

# **PATIENT GUIDE**



# WELCOME TO THE HEMODIALYSIS UNIT

Created by the BCPRA Hemodialysis Committee in partnership with the Health Authority renal programs













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### Welcome

Welcome to our Hemodialysis Unit. We provide hemodialysis care, support, and treatment to people with kidney disease.

In this booklet, you will learn:

- about hemodialysis units
- what happens during hemodialysis
- who is part of your care team
- tests and procedures you might receive
- answers to common questions

Please know that we are here to help. This booklet was developed to answer some of your questions, but feel free to approach any member of the team for more information.

While having hemodialysis, you might hear or read some words or phrases that you don't know. Included in this booklet are some of these words with their definitions, found in the end section titled 'What the words mean.'

Because there is a lot to keep track of before and during each treatment, we have included a 'Hemodialysis Checklist' at the end of this booklet for you to use.

## About hemodialysis

When your kidney function deteriorates to 10-15% of normal, you get a build up of toxins (wastes) in your blood and an increase of fluid in your tissues. This makes you feel unwell and causes symptoms such as nausea, fatigue, itching, difficulty sleeping, forgetfulness, shortness of breath and sometimes, swelling. Hemodialysis removes these toxins and excess fluid from your bloodstream.

Hemodialysis filters your blood through an artificial kidney (called the dialyzer) that is attached to a hemodialysis machine. The machine pumps your blood through the dialyzer and removes excess fluid and waste products.

In order for hemodialysis to happen, we need to access your bloodstream through a "vascular access." Types of accesses include fistula (the best one), graft (the second best one) and permanent catheter. If you have a catheter, remember not to get it wet (a tub bath and not a shower is the best way to bathe as it is easier to keep the site dry). The BC Renal Agency website has a number of helpful handouts about vascular access: www.bcrenalagency.ca/ patients/vascular-access.

People on hemodialysis can enjoy a good quality of life. It is important to attend your dialysis appointments and to follow your treatment plan (which includes medications, diet and fluid advice).

### Hemodialysis settings

Dialysis is offered in a variety of settings. Once you have settled into your dialysis treatment, we will talk with you about the best setting to provide your care.

Some patients need hemodialysis care that can only be provided in a hospital dialysis unit. This care is most often provided on an ambulatory basis (i.e. no overnight hospital stay). However, dialysis is also available for short periods of time to patients admitted to hospital as inpatients. If your dialysis is stable, you may be transferred to another place to receive your hemodialysis. You may move to a community dialysis unit, an "involved" or "independent" dialysis unit or do dialysis at home. We encourage you to learn about the options available in your region and to become as independent as possible. Talk to your health care team about different dialysis settings. You can also visit the BC Renal Agency website for more information: www.bcrenalagency.ca/ patients/home-independent-dialysis.

The website also has a list of BC hemodialysis units and hours of operation: www.bcrenalagency.ca

## Hemodialysis safety

We want to give our patients the best possible care. Patients who play an active part in their own care do better and stay safer.

#### Help stop the spread of germs

People with kidney disease have weakened immune function. This makes washing hands and taking the other steps described in this section especially important.

Hand washing is the best way to stop the spread of germs.

Wash your hands with soap and water or hand sanitizer (rub) before:

- eating and drinking
- touching any cuts, sores or bandages
- touching your eyes, nose or mouth
- leaving the waiting room
- leaving the hemodialysis treatment area

Wash your hands with soap and water or hand sanitizer (rub) after:

- using the toilet
- blowing your nose
- touching any cuts, sores or bandages
- touching garbage

Do not share food, personal care items (such as combs, brushes and razors) or cigarettes with other patients.

Cover your cough or sneeze with a tissue. The germs from a cough or sneeze travel a meter (3 feet or more!) If you do not have a tissue, cough or sneeze into your elbow. Do not cough or sneeze into your hand.

If you have the flu or a cold (coughing, sneezing, etc), ask a health professional for a mask to wear while you are waiting for and during your hemodialysis treatment.

We encourage you and your family to get immunized to help us prevent illness.

#### Prevent falls

During hemodialysis, patients can feel unsteady or light-headed.

To keep you safe:

- Please wear shoes with non-slip soles.
- After hemodialysis, take time to sit up and then stand.
- If you feel unsteady, sit back down and let us know.

During your first visit, we check to see if you are at risk for falling. Let us know if you have any difficulties getting from sitting to standing or moving around. If you have an aid, bring it to your dialysis treatments. If you need help to get around, please ask.

#### A few more suggestions

Hemodialysis units can be confusing. We may overlook something that is important to you. Here are some helpful hints:

- If you don't understand something about your care, ask us to explain it.
- If something seems different about your care one day (e.g., you are given a new medication or you have not been given a medication you usually take), ask us why.
- If you do not see your nurse, doctor or other health care staff wash their hands before giving care, feel free to ask if they have washed their hands.
- If you wish that we not share information with family, let us know.

For more tools and tips on how to be involved in your care, check out this resource: https://bcpsqc.ca/its-good-to-ask

## **Keeping healthy**

It is very important that you continue to see your family doctor for regular health check-ups. If you have any health concerns that are not related to your kidney disease, contact your family doctor.

If you are seeing any other doctors, such as specialists, continue to see those doctors as needed.

We suggest that all patients on hemodialysis get a flu shot every year.

It is also important to maintain your dental

health. See your dentist for regular check-ups. Get any dental problems treated as soon as possible. Make sure you tell your dentist that you are on hemodialysis. You may require antibiotics to prevent infection.

Let us know if you have any changes to your health status or have been to an Emergency Room or your doctors' office (your family doctor or other specialists) between hemodialysis sessions.

## Getting to and from hemodialysis

#### By car

Many people feel tired after their dialysis treatment. Please plan to have someone drop you off and pick you up, especially for your first few treatments (and longer if possible).

After your first few treatments, your doctor will assess whether you are safe to drive yourself. If, after a particular treatment, the health care team feels you are not safe to drive, we will ask you to stay on the unit and make other arrangements. If you do not feel ready to leave the unit or to drive home, please let us know.

#### By other means

HandyDART Transit Service is available in many communities. It is a shared ride service for people with disabilities who are unable to use the public transit system. If you are eligible for HandyDART, your social worker can help you arrange this service.

Other alternative transport options exist but depend on where you live. This website is a

good resource: https://mard.med.ualberta.ca/ mard/db/index-bc.cfm (enter the name of the region, the community you live in and then press search).

You can also ask your social worker about options in your community.

#### Parking & drop-off or pick-up

Check with your unit about parking, drop-off and pick-up as it varies from community to community.

### What you can expect from us

#### Respect

A welcoming and respectful relationship with you and your family is essential to your care. We value the diversity of our patients and work with you to create a care plan that is respectful of your needs.

#### Confidentiality

We keep your personal and health information confidential. We only share information with those team members who are involved in your care. Details are available in a patient pamphlet on the BC Renal Agency website: www. bcrenalagency.ca/sites/default/files/documents/ files/BCPRAPrivacyBrochure\_Final.pdf.

#### Support

We know this is not an easy time for you. There is a lot to learn and a lot happening. We are here to help and support you with your dialysis needs. Feel free to ask questions. In addition, many of our patients tell us they have been helped by the Kidney Foundation of Canada's Kidney Connect Peer Support Program at 1-866-390-PEER (7337) or visit: www.kidney. ca/peer-support.

#### Education

We give all patients and their families an opportunity to get involved in their hemodialysis care. Our education program gives you the information you need to make decisions about your health and treatment. During your hemodialysis treatment, we will share information about available education materials and services.

#### Communication

If you do not speak or understand English well enough to have conversations about your health or to make medical decisions, we can book an interpreter to help us communicate. You do not pay for this. You are welcome to bring a relative or friend who speaks English for general conversation and questions.

If you have concerns about your care or safety, we would like to hear from you! We are committed to working with you to address concerns and find a reasonable solution.

- If you have a complaint, please first speak with the person who provided the service, or to the charge nurse/manager of the unit.
- If you still have a concern and would like to make a formal complaint, please contact the Patient Care Quality Office of the health authority. Contact information can be found at: www.patientcarequalityreviewboard.ca/ makecomplaint.html.

## What we expect from you

#### Respect

Please respect those around you.

- Respect other's privacy.
- Take responsibility for your behaviour and actions.
- Speak respectfully and in a low voice.
- Keep the volume of the TV or radio low or use headphones.
- Do not bring in any strong smelling foods to eat.
- When you wash, please use unscented products.
- Do not use any scented products such as perfume, cologne, or aftershave.

#### Confidentiality

While you are receiving dialysis, you might hear conversations that are private. We ask you to respect the privacy of each patient on our unit and not talk to anyone else about what you hear.

#### Get involved

While on hemodialysis we encourage you to take part in caring for yourself. Tell us about your health. Let us know if you have any worries and concerns about your disease or care.

## Your hemodialysis schedule

We give you a temporary schedule when you start hemodialysis. This schedule can change on a weekly basis. Please check with your nurse. To determine your permanent hemodialysis schedule, we consider your medical needs and other issues that can influence your care. Hemodialysis units provide care for many patients and it may at times be necessary to change patients' schedules. We appreciate your understanding.

Please arrive on time for your scheduled treatment. Not everyone starts as soon as they arrive. We bring you into the unit as soon as we can. Once we bring you into the unit, it can take 30 minutes or more to start your treatment. Our nurses always attend to patients based on their medical and dialysis needs. There may be times when your hook up time must be delayed because of issues with other patients or the machine. We thank you for your patience.

Plan for another 30 minutes at the end of hemodialysis to finish your treatment and for us to make sure you are well enough to go home.

### How long does hemodialysis take?

Your doctor decides how often and how long you dialyze based on:

- the results of your blood tests
- your body size
- the amount of fluid retained between your hemodialysis treatments (measured by weight gain)
- how well your fistula, graft, or catheter is working
- our standards of care and current research

This may change over time. Your doctor may recommend longer runs.

## Do I have to stay on the hemodialysis machine for the whole time?

Our goal is to try and keep you as healthy as possible while on hemodialysis. Many people ask us if the time can be shortened. It is important that you stay for your full hemodialysis run. Hemodialysis treatments only replace a small part (less than 5 to 10%) of the normal function of your kidneys. This is far below the 100% of normal kidney function. If you don't get enough dialysis, your blood will hold on to more waste products and over time you will feel unwell and it can affect your overall health. In general, you will do better with more dialysis rather than less.

#### Did you know?

If hemodialysis treatment time is shortened by 10 minutes a run, this means losing out on 26 hours or 2 weeks of dialysis time in a year!

## What if I need to miss a hemodialysis treatment?

Generally, it is best not to miss treatments. If you absolutely must miss your treatment, please call the unit as soon as you know. We can use the time for another person's treatment and we may be able to reschedule your treatment.

## What if I feel too sick to go to hemodialysis?

The reason for feeling sick may be related to your kidney disease, so coming for dialysis is very important. If you feel sick, call the dialysis unit and get instructions from them. If you have a severe problem such as shortness of breath, chest pain, abdominal pain, unusual weakness, excessive bleeding, etc., call 911 or go to your nearest Emergency Room.

If you are admitted to hospital, please ask your nurse at that hospital to call the Hemodialysis Unit. We will arrange for you to receive your next hemodialysis treatment.

## What if I want to change my hemodialysis schedule?

Please do your best to keep all your hemodialysis appointments. If you need to change your schedule, please give as much notice as possible.

If an emergency arises, contact us as soon as possible. We will try to adjust your hemodialysis times.

Please note: While we will do our very best to adjust your hemodialysis times, we may not be able to re-book missed treatments. We have to consider the needs of many patients.

## The hemodialysis unit

#### Waiting area

Please wait in the waiting area until you are called for your treatment. In the waiting area, there is information and articles about kidney disease, support groups, and other topics of interest.

#### Washrooms

We have washrooms in the unit for patients. Each washroom has a call bell in case you do not feel well or need help. Visitors are to use the public washrooms.

#### Smoke-free and scent-free

There is no smoking anywhere in the building. Many people are sensitive or have allergies to fragrances. Use only unscented soaps and shampoos. Do not wear perfumes or colognes.

#### Food and drinks

We do not provide meals or snacks. We suggest you eat a light meal at home before hemodialysis. Eating while having hemodialysis can make you feel unwell and lower your blood pressure.

If you have diabetes, remember to bring a snack, in case you need it during hemodialysis.

We have an ice machine. Check with your nurse if it is okay for you to have ice or ice water during your treatment.

#### What to bring

Bring a small notebook to write in questions you have or suggestions you are given.

Some units may require you to bring a blanket

and/or pillow. Choose one that can be washed easily in case blood spills on it, and wash it frequently. Ask your nurse whether electric blankets are allowed at your unit.

Bring something to do, watch or read during your hemodialysis treatment. What to bring will depend on what is available at your specific hemodialysis unit. Suggestions include:

- headphones (many units have TVs available)
- music players
- hand held games
- books or e-books
- laptop or tablet (some units have Wi-Fi)

#### Visitors

One or two visitors are welcome on the dialysis unit. Visitors may be asked to leave temporarily in certain situations (e.g., hemodialysis 'hook up' or 'take off' time and during special procedures). Please ask the staff on your unit about specifics around visiting.

## Preparing for hemodialysis treatments

#### Clothes

Wear loose comfortable clothing that allows easy access to your dialysis access site. Wear clothes that can be washed easily, in case blood or other liquids are spilled on your clothes. You may be asked to change into a hospital gown.

#### Medicines

Bring **all medicines** you are taking to your **first treatment**, including:

- over-the counter medicines
- samples of medicines from physicians
- herbal medicines
- vitamins, and supplements

Our pharmacist or doctor checks your medications with you. **After your first treatment**, bring in any new medicines you are taking.

At every treatment, bring with you any medications you need to take during the treatment. Discuss with your doctor or pharmacist whether your medications or the timing of your medications needs to change on dialysis days.

Always carry a list of your medications in your wallet or purse.

#### Arriving

Please arrive on time for your scheduled treatment. Coming in earlier does not get you on hemodialysis faster. You might have to wait a long time before we can start your treatment.

Every time you arrive, wait in the waiting area until we come to get you. This keeps the treatment area clear and is safer for everyone. When it is your turn, we bring you to your hemodialysis station.

#### Weighing in

Healthy kidneys control the fluid balance in our bodies, and dialysis does this job when your kidneys stop working. Healthy kidneys work 24 hours every day removing extra fluid and waste products. When kidneys don't work properly, urine production slows down and sometimes stops completely, so the need to remove the leftover fluid in dialysis becomes very important. Tracking the exact amount of fluid that goes in and comes out of your body isn't practical, so we use a "goal" or "dry" weight to tell the story of how much extra fluid is left in your body. You will weigh in before and after every hemodialysis treatment. When you calculate your weight, remove the weight of your shoes and any heavy clothing. Write down your weight and give it to your nurse. It is best to use the same scale before and after dialysis.

Your doctor decides on your 'goal' or 'dry' weight. This is the weight that is best for you to reach at the end of each dialysis treatment.

Weighing in before your treatment helps us figure out how much water needs to be removed from your body.

As you start to feel better, you might have a better appetite. We might need to increase your 'goal weight.' Watch your weight gain closely. Let your nurse and dietitian know if you think you might be gaining weight.

Did you know? One kilogram [Kg] of body weight is equal to one litre [L] of body fluid. If you need to lose 2 kilograms, the hemodialysis machine removes 2 litres of body water.

## Before you are hooked up to the dialysis machine

- Tell us if you have seen any doctors or had to stay in the hospital since your last treatment.
- Tell us if you have had any changes to medications since your last treatment.
   Remember to bring in any new medications.
- Tell us if you have had any unusual health events since your last treatment. e.g., a fall.

- Tell us if you do not feel well. The nurse will want to complete a detailed check of your health.
- Collect what you need before you settle into your chair or bed.
- Wash your hands with soap for at least 45 seconds. Remember the best way to stop the spread of infection is to wash your hands. If you need to touch your access site after washing your hands, clean your hands with an alcohol hand sanitizer (rub).
- Wash your access site before your treatment. If your access site is in your leg, use the washroom to wash the area.
- We check your heart rate, temperature, and blood pressure (both standing and sitting). Leave the blood pressure cuff on so we can check your blood pressure during your treatment.
- Make sure you can always reach the patient call bell.

## The hemodialysis treatment

### Before your treatment

It is normal to feel nervous when you first start hemodialysis. Your nurse or technician explains how the hemodialysis machine works. Ask as many questions as you need to ask.

If you have a fistula or graft, we insert two needles into your fistula or graft to begin dialysis. We can numb the site with freezing if you find this painful. One needle takes the blood out of your body and the other returns the cleaned blood to your body. To keep your fistula or graft working properly, we place the needles into different parts of the fistula or graft with each treatment. If you have a catheter (neck line), we connect you to the machine using the two different ends of your catheter.

You should not feel any pain once the needles are in place. Tell your nurse if you do have pain or discomfort during your treatment.

Blood may be drawn before dialysis is started. Blood tests are done routinely to make sure your dialysis dose is adequate and to see if changes to your treatment are necessary.

### During your treatment

During hemodialysis, only about 1 cup (250 mL) of blood is outside the body at any time. You do not feel the blood moving out and back into your body.

You could get a low blood pressure during hemodialysis. Tell us right away if you:

- feel dizzy or faint
- feel restless
- are sweating or feeling warmer than usual
- feel sick to your stomach (nauseated)
- feel like you need to move your bowels
- feel your heart racing
- have blurred vision

To treat a low blood pressure:

- We lower the head of your chair or bed to lay you down flat.
- We can raise the foot of the chair or bed to move blood back towards your head and heart.
- We can give you some extra fluid through the hemodialysis machine.

Other symptoms such as muscle cramps or a headache can also occur, but are not common. If you feel anything unusual, let us know right away so we can help you. You can help yourself by keeping to your diet and fluid limits between treatments. Going over your limits increases the amount of fluid that must be removed during treatment. Taking away the extra fluid is one of the things that may make you feel sick.

#### After your treatment

When your hemodialysis is finished, your nurse removes the needles. If you have a fistula or graft, apply pressure to the needle sites for at least 10 minutes to stop the bleeding.

To hold pressure over the needle sites:

- Always clean your hands.
- Put on a clean pair of disposable gloves.
- Hold a gauze pad over the needle site using two fingers. Press at the needle spot and just above.
- Hold constant firm pressure for at least 10 minutes.
- We might take out one needle at a time and ask you to hold each site, one at a time.



Once the bleeding has stopped:

 Place a clean gauze pad over the needle site and tape in place. *Never* wrap the tape around your arm (or leg). If you do, it can reduce the blood supply to your fistula or graft.

- Remove the disposable gloves.
- Wash your hands.

#### Before you leave

We check your heart rate and blood pressure (both standing and sitting) and in some cases, your temperature.

Some people get a low blood pressure after the treatment. If you feel faint, dizzy, or lightheaded after your hemodialysis:

- Sit down right away.
- Tell one of us that you do not feel well.

For your safety, we do not let you leave until you are feeling better. If you do not recover right away, we might arrange for you to go to another area for care until you feel better.

Check that your fistula or graft is still working. We teach you how to do this.

- If you have a graft, check for a strong pulse.
- If you have a fistula, check for a buzzing sensation around the fistula. (We call this a 'thrill').

Weigh yourself again. Remember to wear the same clothing and use the same scale. We want to check that the right amount of water weight was removed. Remove the weight of your shoes and any heavy clothing from this weight.

Always wash your hands with soap. This helps stop the spread of any germs you might have contacted during the treatment.

Carry packets of gauze with you in case your needle sites start to bleed after you leave the unit.

Have someone drive you home after the first few treatments (longer if possible). You might get very tired after hemodialysis so it is safer if someone drives you.

## At home

#### Take it easy

Rest when you get home from dialysis. You might feel quite tired. Many people feel better once they have been on hemodialysis for a few weeks.

#### Care of your access After dialysis

If you have a fistula or graft, take the gauze off 4 to 6 hours after your dialysis treatment. Be careful not to pull off the scab when you remove the bandage. Avoid scratching or picking at the scabs.

If your access starts to bleed after you leave the hemodialysis unit:

- Put firm pressure over the needle sites again for 10 minutes. Do not peek under the gauze during this time. The pressure must be constant over the 10 minutes.
- Check after 10 minutes and make sure the bleeding has stopped.
- Tape a clean gauze pad over the area.
   Leave the new gauze on for 4 to 6 hours before you try to remove it.

If the bleeding does not stop:

- Continue to put firm pressure on the needle site.
- Call for help from anyone who is at home with you.
- If the bleeding does not stop or starts to get worse, do not panic. Continue with the pressure and call 911 for an ambulance.

#### Every day

Check your fistula, graft, or neckline every day or even several times a day to make sure it is working:

- Fistula or graft: Feel for a buzzing sensation (called the "thrill") under the skin where the fistula or graft is.
- Catheter (neck line):
  - Check that all the clamps are closed and the caps are on tightly.
  - If you have pain or swelling around the neckline, you might have an infection. Let your nurse know.

## Call your Hemodialysis Unit right away if:

- You can't feel the "thrill" or if it feels different from usual (fistula or graft).
- There is redness, warmth, pain or swelling in your access arm (fistula or graft) or along your catheter.
- There is any oozing or drainage from your fistula, graft or catheter exit site.
- You have noticeable swelling in your access arm (fistula or graft) or around your catheter, neck or face.
- You are feverish and have any of the above symptoms.
- Part of your catheter outside your skin seems to be getting longer.
- Your catheter is accidentally pulled and there is bleeding around the exit site.

#### Save your veins!

If you have a fistula or graft, save your access arm for dialysis and let others know this. Do NOT take blood pressure on this arm. Do NOT have blood work taken from this arm or have an intravenous started in this arm. It is OK to tell health care workers this, as not everyone will know what a fistula or graft is.

Wear a Medical Alert bracelet (medicalert.ca) or call 1-800-668-1507) or a "purple" bracelet from BC Provincial Renal Agency or carry a card in your wallet (ask a renal staff member for a bracelet or card) to let health care workers know that you are a renal patient and that your veins need to be protected.

#### I AM A RENAL PATIENT. Important info about my veins:

- NO IVs or blood draws on my RIGHT / LEFT arm.
- If IV or blood draw is required, use my hand veins or my other arm.
- NO BPs on my fistula or graft arm
- (if fistula or graft in place).
- If a long-term central line is required,
- use tunneled internal jugular line.
  Use PICC line as last resort.



## Tests, procedures, and appointments

#### **Blood tests**

We do blood tests during your first treatment, and then every 4 - 6 weeks after that. The doctor might order blood tests more often depending on the results from these tests. We use the results of your blood tests to help plan your treatment, diet, and what medications you take.

If you see your family doctor or specialist for a health problem and that doctor wants you to have blood tests:

- **Do not** go to a community laboratory.
- Bring the request form when you come in for hemodialysis.
- We will draw the blood when you are here for dialysis. This avoids you being poked with another needle.
- We send a copy of the results of the tests to the doctor.

#### Other tests and procedures

We take swabs to check for bacteria during your first treatment. We repeat this test every year.

We do blood tests for hepatitis and other bloodborne infections when you start treatment. We repeat this test every year.

We do tests for tuberculosis during your first week of treatment. This includes asking you some questions, a blood test and getting a chest-ray done at the hospital radiology department.

If you have not had an 'electrocardiogram' and an 'echocardiogram' done within the last year, we arrange for you to have them done. (Refer to section 'What the words mean' for an explanation of these tests).

#### Appointments

While you are on hemodialysis, your kidney doctor will see you at the dialysis unit or you will be asked to make regular office appointments with him/her (some kidney doctors work together to care for a group of patients). It is up to you to arrange to get to and from the appointments.

If you cannot get to an appointment, you (or a friend or family member) must call to cancel that appointment.

## About medications

#### **Medication record**

We record all medications you are currently taking in your patient record.

'All medications' means:

- all medicines ordered by your doctor(s)
- medicines you can buy without a prescription such as cold medicines, laxatives and antacids
- pain medicines
- medicine samples
- vitamins
- herbal medicines
- supplements
- natural remedies
- nicotine replacement therapy products
- study or research drugs

#### Changes in your medications

If another doctor orders a medication for you, or you start a new medicine or herbal product, please bring it to your next hemodialysis treatment and show it to the renal nurse or pharmacist. Medication can work differently in a person on hemodialysis. We will check them to make sure they are okay with your hemodialysis.

Always tell your doctors or pharmacists that you are a hemodialysis patient so they can give you a dose that is right for you.

#### **Medication costs**

The BC Provincial Renal Agency (BCPRA) pays for most prescription medications related to your kidney disease, provided that you obtain it from a **specific BCPRA-affiliated pharmacy**. A list of BCPRA-funded medications can be found on the BC Renal Agency website: http://www. bcrenalagency.ca/node/738. The website also has a number of helpful handouts on common drugs used to treat patients with kidney disease: http://www.bcrenalagency.ca/node/1220.

Medications not related to your kidney disease are not paid for by the BC Renal Agency. However, they might be covered by PharmaCare or by your private drug insurance plan. You must arrange payment for these medications directly with your pharmacy.

#### Your medication supplies

All of your kidney medications are ordered through a **specific pharmacy**. This pharmacy is one of 30+ community pharmacies across the province that provides kidney patients with medications paid for by the BC Renal Agency.

As soon as you have only a **2-week supply** of medications left, call your specific community renal pharmacy to order more using the phone number on the medication label. It may be possible to have your kidney medications delivered to you at home, the hospital, or dialysis unit. Remember - We do not order your kidney medications for you. For medications not related to your kidney disease, you can choose to order them from the same pharmacy as where you get your kidney medications or order them from a different local pharmacy. For your safety, we strongly encourage you to obtain all of your medications from **one single pharmacy**.

Be prepared for an emergency. Always have at least a 2-week supply of kidney medications.

## Hemodialysis and travelling

It is possible for dialysis patients to travel. You make your own arrangements for dialysis at a centre where you are travelling. Your home unit will coordinate your treatment with the dialysis centre you choose. Your home unit needs at least 6 weeks' notice to prepare your travel paperwork. For travel outside BC, 3 months notice is required. If you wish to travel, the staff on the hemodialysis unit can provide you more information.

### Your hemodialysis care team

#### Nurses

Our nurses take care of you during your treatment. This includes assessing you, reviewing blood test results, connecting you to the hemodialysis machine, monitoring the machine for any alarms, taking you off the machine when your hemodialysis is complete, and checking that you are well enough to go home. Your nurse works with you to make a plan for your care. Hemodialysis nurses receive special education about caring for patients on dialysis. In some units, nurses may be assisted by care aides. If you have questions about your treatment, please ask your nurse. The nurse will help you and your family to learn more about kidney disease.

## Charge Nurse, Patient Care Coordinator, Team Leader or Clinical Nurse Leader

These nurses are in charge of running one or more hemodialysis units.

Speak to this nurse when:

- You have questions or concerns your nurse or other team members cannot answer.
- You would like to make changes to your treatment schedule.

#### Vascular Access Nurse

The vascular access nurse talks with you about the options for vascular access such as fistula or graft, and helps you decide which option is the best one for you.

The vascular access nurse works closely with the nurses on the hemodialysis unit to monitor the health of your access and help with any problems with your vascular access. The vascular access nurse may arrange for special tests and procedures.

#### Transition Nurse or Patient Navigator

Some hemodialysis centres have a transition nurse or patient navigator (nurse). This nurse helps patients learn about treatment options and to smooth the way when transferring from one treatment option or hemodialysis unit to another.

#### **Nurse Practitioner**

Some hemodialysis centres have a nurse practitioner. A nurse practitioner is a nurse with

advanced education. The nurse practitioner diagnoses and treats some medical problems, and orders medications. He or she manages your medical care and works with you and your doctors to make a plan of care that is best for you.

#### Nephrologist (Kidney Doctor)

A nephrologist is a doctor who has advanced education related to diseases of the kidney. One nephrologist or a group of nephrologists is responsible for your care.

Your nephrologist(s) cares for your kidneyrelated concerns and will work in partnership with your family doctor, who will still look after your other concerns. If you do not have a family doctor, we can give you a list of doctors taking new patients.

#### Dietitian

Eating well is important to improve your health and how you feel on dialysis. People on dialysis are more likely than other people to be malnourished. Your renal dietitian will watch for any signs you are becoming malnourished and will work with you and your doctor to prevent or improve this. The dietitian will help you choose foods that fit with your way of life, put your blood tests in the right range, avoid symptoms like thirst and feeling tired, and keep you as healthy as possible. If you need nutritional supplements to get enough protein, calories, vitamins and minerals, your dietitian will recommend them. The cost of these is covered by the BC Renal Agency and your dietitian will order them for you.

Your dietitian will meet with you regularly, to go over your lab tests and to see how you are

doing. Your dialysis diet may change if your health changes.

Ask to speak to your dietitian if you have questions about your food or nutrition, or if you have changes in your appetite or weight, or trouble with digestion.

#### **Social Worker**

Whether you have known for some time that you would eventually need dialysis, or it has come as a shock, starting dialysis treatments is a stressful time. Most individuals and their families experience a period of emotional and practical adjustment. Each individual's experience is different. The social worker can help you and your partner/family adjust to the changes that might arise during your transition to hemodialysis. The social worker can also help locate and access community resources and help with such things as transportation, parking, home support, financial aid, employment or retraining, housing, advance care planning, etc.

If you wish to speak with your social worker, ask your nurse to contact him or her.

#### Pharmacist and Pharmacy Technician

Our pharmacist regularly reviews the medications you are taking to make sure they continue to be the right ones for you. In addition, the pharmacist will be involved in making drug therapy decisions with you and your kidney doctor. If you have any questions or concerns about your medicines, ask to speak to the pharmacist. In some centres, a pharmacist and pharmacy technician will work together to review your medications. You will use a community pharmacy to get your renal medications.

#### \*\*PLEASE NOTE — VERY IMPORTANT\*\*

- Ensure that your community pharmacist is aware you have chronic kidney disease and ask them to attach a note to your personal file in their computer system.
- Ensure that you ask your doctors and pharmacists, "Is this medication okay with my level of kidney function?" for ALL written prescriptions, or any over-thecounter medication or herbal supplement you intend to use.

#### **Renal Technician**

Some hemodialysis centres have renal technicians. Renal technicians set up, take apart, and clean the hemodialysis machines.

Together with the nurses, the technician:

- listens for and attends to any machine alarms
- helps provide effective hemodialysis
- tries to make you feel comfortable and safe during your treatment

#### **Biomedical Engineering Technologist**

You might meet one of our technologists during your treatment. They have special training and maintain the hemodialysis machines to the highest standard of quality.

#### Unit Coordinator or Clerk

Our unit coordinator or unit clerk keeps your chart organized and processes any doctors' requests for tests, medicines or procedures. When your nephrologist wants you to see other health professionals or go for tests, the unit coordinator or clerk makes the appointments and places a note in your chart for your nurse to give you.

## Resources

In addition to your kidney team, additional resources that may be helpful include:

#### HealthLink BC

Dial 8-1-1 (if hearing impaired, dial 7-1-1) Talk to a nurse 24 hours/day, 7 days/week Pharmacist available 5 pm - 9 am daily Dietitian available 9 am - 5 pm, Monday to Friday www.healthlinkbc.ca

#### **BC Renal Agency**

Provides useful patient information www.bcrenalagency.ca/patients Ph: 604-875-7340

#### Kidney Foundation of Canada, BC & Yukon Branch

Provides many types of support, including information pamphlets, short-term financial assistance, interest-free loans, etc. www.kidney.ca/BCHome Ph: 604-736-9775 / 1-800-567-8112 within B.C. Peer Support Program: 1-866-390-PEER (7337) or visit: www.kidney.ca/peer-support

#### **Regional Community Pharmacies**

www.bcrenalagency.ca/kidney-services?s=2&r=All

#### **BC Transplant**

www.transplant.bc.ca Ph: 604-877-2240

#### **BC Ministry of Health: Pharmacare**

www2.gov.bc.ca/gov/topic.page?id=D1A5394E2B5F4A358A65C07D202E8955 Ph: 604-683-7151 / 1-800-663-7100

#### BC Ministry of Health: Medical Services Plan Premium Assistance

http://www2.gov.bc.ca/gov/topic.page?id=58BEE5442CDE47DDA7766B013F048CEC Ph: 604 683-7151 / 1 800 663-7100

#### Canada Revenue Agency, Disability Tax Credit

http://www.cra-arc.gc.ca/tx/ndvdls/sgmnts/dsblts/menu-eng.html Ph: 1-800-267-6999

## What the words mean

#### Blood test

A sample of blood taken and sent for testing. This is usually taken from the hemodialysis machine during treatment. It can also be taken from a vein in the arm using a needle.

#### CPO (Carbapenemase Producing Organisms)

A CPO is a normal bacteria (often found in your bowel) that has developed the ability to stop most antibiotics from working. A person can have normal CPO bacteria in their bowel and not have any health problems. If an infection develops from this bacteria, then treatment will likely be difficult. Sometimes these bacteria are called other names such as CRE or CPE.

## Darbepoetin (Aranesp) and Erythropoietin (Eprex)

Medications used to treat a person with a less than normal number of red blood cells (called anemia). People with chronic kidney disease can have anemia.

#### Dialyze

To have your blood filtered through a hemodialysis machine.

#### Dialyzer

A special filter in the hemodialysis machine that removes wastes from the blood. The dialyzer is an 'artificial kidney.'



#### Electrocardiogram (EKG or ECG) Test

'Electro' means electrical activity, 'cardio' means heart, and 'gram' means a print out. This is a test that checks the electrical activity of the heart and is represented as lines printed on paper.

#### Echocardiogram

Instead of electrical activity, this test used sound waves to get images of the heart.

#### Hemodialysis

When a machine is used to clean or filter wastes and remove extra fluid from the blood (A job normally done by the kidneys).

#### 'Hook-up' time

The time your nurse assesses you and connects you to the hemodialysis machine.

#### 'Take-off' time

The time when your nurse disconnects you from the hemodialysis machine and checks to make sure you are well enough to go home.

#### Hepatitis B

An infection caused by the hepatitis B virus, causing irritation and swelling of the liver. Spread by contact with infected blood or body fluids. The liver usually recovers within 4 to 6 months.

#### Hepatitis C

An infection caused by the hepatitis C virus, causing swelling of the liver. Spread by contact with infected blood or body fluids. This infection can cause permanent damage to the liver.

#### MRSA (Methicillin Resistant Staphylococcus Aureus)

An infection caused by the bacteria staphylococcus aureus, which is resistant to the antibiotic Methicillin. These bacteria normally live on human skin and in the nose. An infection from these resistant bacteria can be difficult to treat.

#### Tuberculosis

An infection caused by the bacteria 'tubercle bacilli.' You can breathe in these bacteria from someone who has the infection. While the infection starts in the lungs, it can spread to other parts of the body, such as the brain, bones, or joints.

#### Uremia

A term used to refer to symptoms associated with kidney failure such as feeling tired (fatigue), nauseated, itchy or losing your appetite.

#### Vascular access

Can be a fistula, graft, or catheter that allows access to your bloodstream over and over. The vascular access takes your blood to the hemodialysis machine and returns your blood to your body after it has been cleaned.

• Fistula

Often referred to as your AVF (arteriovenous fistula). The creation of the fistula requires an operation so needles that connect you to the hemodialysis machine can be inserted.

Graft

Often referred to as your AVG (arteriovenous graft) or 'graft.' The creation of the artificial graft requires an operation so needles can be inserted that will connect you to the hemodialysis machine.

Permanent catheter Often referred to as a "perm cath," CVC (central venous catheter) or TCC (tunnelled cuffed catheter). This tube is inserted into your chest. It might be used if your hemodialysis needed to be started urgently.

#### VRE (Vancomycin Resistant Enterococcus)

An infection caused by the bacteria called 'enterococcus' and resistant to the antibiotic Vancomycin. These bacteria normally live in the human bowel and can sometimes cause an infection. An infection from these resistant bacteria can be difficult to treat.

## **Hemodialysis Checklist**

#### First visit only

- Bring all your medicines, including herbal medicines, vitamins, and supplements.
- Let us know at least one week before if we need to book an interpreter.
- □ Arrive 30 minutes before your first hemodialysis start time.

#### Preparing for every visit

- □ Wear shoes with slip-resistant soles.
- U Wear loose fitting clothes that are easy to wash.
- Bring any medications you need to take during your treatment.
- Bring in any new medications for us to check.
- Bring a book or electronic device to read.
- Bring a list of any questions you might have.
- Bring a small notebook to write questions or advice.
- □ \_\_\_\_\_

#### Every visit

- Arrive on time for your scheduled hemodialysis start time.
- □ Weigh yourself before your treatment.
- □ Write down your weight (subtract the weight of your shoes and any heavy clothing).
- Tell us about any changes to your medications.
- Tell us about any changes in your health or if you have stayed overnight in the hospital for any reason.
- $\Box$  Wash your hands with soap.
- $\Box$  Wash your access site with soap.
- Check to make sure your call bell is within reach.
- □ Weigh yourself after your treatment.
- □ Write down your weight (subtract the weight of your shoes and any heavy clothing).
- □ Clear your table before you leave.
- □ Make sure you have some packets of gauze with you.
- □ Remove your bandage 4 to 6 hours after you leave the hospital.
- □ \_\_\_\_\_

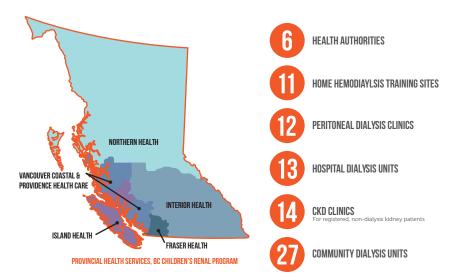
### Regular checks

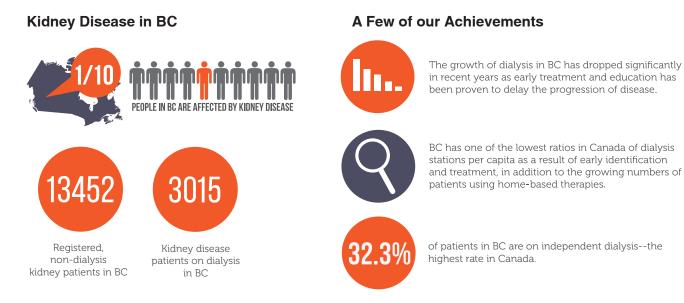
- Check your fistula, graft, or neckline twice a day.
- □ See your family doctor for regular check-ups.
- □ See your dentist for regular check-ups.

## The BC Renal Agency

#### Who we are

The BC Provincial Renal Agency (BCPRA) is the driving force behind the BC renal network, funding and coordinating care for patients across the province. No matter where they live in BC, kidney patients have access to the same standard of care and treatment options. As a result, people with kidney disease in BC enjoy better health outcomes than kidney patients elsewhere in Canada.





For more information about kidney services across the province, visit bcrenalagency.ca. The agency website also offers helpful information for kidney patients on medication, diet, independent dialysis options, tips for living well with kidney disease, and many other topics.



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Welcome to the Hemodialysis Unit: Patient Guide