advanced disease experience distressing symptoms, including chronic pain, fatigue, cognitive impairment, depression and emotional stress. Increasingly, people with CKD on dialysis are often elderly and have complex medical histories.

In addition, the life expectancy for people on dialysis is poor. The one-year survival rate for Canadians on dialysis is 85 per cent (2009 data), while the five-year survival rate is 43 per cent (2006). Life expectancy for elderly people is even worse: only 25 per cent of patients older than 75 years survive for five years.

Many people want to know what their dying experience will be like should they choose withdrawal of dialysis. Often, different feelings arise, and for some bringing up the topic of stopping treatment may feel uncomfortable. Some people have shared thoughts that withdrawal is giving up, or is a form of suicide. People may wonder if there is pain or other uncomfortable physical sensations when they withdraw from treatment. Your renal team is committed to assist you in making connections with the palliative services within the hospital setting or in your own community depending on where you wish to die, to diminish symptoms. We know that all of these feelings and concerns are not only valid but common. We acknowledge that having control of what is important to you allows you to die with dignity.

Medical Assistance in Dying (MAID)

In May 2017, MAID became law in Ontario. If you are thinking about medical assistance in dying, talk to someone who can help inform you about your potential options: a doctor, nurse practitioner or other health care provider. You can also speak with your family, friends or a spiritual advisor. If your suffering continues and you want to consider a formal request for medical assistance in dying you will need to speak with your doctor or nurse practitioner.

www.health.gov.on.ca/en/pro/programs/maid/docs/maid.pdf

Your dialysis team members are always available to discuss your questions and feelings regarding preparation for death. We can help you and your family to establish a plan that addresses your needs with compassion and an understanding that you are unique in your journey but not alone.

DIALYSIS AND SUPPORTIVE CARE

Questions ?

- Are you interested in keeping your symptoms related to your medical problems controlled so that you can enjoy your life to the fullest?
- Have you ever heard about or had discussions with your dialysis team about Palliative Care and Symptom Management?
- Did you know that you have access to Palliative Care through CCAC in your home to help with managing your symptoms?

NOTES: _____

Chapter 6

Advance Care Planning

Advanced Care Planning

Advanced Care Planning (ACP) means having discussions with your family and friends, especially your future or current Substitute Decision Maker (SDM). A Substitute Decision Maker is the person or people who will provide consent or refusal of consent for care and treatments for you if you are not capable to do so for yourself. Advanced Care Planning can include choosing a Substitute Decision Maker as well as expressing your wishes about care that you want or may not want.

ACP can include discussions with your health care providers to ensure that you have accurate medical information on which to make decisions (consents) or to express wishes about future care and treatment. It can also include writing down your wishes, and even involve talking with legal professionals.

It is a way to give those who will be required to provide consent for your medical treatment and care the confidence to make decisions on your behalf when you are mentally incapable to do that for yourself.

We are always available to discuss your goals of care wishes. We strongly encourage you to talk to your family about your care wishes and quality of life; sharing with them what is important to you. Should your treatments no longer have sufficient benefit or other health conditions affect your quality of life, withdrawing from treatment is a respected treatment decision. Ensuring you receive supportive, end of life care is important part of your medical care. Please speak with your renal team regarding further discussions about Advanced Care Planning.

<http://www.advancecareplanning.ca/>

ADVANCED CARE PLANNING



Questions ?

Advanced Care Planning

- Do you know who your legal substitute decision maker is? Do you know how to go about choosing the SDM?
- Does your SDM understand your wishes and will speak on your behalf if you are unable to do so?
- Do you feel that your dialysis team and close family members know what your personal wishes are in relation to your advanced care plan?
- After reading about advanced care planning, would you find it beneficial to meet with your family and our dialysis team to discuss this further?

- NOTES: _____

Chapter 7

Emergency Preparedness

Medical Emergency

You might experience some problems outside of regular dialysis hours and not know who to call for medical assistance. If you are experiencing an emergency you should call 911 or go to closest emergency department. If you need to speak to a nephrologist after hours for an urgent matter you can call 519-685-8500 and ask to speak to the nephrology fellow on-call.

Medical Alert

Why should you wear a medical alert?

People on hemodialysis should wear a medical alert bracelet. If you are injured or unable to talk, medical workers need to know quickly that you are a person on dialysis or a transplant recipient.

How does it work?

Your medical alert is worn as a bracelet or necklace with an international symbol.

If needed, the computerized medical information you gave will be available in seconds to doctors and nurses...anywhere in the world. This important information will help medical personnel to give proper care...and could save your life.

In a disaster, the phone lines may be down. However, the alert will tell the medical people that you are on dialysis.

Helpful Tips:

1. A bracelet should be worn on the opposite side of your fistula. If it was on your access arm it could stop the blood flow and damage your fistula if it was pulled up your arm.
2. A necklace might be missed if your upper body clothes are rolled up.



PRACTICAL MATTERS

Usually your medical alert is custom engraved with your main medical conditions, personal ID number and a 24-hour hotline number.

Medical Alert: Personal I.D. Number: _____

24 Hour Hot Line Number: _____

*adapted from BC Renal Agency

Should you require emergency medical attention, it is important that you provide this information to your caregivers.

NOTE: A copy of this sheet should be with you at all times.

Please print the information clearly, and update it if any of the information changes.

Name: _____

(Last)

(First)

Date of Birth: _____

Address: _____

Phone: _____

Email Address: _____

Personal Health Number: _____

Your nearest relative,

or someone to be contacted in case of an emergency.

Name: _____

(Last)

(First)

Relationship to you: _____

Address: _____

Phone: _____

Email Address: _____

*Adapted from BC Renal Agency

Your Medical Condition and History

NOTE: A copy of this sheet should be with you at all times.

If you need to go to another hospital or clinic in the event of a disaster, or if your records are unavailable or destroyed, this information will help any temporary care givers in understanding your special needs. You should update this annually and when treatment modalities change.

Date Completed: _____

Cause of Kidney Disease: _____

Other Medical Problems: _____

Infectious Precautions: _____

Allergies: _____

Blood Type (if known): _____

*Adapted from BC Renal Agency

Disasters often strike quickly, and without warning

A disaster is defined as a major event that directly affects care to you. People on dialysis are at risk because they need power and water for their treatment. These may not be available for several days if it is a big disaster. Telephones may not work. You may not be able to use roads and bridges, emergency rooms will be crowded, and hospitals will give first attention to people who are injured. For these reasons dialysis treatments may not be available.

Here are some ideas on how to handle the first several days until things can return to normal. Patients and families should study this booklet and make a plan.

Disaster Instructions

Here are some simple instructions.

1. Stay at home, unless you are hurt.
2. Begin emergency diet plan (see below)
3. Wait at home for instructions and details about hemodialysis on TV, radio, messenger or phone.

(Find out your local emergency radio station)
4. If you must go to an emergency shelter, tell the person in charge about your special needs.
5. Patients must take as much responsibility as possible for getting where they have to go, keeping in contact with the unit and *being available to come for dialysis at any time - day or night*. You may have to stay at the dialysis centre if transportation is a problem.
6. You may have to be moved from your home. This may not be by ambulance but with military vehicles, volunteers, or by air. Bring your medications with you. See the section on Medications for more details.

7. Keep an extra pair of glasses with your emergency supplies.
8. Please notify your hemodialysis facility of address and telephone changes.

Remember: Hemodialysis centres may not be able to give your regularly scheduled dialysis treatments.

Emergency Diet Plan for People on Hemodialysis

It is very important that you eat, but choose food wisely and limit fluid intake.

Some emergencies (such as a snowstorm), allow you to stay in your home but you may not be able to get to dialysis for a while. If you have hydro and your stove and fridge are working, you will be able to cook and eat your usual diet but you will need to make the changes listed below in the Emergency Diet Plan. If you do not have power to operate the fridge and stove, refer to the sample menu for eating without a stove or fridge on page 52.

Emergency Diet Meal Plan.

Refer to your Nutrition and Dialysis poster and use the following meal plan as a guide:

Meat and Alternatives:

Limit your intake of these protein foods to either one half your usual intake or to 2-3 units per day.

Fruits and Vegetables:

Limit to 3 units per day.

Grains and Starches:

Follow your Nutrition and Dialysis poster recommendations. If you need extra food to satisfy your appetite, choose extra servings of Grains and Starches. These foods are good choices because they are lower in potassium than fruits and vegetables and milk and alternatives.

If you have diabetes, eating more of these foods will increase your blood sugars. Use the guidelines from your diabetes care team for adjusting the amount of insulin you should take.

Milk and Alternatives:

Limit milk to $\frac{1}{4}$ cup per day. Avoid yogurt, pudding and cream soup.

Fluids:

Limit your fluid intake to one half your usual daily intake. For example, if you usually drink 1 litre (4 cups) each day, reduce this to 500 ml (2 cups).

Other Foods:

Foods in this group may be eaten in any amount. They are very low in potassium, phosphorus. But keep in mind that some of these foods are high in carbohydrate and will raise your blood sugars if you have diabetes.

Nutrition Supplements:

If you usually drink Nepro, Novasource Renal, Ensure, or Boost, etc. limit to no more than 1 per day.

Emergency Pantry Provisions

It is recommended that everyone have a 3 day supply of non-perishable food and water available. Plan to have 1 – 2 litres of water available for each person for each day. This will be for drinking, food preparation, hygiene and dishwashing.

Meat and Alternatives

- Canned fish (salmon or tuna). Choose canned fish with 'No Salt Added'.
- Peanut butter
- Frozen meat, poultry, fish (not battered)

Fruits and Vegetables

- Canned peas, green or yellow beans, carrots, mixed vegetables (no salt added for hemodialysis)
- Frozen vegetables and fruits
- Canned fruit (drain before eating. Do not drink the juice)

Grains and Starches

- Dry cereals (e.g. Cheerios, Special K, Corn Flakes, Rice Krispies, Special K, Frosted Flakes, etc.)
- Hot cereals (e.g. oatmeal, cream of wheat) – avoid instant cereals. They contain added salt.
- Crackers (unsalted soda crackers, rice crackers, melba toast)
- White bread, rolls, pita, bagels, soft shell tortillas

PRACTICAL MATTERS

- Muffins (e.g. lemon cranberry, blueberry)
- Cookies (e.g. oatmeal, vanilla cream, arrowroots, digestives, social teas)

It is recommended to consume and replace canned food and dry goods once a year.

Equipment

- Manual can opener, bottle opener, sharp knife, scissors
- Cooking pot and utensils
- Knives, forks and spoons (disposable)
- Cups, plates, napkins (disposable)
- Fuel stove and fuel
- BBQ with full extra propane tank (don't use a BBQ indoors)
- Waterproof matches and plastic garbage bags
- Small bottle of household bleach
- Alcohol hand washing solution
- Plastic jug for storing water or bottled water

PRACTICAL MATTERS

Sample Menu for Healthy Eating without a Stove or Refrigerator

	Day 1	Day 2
Breakfast	Cold cereal with 2 ounces milk 2-4 oz. water/coffee/tea	Muffin (e.g. lemon cranberry or blueberry) 4 oz. apple or cranberry juice
Morning Snack	2 digestives or 3 arrowroots	15 grapes or 1 small peach
Lunch	Salmon sandwich on white bread, ¼-½ cup salmon with vinegar (no mayo) 1 medium apple or ½ cup drained canned fruit 4 oz. cranberry juice	Peanut butter sandwich on white bread, 2 Tbsp. peanut butter 3 arrowroots 4 oz. water 10 baby carrots
Afternoon Snack	Shortbread cookies	3 vanilla or strawberry wafer cookies
Supper	2 oz. BBQ chicken (if you have access to a BBQ) ½ cup canned corn 1-2 slices white bread dipped in oil & balsamic vinegar 4 oz. water or Crystal Light	1-2 oz. tuna sandwich on white bread (no mayo) ½ cup canned fruit (drained) (diet) butterscotch pudding 4 oz. water or Tang
Bedtime Snack	4 melba toast or 7 unsalted crackers 1 Tbsp. peanut butter 2 oz. water	Granola bar (Nature Valley or Chewy cranberry or apple flavour)

PRACTICAL MATTERS



Questions:

- What is my emergency plan?
- Who are the people to help me in an emergency?
- How will I get to dialysis?
- What can I eat?

NOTES: _____

Medications

What medications will I take, and what do they do for me?

Medications are important when you are on dialysis. Medicine works with dialysis, your diet, and your fluid control to keep you healthy. Medications replace some of the work of the kidneys.

Listed below are some common medications taken by dialysis patients. Your doctor or nurse will tell you about the medications which you need to take. Always take your medications as prescribed because they play an important role in keeping you healthy. Never take or change a dose of any medication without first talking to the dialysis unit staff.

Common Medications:

PHOSPHATE BINDERS

Most dialysis patients take medication called “phosphate binders”. Phosphate is a substance found in the body that comes from the food we eat. Healthy kidneys normally remove extra phosphate and pass it out in urine. Phosphate is not removed very well even with dialysis and it builds up in the blood. Over a period of time excess amounts of phosphate in the blood can cause problems such as itchiness, red eyes, painful joints, bone disease and heart problems. Phosphate binders are taken to help keep extra phosphate from building up in your body. There are different kinds of phosphate binders such as calcium carbonate (Tums® chewable tablets or Calcium Carbonate tablets), Sevelamer (Renagel®) and lanthanum (Fosrenol®). They must be taken with your meals and sometimes snacks. By keeping your phosphate levels low you are helping prevent bone problems. Take your binders every day as instructed.



IRON

Iron helps your body make red blood cells. You may need to take iron pills but most people on hemodialysis receive iron intravenous during their dialysis treatment. If you are taking iron pills these are usually taken as 2 or 3 pills at bedtime. They should be taken exactly as instructed. They should not be taken at the same time as your phosphate binders.



ERYTHROPOIETIN OR ARANESP

Erythropoietin, also known as EPO, is a substance normally made by the kidneys to help the body make red blood cells. Many dialysis patients take EPO in order to help raise the level of red blood cells in the blood. If you do not have enough red blood cells you can become anemic. Anemia can make you feel tired and have decreased energy. Aranesp is a form of EPO that is given intravenously to people on hemodialysis during their dialysis treatment.

VITAMIN B & C

All people who require hemodialysis are prescribed a vitamin call Replavite. As fluid is removed on hemodialysis water soluble vitamins such as Vitamin B and C are also removed. Taking Replavite reduces any Vitamin B and C shortages which may occur due to hemodialysis. It is important you do not take any other vitamins other than what your dialysis health care provider is aware of as some vitamins and minerals (vitamin A, magnesium) can build up in people on dialysis.

VITAMIN D

You may be prescribed a form of vitamin D to help your bones stay strong and healthy. Over-the-counter vitamin D3 needs to be activated by the kidneys in order to work in the body. Calcitriol (Rocaltrol®) and alfacalcidol (One-Alpha®) are prescription forms of vitamin D that are already activated. They are used to lower a hormone called parathyroid hormone or PTH. This hormone is released by the parathyroid glands in the neck and is often high in people with kidney disease. Having high levels of PTH for long periods of time can cause calcium to be removed from the bones and weaken them. The dose of calcitriol or alfacalcidol is based on your blood test results. These capsules may be taken every day or three times per week. It is usually recommended to take these capsules at bedtime.

LAXATIVES

A laxative is the common name for medication to relieve constipation. It is often difficult to increase the fiber due to the renal diet and often laxatives are needed. While many types of laxatives are available at the drug store, you should take only what is prescribed for you as some laxatives are not recommended for patients on dialysis. You can also speak to the dietitian about ways to increase fiber in your diet without increasing your potassium or phosphate levels (i.e. choose an apple instead of apple juice).

Some laxatives that are safe for patients on dialysis to take are Peg 3350 (Restoralax®), lactulose and Senokot®. Speak to your doctor or nurse practitioner before starting these medications. Laxatives that contain magnesium (i.e. Milk of Mag) and phosphate (i.e. Fleet® products) should be avoided by patients with kidney disease.

If you require a bowel preparation for colonoscopy, let your kidney team know. Some bowel preparations, such as Pico Salax® contain large amounts of magnesium and should be avoided by patients on dialysis.

KAYEXALATE

Sodium Polystyrene Sulfonate (Kayexalate) is a medication which will help decrease the potassium level in the blood if for some reason you miss a dialysis treatment, such as in the event of a snow storm. It is only to be taken upon direction from the hemodialysis unit and must be kept on hand.

RECOMBIVAX

Hepatitis B is an inflammation of the liver caused by a virus. This virus is carried in the blood and people on hemodialysis are more at risk than people not on hemodialysis. Although hepatitis can be severe, it is uncommon and unlikely to occur if dialysis patients and staff are aware of the practice methods to avoid spreading of the disease. Great care is taken with blood cannulation; starting and stopping dialysis; disposal of needles, blood lines, and dialyzers; and cleaning of the dialysis machines. This is the reason for the protective gowns, gloves, masks/shields worn by the staff.

This vaccination is available to immunize you against Hepatitis B. It is recommended for all patients on hemodialysis. Receiving the vaccine involves a series of 3 injections in the shoulder - initially, in 1 month and in 6 months. They will be given in the hemodialysis unit. Response to the vaccination is then checked by a blood test. Sometimes 3 more injections given monthly are needed and occasionally if your

blood levels decrease a booster dose is required. If your body does not respond to the vaccine you will be declared a non-responder and will no longer receive this vaccination.

What special medications might I need?

There are some other medications which are used by many dialysis patients in some situations. You may need to take one of these sometime in the future. Some of the common medications are:

Antibiotics

Antibiotics fight infection. If you get an infection, you may be prescribed an antibiotic to get rid of the infection. Antibiotics can be taken as a pill or liquid or intravenously. The dialysis unit staff will tell you exactly the type of antibiotic to use if you need one, and how often to take the medication.

If you have a central venous catheter and you are having dental work you will require antibiotic coverage. This can be prescribed by the dentist or by the dialysis doctor or nurse practitioner. Please notify your dialysis nurse if you are scheduled for dental work.

Blood pressure pills

Because your kidneys can no longer manage your fluid levels and your blood pressure, you may need to take blood pressure tablets to help dialysis do the job. These are also called “anti-hypertensives”. This medicine helps reduce the high pressure of blood circulating through your veins so there is less strain on your heart.

NEVER TAKE ANY MEDICATIONS WITHOUT FIRST TALKING TO YOUR DIALYSIS NURSE, DOCTOR OR NURSE PRACTITIONER!

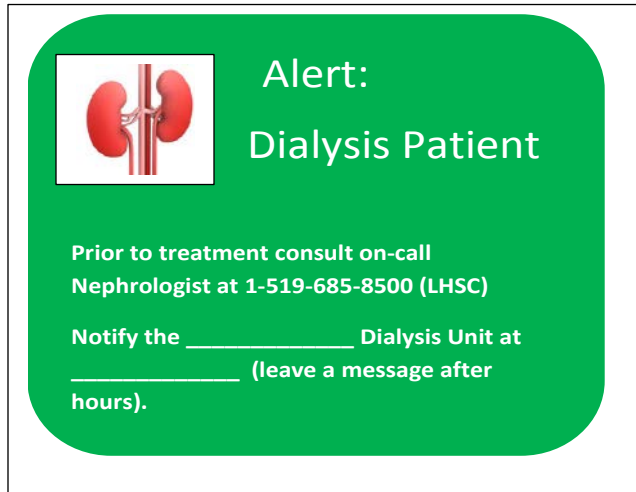
Any medication should be taken with careful guidance. This is especially important in people who have renal failure since there are many medications that are cleared from the body by the kidneys. Your dialysis health care provider will choose special medications and dosages for your needs.

If you are prescribed a new medication, please bring the bottle in to dialysis and show your dialysis nurse. They will check to make sure that the drug and dose are safe for you. If you see a new doctor in a walk in clinic or the Emergency department, let them know that you are on dialysis and ask if the medicine they are prescribing is safe for you. It is also

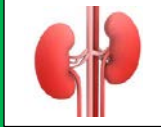


PRACTICAL MATTERS

a good idea to let your community pharmacy know that you are on dialysis. They can double check your medication doses as well. The following is a sample Alert to carry with you to inform your medical team that you are a dialysis patient.

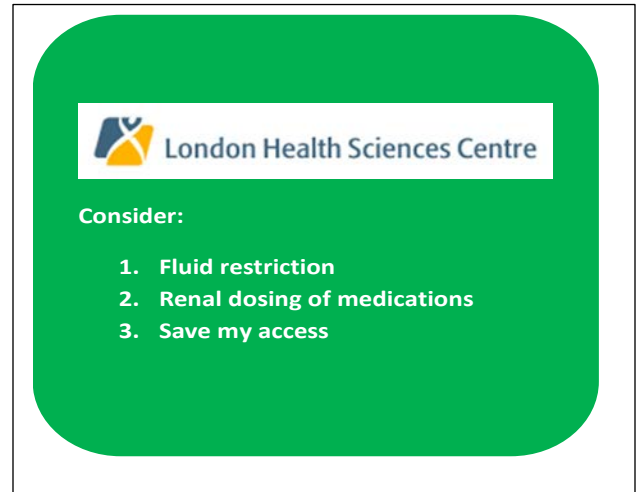



Alert:
Dialysis Patient



Prior to treatment consult on-call
Nephrologist at 1-519-685-8500 (LHSC)

Notify the _____ Dialysis Unit at
_____ (leave a message after
hours).



 London Health Sciences Centre

Consider:

1. Fluid restriction
2. Renal dosing of medications
3. Save my access

Coughs, Colds & the Flu

Information for Dialysis Patients

The common cold is an easily spread. The average person can expect to contract a cold about one to three times per year. Cold viruses can survive for several hours on hands or hard surfaces and it only takes brief contact with an infected person or object for transmission of the virus to take place. The virus enters the body when you touch your eyes or rub your nose. Washing your hands frequently is the best way to protect yourself from catching a cold. The most common cold symptoms are a runny and stuffy nose, sneezing, sore throat, and cough. Symptoms usually last about 7 days but may persist up to two weeks in some cases.

The flu (or influenza) is a much more serious condition. Many people who are suffering from cold symptoms incorrectly describe their condition as “the flu”. The flu is contracted by coming into contact with the respiratory secretions of a person with the flu virus. The flu is associated with fever, chills, headache, and muscle



aches while the cold is not. Symptoms such as sore throat, cough, and stuffy nose usually persist for 3 to 4 days after the fever is gone.

Flu Vaccination

All individuals with kidney disease 6 months of age or older should be vaccinated yearly against the flu. This is because your immune system does not work as well when your kidneys are not functioning. Ask your family doctor or community pharmacist for the flu vaccine between September and December of each year.

Pneumonia Vaccination

All individuals with kidney failure 2 years of age or older should also be vaccinated against pneumonia. This vaccine will protect you against strains of the most common bacteria that cause pneumonia. The vaccine is given once and then repeated 5 years after the first dose. No further vaccinations are needed and you will have life-long protection. The vaccine will be given in the hemodialysis unit.

Selecting an Over-The-Counter Treatment

Always ask your community pharmacist for help with choosing a product sold over-the-counter. Tell them that you are on dialysis and about any of your other medical conditions.

When you have a cold or the flu it is best to treat each of your symptoms individually rather than using products which provide ingredients to cover every possible symptom. This is because you likely will only be experiencing one or two symptoms at a time and the more unnecessary medication you take the more at risk you will be for experiencing medication side effects.

If you have high blood pressure, avoid using syrups, tablets, or capsules that have the words “Nasal Decongestant” on the package. Nasal decongestants work by narrowing the veins in your nose to relieve the swollen congested feeling. But they also narrow blood vessels in the rest of your body and can increase your blood pressure. If you have a stuffy nose you can use a nasal decongestant spray for three days or less. The nasal sprays are less likely to cause increased blood pressure because very little of the spray is absorbed outside of your nasal passage.

Many cough syrups and cough drops contain sugar. If your diabetes is well-controlled, using these medications short-term for a cold is usually not a problem. If your diabetes is not well-controlled or you would like to avoid the extra sugar there are sugar-free formulations such as Balminil DM Sans Sucre or Koffex Sans Sucre.

PRACTICAL MATTERS

Some examples of sugar free cough drops are Bentasil, Sugar-free Fisherman's Friends and Sugar-free Cepacol. Ask your pharmacist to help you choose a product.



Diarrhea

You can take Loperamide (Imodium®) tablets for diarrhea in the usual dose. Do not take more than 8 tablets per day. Please tell your dialysis nurse if you are having diarrhea.

Heartburn

Most over the counter medications for heartburn are fine to use occasionally. If you find that you are using heartburn medication every day you should contact your doctor or nurse practitioner. There may be a more serious problem such as an ulcer, and many of the medications used to treat heartburn have ingredients which, if used often, can accumulate in people with kidney disease.

Fine to take occasionally	Avoid
Amphogel®	Maalox®
Gaviscon®	
Tums®	



Herbal Products

Herbal products may interact with the other medications you are taking. You should check with the dialysis unit staff before using.

Pain Medications

Acetaminophen (Tylenol®) is safe to use. If you have liver problems you should check with a health care provider first. Do not take more than 12 regular strength tablets or 8 extra strength tablets per day. Acetaminophen will relieve pain and fever but NOT inflammation.

Ibuprofen (Motrin® or Advil®) or naproxen (Aleve®) will relieve pain, fever, AND inflammation and are fine to use occasionally. If you have a history of ulcers or a stomach bleed you should try to avoid these medications. These medications should not be taken regularly as they can increase blood pressure or decrease your urine output. Check with your nephrology team before taking one of these drugs.

Sleep

Most over-the-counter sleep medicines are just allergy medications which cause drowsiness. They are not often very effective. Melatonin 3mg daily at bedtime has been shown to be effective and safe in hemodialysis patients in a short term study. If you have problems with sleeping contact your family doctor.

Dry Skin/Itch Information

Dry, itchy, scaly skin is common for people on dialysis. Taking your phosphate binders to lower your phosphate level can help to stop itchy skin. The best way to relieve dry skin is to use a moisturizer at least twice a day. Too much water can cause the skin to dry out. Showering or bathing more than once a day should be avoided to prevent dry skin.

Causes

Approximately 60 percent of dialysis patients complain of itchy, dry skin, which is often generalized but may be most prominent on the back. A number of factors may contribute to these symptoms:

- dry skin due to impaired sweat glands
- high phosphate
- inadequate dialysis

- anemia (low blood counts)
- high aluminum levels
- high vitamin A levels
- decreased immune system
- washing with excessively hot water
- using non-moisturizing soap
- showering or bathing more than once a day and for long periods of time

Treatment

Emollients or moisturizers are creams that can be applied to the affected area to prevent water from evaporating from the skin's surface. Emollients also smooth over the scaly edges that can flake off and cause intense itching. Emollients should be applied after washing or showering and frequently throughout the day.

Lotions, which have a high water and low oil content, can worsen dry skin via evaporation and trigger a flare. In contrast, thick creams (eg, Eucerin, Cetaphil, Nutraderm), which have a low water content, or ointments (eg, petroleum jelly, Aquaphor, Petrolatum), which have zero water content, better protect against dry skin.

Creams and lotions that contain keratolytic agents, such as urea, salicylate, lactic acid, vitamin A, and propylene glycols are also available. These lotions are not as moisturizing as emollients but are more effective on thicken skin areas such as the heels.

Type of Product	Product	Active ingredients
Creams	Cetaphil cream	Propylene glycol, petrolatum
	Eucerin cream	Petrolatum, mineral oil, lanolin
	Glaxal Base	Nonmedicated hypoallergenic base
Ointments	Aquaphor ointment	Glycerin, petrolatum

PRACTICAL MATTERS

	Petrolatum jelly	petrolatum
Keratolytic Products- for thick skin	Eucerin 10% urea lotion	10% urea
	Uremol 10% lotion	10% urea
	Atrac-Tain® Cream	10% Urea, 4% AHA

Application

Moisturizers should be applied generously and frequently, particularly after washing, or being outdoors in cold weather for long periods of time. Skin care products that contain alcohol and fragrances are more likely to dry out the skin and should be avoided. Most moisturizers and lotions require at least twice-a-day application for the prevention of dry skin. Ointments are usually applied at bedtime.

Medication Coverage

If you are on hemodialysis some medications are covered by special approval from the Ministry of Health for those on the Ontario Drug Benefit (ODB) Plan. The following medications are covered by ODB based on the Exceptional Access Program (EAP) criteria listed below.

Medication Name	Approval criteria	Duration of approval
<ul style="list-style-type: none"> Calcium carbonate (e.g. Tums®, Apo-Cal®) 	<ul style="list-style-type: none"> For patients with hypoparathyroid disease or chronic renal failure 	<ul style="list-style-type: none"> 5 years
<ul style="list-style-type: none"> Replavite® multivitamins DIN: 02244872 	<ul style="list-style-type: none"> For patients receiving hemodialysis or peritoneal dialysis 	<ul style="list-style-type: none"> 5 years

http://www.health.gov.on.ca/en/public/programs/drugs/publications/trs/trs_guide.pdf

The nephrology team will phone in an EAP request and will obtain approvals for these medications when they are first prescribed. You may need to pay for the first bottle of these medications while the request is being approved. Your next refills should be covered, however; you may need to ask your pharmacy to check your coverage.

Difficulties Paying for Medications

If you are having difficulties paying for your medications please let your nurse know as soon as possible so they can contact the Renal Program social worker to evaluate your financial situation. There are programs available to help you with your medication costs.

You can use this chart to help you with your medications

Medication	Direction	Morning	Noon	Supper	Bedtime	Comments



Questions?

- Why and when do you take phosphate binders?
- Why do you need iron and Aranesp?
- When might you need to take antibiotics?
- Why is it important to take vitamin B, C & D?
- How can you keep your bowels regular?

- NOTES: _____

Lab Values for Hemodialysis

What you do to improve your blood work results?

- Check your Renal Eating Plan poster on a regular basis and eat the required number of units/servings indicated on your daily meal plan.
- Ask your Renal Dietitian how to keep your blood values in the desirable range.
- Take your medications as prescribed.
- Discuss with your healthcare team your concerns regarding your blood work.

Blood Values

Blood Test	Desirable values for people on hemodialysis	Your Value	Function/Source
Urea	Varies according to protein intake.		Normal waste product of protein breakdown. Affected by the amount of protein in your diet and your kidney function.
Percentage of urea reduction	Greater than 65%		Measures the amount of removed with each hemodialysis treatment.
Creatinine	Varies according to individual muscle mass, kidney function and amount of dialysis		Normal waste product of muscle breakdown. Controlled by normal kidney function and dialysis.

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Potassium	3.5 - 5.0	<p>A mineral that affects the muscle action of your heart.</p> <p>High levels can cause your heart to stop.</p> <p>Low levels can cause weakness and shaking.</p> <p>Found in all foods especially fruits, vegetables, meats, and dairy products.</p>
Phosphate	1.13 - 1.78	<p>Called phosphorus in food - in the blood it is called phosphate.</p> <p>Too much phosphate in the blood will cause calcium to leave the bones and make them brittle/weak.</p> <p>Avoid the foods on your Eating Plan poster marked with the bone symbol.</p> <p>“Phosphate binders” (examples: Tums, Calcium Carbonate, Apocal, Renagel, Basaljel) at meals and snacks help to keep levels normal.</p>
Calcium	2.1-2.4	<p>A mineral used by the body to make bone and help</p>

PRACTICAL MATTERS

			<p>muscle movement.</p> <p>It is linked with phosphorus.</p> <p>Vitamin D is needed to make it work. Found in dairy products and meat.</p>
Hemoglobin	Varies-usually 105-115 G/L		<p>Carries oxygen to all the cells in your body.</p> <p>Low levels cause shortness of breath, weakness and lack of energy.</p> <p>This value is NOT affected by diet.</p>
Parathyroid hormone (PTH)	Varies usually less than 60		<p>PTH is a hormone that helps regulate the calcium and phosphate in your blood.</p> <p>Can become elevated phosphate control is very important to keeping this hormone under control.</p>
Albumin	38-50		<p>Albumin is a protein in your blood.</p> <p>Protein helps to build and repair all tissues and cells.</p> <p>Albumin is often used as an indicator of your nutritional status.</p>
Glucose	3.6-6.1		<p>Also called blood sugar.</p> <p>The sugar in your blood is controlled by the food you</p>

PRACTICAL MATTERS

			eat (sugars and starches) and the available insulin in your body. Your body uses glucose for energy.
Kt/V	Greater than 1.2		Measures how effective your dialysis Includes both dialysis and your kidney function (urine output).
nPNA	Greater than 0.9		Measures how much protein you have eaten during the collection period.

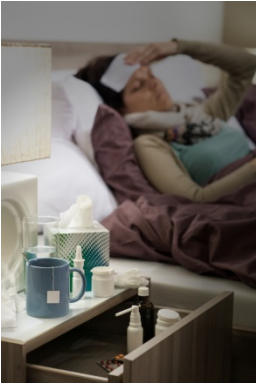

NOTES: _____

Infection Prevention

People who undergo hemodialysis have a higher risk of infection because of 3 major reasons:

1. People with chronic kidney disease (CKD) have weakened immune systems and are more at risk for infection
2. Frequent use of catheters or insertion of needles to access blood stream
3. People on dialysis are frequently in the hospital where lots of germs can be found

Vaccine Preventable Infections

<p>Influenza</p> <ul style="list-style-type: none"> – Influenza or the “flu” is a respiratory infection that infects the nose, throat, and lungs – The flu is spread mainly by droplets that are made when people with flu cough, sneeze or talk – The single best way to prevent the flu is to get a flu vaccine each year 	
<p>Hepatitis B</p> <ul style="list-style-type: none"> – Hepatitis B is a serious infection that affects the liver. It can cause acute (short-term) or chronic (long-term) infection and liver cancer – Hepatitis B virus is easily spread through contact with the blood or other body fluids of an infected person – Hepatitis B vaccine can prevent hepatitis B infection 	

Hand Washing

Good hand washing is the most important way for you to prevent the spread of infection.

If you have access to the internet there are some instructional videos that you may find helpful.

Short Hand washing videos:

Soap and water

<https://www.youtube.com/watch?v=sDUJ4CAYhpA&list=PLQAG2eEzugE84RFkUjlvZmZhEsNxnn7ge&index=2>

Alcohol hand wash

<https://www.youtube.com/watch?v=sDUJ4CAYhpA&list=PLQAG2eEzugE84RFkUjlvZmZhEsNxnn7ge&index=2>



Here is some information on **good hand washing techniques**.

CLEAN HANDS PROTECT LIVES.
Your Health Care – Be Involved

How to HANDWASH

1. Wet hands with warm water.
2. Apply soap and lather onto hands.
3. Wash both sides of hands and between fingers.
4. Rinse hands under running water.
5. Pat hands dry with paper towel. Turn off tap with paper towel.

OHA ONTARIO HOSPITAL ASSOCIATION
www.oha.com/patientsafetytips
Ontario

While in the hospital you may want to use the **alcohol hand wash** available in the hemodialysis unit.

CLEAN HANDS PROTECT LIVES.
Your Health Care – Be Involved

How to HANDRUB

1. Apply hand rub gel or foam to palm of hand.
2. Spread over both sides of hands and between fingers.
3. Rub hands together for at least 15 seconds or until dry.
4. Once dry, your hands are safe.

 **ONTARIO HOSPITAL ASSOCIATION**

www.oha.com/patientsafetytips

 **Ontario**

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Questions?

- What are two ways to protect you from infection?
- Do I feel confident and supported to ask health care workers to wash their hands before starting my care?

NOTES: _____

PUT YOUR BEST FOOT FORWARD:

People on hemodialysis are at risk for foot problems and it is important to take care of your feet.



Foot Care Tips

1. Check your feet every day:

- Look at your bare feet every day for cuts, blisters, redness and swelling.
- Use a mirror to check the bottoms of your feet or ask a family member for help if you have trouble with your vision.

2. Wash your feet every day:

- Wash your feet in warm, not hot, water every day using a mild soap.
- Dry your feet well. Be sure to dry well between the toes.
- Do not soak your feet as this can dry your skin.

3. Keep the skin soft and smooth:

- Rub a thin coat of skin lotion over the tops and bottoms of your feet. Wipe off excess lotion that is not absorbed.
- Do not apply lotion between your toes.

4. Smooth corns and calluses gently:

- If your feet are at low risk for problems, use a pumice stone to smooth corns and calluses.
- Do not use over-the-counter products, razor blades or other sharp objects on corns and calluses.

5. Take care of your diabetes:

- Work with your health care team to keep your blood sugar under good control.

6. If you can see and reach your toenails, trim them regularly:

- Trim your toenails straight across and file any sharp edges.

- Do not cut the nails too short.
- If you are not able to trim them yourself, have someone help you.

7. Wear shoes and socks at all times:

- Never walk barefoot, even indoors. Consider buying a pair of shoes that are just for indoors.
- Wear comfortable shoes that fit well and protect your feet.
- Choose clean socks that fit well. Socks that have no seams are best.
- Feel inside your shoes before putting them on each time to make sure the lining is smooth and there are no objects inside.

8. Protect your feet from hot and cold:

- Wear shoes at the beach or on hot pavement.
- Wear socks at night if your feet get cold.
- Do not test bath water with your feet.
- Do not use hot water bottles or heating pads.

9. Keep the blood flowing to your feet:

- Wiggle your toes and move your ankles up and down for 5 minutes, 2 or 3 times a day.
- Do not cross your legs for long periods.
- Do not wear tight socks, elastic, or garters around your legs.
- DO NOT SMOKE.

10. Be more active:

- Plan your physical activity program with your doctor or health care professional.

11. Check with your health care team:

- Feet require regular attention. Make sure that your doctor or health care professional checks your feet on a regular basis.
- Notify someone right away if you find a cut, sore, blister, or bruise on your foot that does not begin to heal after one day.

Take care of your feet for a lifetime.

Adapted from:

Canadian Diabetes Association (2011), Foot care: A step toward good health.

Retrieved November 3rd, 2011, from

http://www.diabetes.ca/images/aboutdiabetes/CDA_FootcareFINAL_flexitol.pdf

What is your Risk for Amputation?

HIGH RISK FOOT:

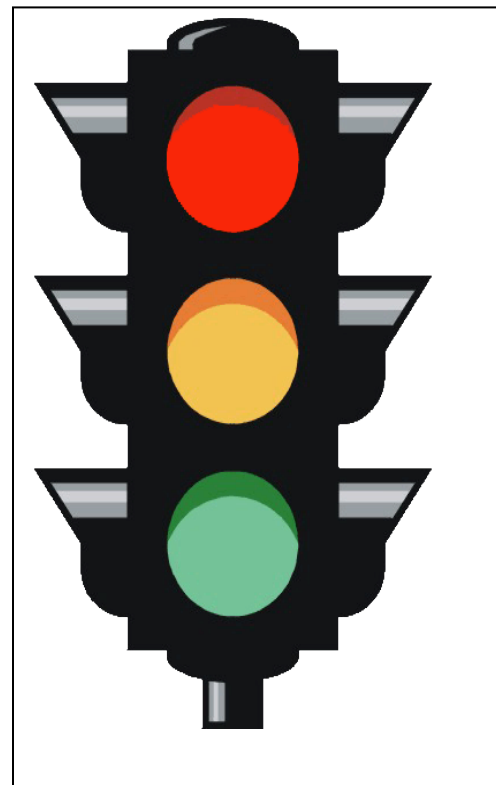
- History of ulcers/amputations
- Current foot ulcer

MODERATE RISK FOOT:

- Loss of normal feeling in the foot with or without an abnormal foot shape
- Absent pulses/poor circulation
- No history of ulcers/amputations
- No current ulcers

LOW RISK FOOT:

- Normal feeling in the foot
- Normal foot shape
- Good pulses/circulation
- No history of ulcers/amputations
- No current ulcers



Additional Resources for Foot Care

The Southwest Regional Wound Care Program advocates for the public's right to equitable, evidence informed skin and wound care in all health care settings in the South West Local Integration Health Network (LHIN). On their website you can find information about:

- Types of skin and wound problems and what treatments and / or preventative measures to be a part of your plan of care
- Measures you can take to prevent skin and wound issues
- How you can help heal your wounds- (remembering you are the most important member of the health care team.)
- Available resources in your community

www.swrwoundcareprogram.ca



Questions:

- What is my risk for a foot ulcer?
- How often should I be checking my feet?
- Who should I tell if I find a problem?

NOTES: _____

Smoking Cessation

Smoking is linked to a number of health problems including: heart disease, lung cancer, chronic obstructive lung disease, other cancers, peripheral vascular disease, stroke, high blood pressure, high cholesterol, infectious diseases, osteoporosis, peptic ulcer disease, tooth decay and gum disease, and cataracts. Patients with chronic kidney disease are already at a high risk for cardiovascular disease and smoking further adds to this risk.

Quitting smoking will greatly reduce your risk for developing these diseases and significantly improve your overall health. The benefits can be seen within minutes of quitting and will continue to increase the longer you go without smoking.

Benefits of smoking cessation relative to quit time

Time	Health Benefit
20 mins	Blood pressure and pulse return to normal.
Eight hours	Oxygen levels return to normal.
24 hours	Lungs start to clear out mucous and other smoking debris.
48 hours	Risk of heart attack begins to decrease. There is no nicotine left in the body. Ability to taste and smell is greatly improved.
72 hours	Breathing becomes easier. Energy levels increase.
Two to 12 weeks	Circulation improves. Lung function increases.
One year	Risk of coronary heart disease associated with smoking is reduced by about half.
Five years	Risk of heart attack falls to about half that of a smoker. Risk of stroke returns to the level of people who have never smoked.
10 years	Risk of lung cancer falls to about half that of a smoker.
15 years	Risk of lung cancer is reduced to close to that observed in nonsmokers. Risk of coronary heart disease falls to that of nonsmokers.

Smoking cessation methods

Both non-medication and medication therapies are important for successful smoking cessation.

Non-medication therapies include:

- Counseling by health care professionals
Telephone quit lines
- Individual and/or group counseling
- Hypnosis
- Acupuncture
- Computer/Internet counseling
- Behavioural and/or motivational therapy



Medication Therapies

Nicotine replacement therapy (NRT)

- Nicotine replacement therapy involves “replacing” cigarettes with other nicotine substitutes (gum, lozenges, inhalers, patches).
- This therapy works by delivering smaller amounts of nicotine to the body to relieve the withdrawal symptoms without the tars and poisonous gases found in cigarettes.
- Nicotine replacement therapy is safe and can be used at the usual doses in patients with chronic kidney disease on hemodialysis.

Non-nicotine medication therapies

- Require a prescription from your physician or pharmacist.
- Work by reducing the cravings and withdrawal symptoms which will make it easier for you to quit.
- Do not contain nicotine and are intended for short term use only.

Bupropion (Zyban®): is safe to use at the usual doses for smoking cessation in patients with chronic kidney disease on hemodialysis

Varenicline (Champix®): is safe to use in patients with chronic kidney disease on hemodialysis but at smaller doses

PRACTICAL MATTERS

Be sure to inform your physician and/or pharmacist of your kidney health status before starting any smoking cessation therapy.

Smoking Cessation Resources

Canadian Cancer Society Smokers' Helpline

<http://www.smokershelpline.ca>

Toll-free quit line: 1-877-513-5333

Canadian Lung Association

<http://www.lung.ca/smoking>



Chapter 8

Supports for those with Kidney Disease

What to know about your Renal Social Worker and the supports available to you.

This chapter will provide you with information about the team of social workers that are available to assist you with understanding what resources are available within the renal program and in your community as you begin your hemodialysis journey. These resources include your renal team members, such as social workers, dietitians, pharmacists, nurses, nurse practitioners and support staff. We have also included additional information regarding your goals of care and the discussions the renal staff may have with you to ensure we are adhering to your wishes at all points in your treatment journey.

Living with kidney disease and being on hemodialysis can be difficult. The stress of hemodialysis can affect your mood, relationships with others, finances and your quality of life. People on hemodialysis are more likely to experience depression than people who do not require hemodialysis. It is important to know that you are not alone and there are supports to help. There is a social worker in all of our hemodialysis units who can listen to your concerns and help to access community resources.

Renal social workers are members of the health care team, professionally trained in providing individual support and counselling, and to assist you and your family to adjust to your illness. Social workers can provide information, education, counselling to help with the adjustment to your illness, advocacy and referral to community resources. Social workers can also assist in assessing and referring you to local Mental Health Services or to an agency for family counselling if needed. You may have met social workers earlier in your journey who have assisted you with decision-making around dialysis treatment options and what works best for you and your family. At times, a social worker may help to arrange family meetings with your loved ones and your team to discuss health and treatment changes.

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Some reasons to reach out to a social worker may include:

- Adjustment to your illness and treatment.
- Confusion or being unsure about starting or stopping dialysis treatments.
- Relationship changes in your family due to starting dialysis.
- Grief and loss, which may include feelings associated with loss of employment, changes in your role in the family, or loss of a loved one.
- Helping you to communicate with your team members when you wish to make changes to your treatment including the wish to stop treatment.
- Transportation to and from dialysis concerns.
- Questions about travelling.

Resources within our program that may be available to you include the Renal Patient Assistance Fund which is strictly donor funded and was created to specifically support kidney patients who are assessed as having short-term, treatment related financial needs that impact your quality of life and your health care. Please speak to your social worker to discuss your needs and to be assessed for funding support. The funding is not available for ongoing, long-term support, for out of province travel, or retroactive expenses.

Resources within the community include the South West LHIN Home and Community supports which is a service that gets people the care they need to stay well and stay safe in their homes. Through a personal visit in your home they will determine the care support they can provide. You can make a request for services, your family can, or the dialysis staff can call 519- 473-2222 for the local services or to help find the right office in your home community.

Kidney Foundation-Southwestern Ontario Chapter helps dialysis patients by keeping in close contact with the renal programs at all three hospitals in London through nursing staff, support groups, and the renal social workers. This enables the Kidney

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Foundation to keep informed of the special needs of renal patients living within the Chapter boundaries. All the funds available for patient services, research and organ donor awareness programs are raised by hundreds of the Chapter's volunteers. The Chapter is strongly committed to serving the needs of you, the renal patient. The Patient Services Program funds a wide range of activities such as patient manuals, Camp Dorset, social events, Medic-Alert bracelets and peer support counselling to name a few. For more information call 1-800-667-3597 or www.kidney.ca/london.

Peer Support Program-Kidney Foundation, Southwestern Ontario Chapter, the major goal of this program is to help patients and their families adjust to living with kidney disease, thus enabling them to live fuller, more productive lives. They provide emotional and psychological support to patients and families as they adjust to life as a dialysis patient. The peer support volunteers work with individuals facing life circumstances similar to their own. If you feel you want to use this service, call 1-800-667-3597 or www.kidney.ca and look for the peer support program.

Medical emergencies may occur outside of the regular dialysis hours and you may not know who to call for medical assistance. If you are experiencing an emergency you should call 911 or go to the closest emergency department. If you need to speak to a nephrologist after hours for an urgent need you can call 519-685-8500 and ask to speak to the nephrology fellow on call.

Goals of Care

No one person will have the same journey with kidney disease. As your kidney function changes, you will need to make decisions about your care wishes. Some people choose to not start dialysis and allow their deaths to occur naturally with palliative care support. We continue to provide support should this treatment choice, called conservative care, be in line with your wishes. Some people wish to have a trial of dialysis to see if it provides an improvement in their quality of life and should this not be the case, they may decide to withdraw from treatment. Individuals who begin renal replacement therapy will find that there are times when their treatments go smoothly and times when adjustments need to be made to their treatment plans. Many things can influence your health and the success of your treatments. There may come a time when you question whether you want to

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continue with dialysis treatments, as your quality of life is no longer what you want it to be.

Knowing your Goals of Care can help us to ensure that we are honouring your wishes regarding your treatment and your health. Goals of care refer to having conversations with your family and friends about what is important to you around your health and treatment choices. It is especially important to discuss this with those people whom you are choosing as your Substitute Decision Maker or SDM. A SDM is the person or people who will make treatment decisions for you if you are not capable to do so for yourself. Goals of care conversations are ongoing discussions about your wishes. Having ongoing conversations with your health care providers as well ensures that you have accurate medical information to base your decisions on, to give us consent, or to express wishes about future care and treatments. Legally, a Power of Attorney for Personal Care, (health) and Power of Attorney for Property (finances) are drawn up with your lawyer, or completed using a free POA kit. You can download a free kit from the internet, or ask your social worker for one. It is important that you share your care wishes with your family and your health care team. You may wish to visit this website to learn more about the purpose of communicating your goals of care.

<http://www.advancecareplanning.ca/>.

Advanced chronic kidney disease is a complex disorder for which there is no cure. Every year, thousands of Ontarians are treated with dialysis as either a life-saving bridge to kidney transplantation or as long-term maintenance, while others choose a palliative or conservative approach. Conservative care is a holistic, person-centered approach to caring for patients with a life-limiting illness and their families. It can occur alongside a chosen treatment (like dialysis), with a focus on preventing and easing suffering and promoting quality of life. Treatment goals are based not solely on the patient's physical condition but also on personal goals, preferences, and prognosis.

Your team members are available to help you and your family members understand what will happen should you choose to discontinue dialysis. Speak to your social worker, nurse, physician or spiritual provider about your questions. We are

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committed to helping you link with community resources within the hospital or in your own community to ensure a plan for ongoing care is established that meets your needs with compassion and understanding.



Questions?

1. Do you know who your social worker is in your hemodialysis unit.
2. Living well with kidney disease is our goal as your Renal Team. Do you feel you understand or have enough information to make the best choices regarding your care on dialysis?
3. What additional resources would help you make the best decisions regarding you health care choices.?

NOTES: _____

Your Feedback is Important to Us!

We would like your input on how helpful the resources in this handbook were to you. Any feedback is confidential and will be used for future development of this resource. Please inform your Renal Team of any concerns or feedback regarding this handbook.