

# Transitioning to Home Hemodialysis Patient Guide

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You have decided, with the support of your kidney care team, to begin home hemodialysis (HHD). This guide provides information to help you prepare for a smooth transition to HHD.

Transitioning to HHD has 6 steps. During each step, your health care team will be there to provide support. The amount of time that you spend at each step will depend on your health and recommendations by your health care team.

# What can I expect to happen at each step?



# Step 1: I have decided that HHD is the best option for me



# What to expect

After receiving education and discussing your treatment options, you have made an informed treatment choice to start HHD. Your kidney care team will be notified of your treatment choice and an appointment will be arranged for you and your family to meet with the HHD team. This orientation appointment is designed to give you more information and answer any questions you may have about managing your HHD.

# Things to think about and discuss

Taking an active role in your health and your HHD treatment has many benefits. It puts you in control of your life. You become a partner with your kidney care team and knowledgeable about all areas of HHD.



You may want to begin reviewing the "Home Hemodialysis" section on the BC Renal website: BCRenal.ca ⇒Health Info ⇒Kidney Care ⇒ Home Hemodialysis

You will learn everything included in these modules during training, so don't worry if it seems like a lot of information. At this stage, it's a good introduction to what you'll be learning.

We know you will have many questions about HHD. It's helpful to have a written list of questions to ask the kidney care team during your appointment. Some examples of the questions you might ask and decisions you need to make now are on the next page.



- Is there a lifting requirement and if so, how many pounds?
- What types of supports are available to me if I choose home hemodialysis?
- How will I be trained to perform home hemodialysis?
- Where does the training take place?
- What does my day look like on HHD?
- What will my daily responsibilities for myself and/or my partner look like?
- Who do I call if I have questions about my care?
- Is travelling possible on HHD?
- What is the best machine choice for travel?
- Is intimacy an issue with HHD?



### DECISIONS I NEED TO MAKE NOW

After receiving more information about HHD at your appointment, you should ask yourself:



- Will HHD be the best treatment option for my lifestyle?
- How will HHD fit into my life?
- Who will help me with HHD when I need help?

# Step 2: Preparing for HHD

# What to expect

During this time, you and your healthcare team will continue to monitor your overall health. Your health will guide when certain procedures will take place. As your kidney function decreases, you and your team will make decisions around preparing for HHD. When the time to begin dialysis is determined, the HHD team will work with you to develop a detailed HHD care plan.

This may include:

- Vascular access creation- a vascular access refers to the surgical insertion of a fistula, graft, or catheter to provide access to the bloodstream for dialysis.
- Home hemodialysis training- takes place at the Home Hemodialysis Clinic over a period of several weeks. You are expected to attend all training sessions. You may bring a family member or a support person with you. Each training day is approximately 6 hours.

 Patient responsibilities- your role includes understanding HHD well enough to manage and perform dialysis at home, ordering supplies and calling for help if/when needed.

# Things to think about and discuss

It is very important that you follow the treatment plan developed with you. You will be taking a very important step towards a healthier life by understanding your health and the important role you play in your treatment. Discuss any life situation changes that may impact your ability to do HHD with your healthcare team. Some examples of changes that are important to share include:

- You think that HHD may not be the right choice for your lifestyle.
- You are planning to move to a new home or community.
- You no longer have someone to support or help with your HHD treatment.
- You are experiencing changes that are making it difficult to do or perform familiar activities. These changes may be your memory, vision, hearing, dexterity, mobility, strength or energy levels.



- Will changes in my health condition such as my eyesight, dexterity, or strength have an impact on my ability to do HHD?
- When will my vascular access be inserted?
- When will I start dialysis?
- I live out of town. Is there funding available to help cover the cost of travel and accommodations when I attend HHD training?
- What accommodation options are there?
- Do I need written permission from my landlord to allow for minor renovations in my rental?



## DECISIONS I NEED TO MAKE NOW

During this time, it is important for you to consider the following:

- How will HHD fit into your daily life?
- <u>What</u> support will you need to do HHD at home?
- Who will you ask if you need help?
- Where will you do HHD in your home? Where will you keep your HHD supplies?
  - A box of dialysis solution weighs approximately 20 kgs. You will need storage space for about 30-60 boxes.
- Renters: Will my landlord agree to minor renovations to accommodate the HHD machine?

# Step 3: It is time to have a vascular access created

# What to expect

In order to perform Home Hemodialysis, a 'vascular access' is required to access your blood. A vascular access must be inserted before you start dialysis treatments as it does require a surgery and healing time. You will meet with the surgeon and a vascular access nurse may use an ultrasound to look at the veins in your arm.



There are three types of vascular accesses that can be used for home hemodialysis:

- 1. Fistula
- 2. Graft
- 3. Central Venous Catheter

Once your surgeon has decided the best vascular access option for you, your kidney healthcare team will provide specific information about insertion of your vascular access.

This information includes:

- Date, time, and location of the vascular access insertion. Depending on the type of vascular access that is best suited for you, it may take 6-8 weeks for your vascular access to be ready for dialysis. The procedure may be done in a special procedure room or in an operating room.
- Location of the vascular access. A fistula or graft is usually placed in your non-dominant arm (i.e. the arm you do NOT write with). A catheter is tunneled under the skin near your chest, with part of the catheter exposed in your upper breast area.
- How to prepare for the vascular access insertion procedure.
- What to expect during the vascular access procedure
- How to care for your vascular access after it has been inserted.

# Things to think about and discuss

- You will be given a handout with all the information you need to know to prepare for the vascular access insertion. Follow the instructions provided.
- Arrange to have someone drive you to the procedure and pick you up afterwards.
- Plan for any help you might require following the vascular access insertion procedure.
- Make sure you have all the necessary supplies to care for your vascular access after the procedure.
- Call your kidney care team if you have any questions or concerns.

There are many tools and pamphlets on the BC Renal website to assist you. Please visit the website:

BCRenal.ca ⇒Health Info ⇒ Managing my Care ⇒ Vascular Access



- Who can I get to help me in the home if needed after my vascular access surgery?
- How do I keep my vascular access healthy?
- When should I call my kidney doctor (nephrologist) or kidney care clinic?

# DECISIONS I NEED TO MAKE NOW

- Who will I get to drive me home from my procedure?
- Who can I get to help me in the home after my vascular access procedure?
- How will I bathe knowing that I cannot get my vascular access wet?

# Step 4: After the vascular access has been created



## What to expect

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A nurse from the vascular access team will make arrangements to meet with you and remove the sutures from your incision within 10-14 days. During this appointment, the nurse will listen to your vascular access using a stethoscope. The nurse may request that you return to clinic for further assessment of your new vascular access. Your vascular access is your lifeline, so it is important to care for it exactly as you have been instructed.

# When to call your healthcare team

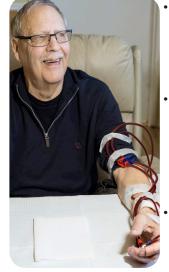
- You cannot feel the "thrill" (buzzing under the skin that you can feel with your fingertips)
- There is redness that appears agitated, warmth, or painful at the incision site of your fistula/graft/catheter
- If there is any oozing or drainage from your fistula/graft/catheter
- If you are bleeding from your fistula/graft/ catheter.
- If there is noticeable swelling or itching in your fistula/graft/catheter.
- Any difficulty moving the fingers in your fistula/graft arm.
- If you have a fever.

The BC Renal website has a number of resources to help you care for your vascular access. Please refer to the website:

BCRenal.ca → Health Info → Managing my Care → Vascular Access







- How do I feel for the "thrill"? (buzzing under the skin)
- How do I listen for a "bruit"? (swooshing sound under the skin)
- How do I perform my vascular access exercises?

## DECISIONS I NEED TO MAKE NOW

- How will I organize my dialysis area knowing that I will only have one hand and arm to move around during treatment?
- How will I preform my daily activities to protect my vascular access? ie carrying groceries, purse etc.

# Step 5: Home hemodialysis training is starting



## What to expect

Once your vascular access has healed, and you and your kidney healthcare team decide it is the right time to start dialysis; your HHD training will be scheduled. You will be given a date, time and location. The length of training will be determined by your HHD program and generally takes place during the day Monday-Friday. Your healthcare team is available to offer support to you during this process. You may need to have 2-3 dialysis sessions in the hospital to check your important vital signs before you move to home hemodialysis training. During your HHD training, you and your nurse will walk through the steps needed to manage you HHD treatment at home. You will learn how to set up your HHD equipment and how to do the treatment. During HHD training, you will be performing HHD yourself. Your HHD nurse will decide when you are ready to do HHD yourself at home.

Topics covered in detail during your training are:

- Managing your HHD care independently
- Caring for your vascular access
- How to use the home hemodialysis machine
- How to measure your vital signs
- What to do in an emergency
- How to solve HHD related problems at home

For more details on Home Hemodialysis training, please refer to the **Home Hemodialysis Patient Workbook** that can be found at:

BCRenal.ca → Health Info → Kidney Care → Home Hemodialysis → Patient Workbook

# Your commitment

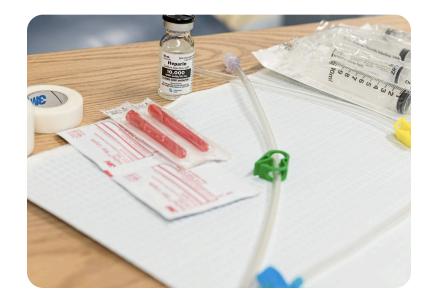
Home hemodialysis requires your commitment. You will be asked to sign a document declaring your dedication to the training process.

# **Attending training**

We understand that patients who live in rural communities may choose to relocate to their training clinic area during training. If you would like to discuss planning, please contact your healthcare team. The healthcare team may be able to offer some assistance with finances, travelling, parking, accommodations, and so forth.

## Home renovations and supplies

In order to operate the dialysis machines, there are times when a renovation is required for electrical access and/or water flows required to operate the machine. A representative from the dialysis machine company will come to your home and make recommendations for certain renovations. If dialysis related renovations are needed, your healthcare team will help you arrange for your home to be modified to accommodate the equipment. There is no cost to you. Equipment and supplies are delivered right to your home into your designated dialysis area.





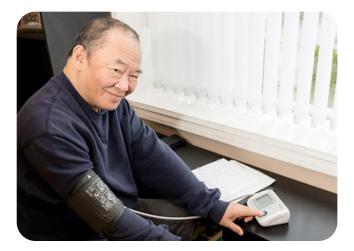


- Who will monitor my health when I am at home?
- Who do I call if I am having problems with my HHD treatment at home?
- How do I order my HHD supplies?
- I want to do HHD while I sleep, what will be different about my treatment?
- How do I prevent infections?
- How will I know if I have an infection?
- Will there need to be changes in my medications?
- Will my diet change now that I am on HHD?

# DECISIONS I NEED TO MAKE NOW

- Where will I keep my supplies?
- Where will I do my HHD treatment at home?
- Will I dialyze in a chair, or bed, when I am home?
- Is there enough room in my chosen treatment area to move the machine to clean around it?
- Has my well water been tested recently?
- Is my septic system able to hold more waste?
- How will I keep my pets out of the area when I am doing HHD treatments?
- Will I need to change to a different pharmacy?

# Step 6: I am doing HHD by myself at home



## What to expect

**Congratulations!** You are ready to do HHD at home. It is natural to feel overwhelmed when learning to perform HHD. Overtime you will become more comfortable performing your treatments. You will develop a routine that allows HHD to fit into your daily life.

# A CARE TEAM

- Will I be able to switch from daytime to nighttime HHD?
- Who can help me if I am having trouble with money, finances, or transportation etc.?
- What exercise can I do now that I am on HHD?
- What help is there to explain my wishes for future health care?
- Is there support to help tell my family, or loved ones, what is important to me?
- How can I prepare for emergencies?
- What if myself, or my caregiver, needs a break from HHD, is there support for respite?
- What do I need to know about making travel arrangements?
- How will my information be shared with my family doctor and local pharmacy when my prescription changes?
- How will I share information with my kidney team if my family doctor makes prescription changes or recommendations?



- How will I get to any clinic appointments?
- Who would I call if I need help?
- When are the best times for me to do HHD procedures or exchanges?
- When is the best time for me to do my HHD treatment?
- Which local laboratory will I visit for my blood work?

# Notes to myself:

 Bring the "Transitioning to Home Hemodialysis" booklet to all of my appointments

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# **Important Contacts**

Home Hemodialysis clinic phone number:

Home Hemodialysis nurse:

Social work:

Dietitian:

Hospital switchboard:

In case of an emergency call:

My advanced care plan is kept:

Future clinic appointment dates:



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