



How you want to be treated.

Introduction to the BC Home Parenteral Nutrition Program (Adult Patients)

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YOUR DOCTOR HAS REFERRED YOU to the BC Home Parenteral Nutrition (HPN) Program. This handout gives you information on what you can expect.

What is parenteral nutrition?

Parenteral nutrition (PN) is a medical and nutrition therapy usually given in the hospital. In the hospital, this therapy is usually called “total parenteral nutrition” or TPN.

When a person does not have a gut (gastrointestinal tract) that works, they might not be able to absorb the nutrients and fluid in the foods they eat and drink. PN gives people the nutrients and fluid they need to stay healthy.

PN is made up of nutrients in a special liquid (also called a solution). The solution goes directly into your blood through a central venous catheter, often called a CVC. A CVC is a long, flexible tube that is inserted under the skin into a large vein that returns blood to your heart. A special pump, called an infusion pump, is used to push the solution through the CVC into your blood.

The PN solution contains the nutrients you need and would normally get in food. The solution usually contains protein, fat, carbohydrates, electrolytes, vitamins, minerals and fluid.

What is home parenteral nutrition?

“Home parenteral nutrition” (HPN) is PN that you give yourself at home. HPN is a good option for people who:

- do not need to be in hospital except to have PN
- need to be on PN for at least three months
- are able to learn how to infuse their PN at home or have a family member, friend or caregiver who can help with this

What is it like to be on home parenteral nutrition?

When a person is on HPN, they have more freedom than being in the hospital. People on HPN can go out and do things – even while their nutrition is infusing. However, HPN is not easy. Here are some things to consider:

Time: You will spend about 1.5 to 2 hours per day to:

- care for your CVC
- get your solutions ready to infuse
- hook up to the solution
- unhook from the solution
- look after your infusion pump

Usually, patients are hooked up to their infusion pump for about 14 hours at night while sleeping. Some patients might need to be hooked up for longer, depending on their nutrient and fluid needs.

You are also expected to:

- go for blood tests regularly. The blood tests check to see if the solutions are giving you the nutrition and fluid you need. The doctor will decide how often you need to have blood tests done.
- stay in contact with our care team by phone. Our team will phone you to talk about your blood tests and any changes we need to make to your HPN solutions.
- come to St. Paul’s Hospital at least once a year for a follow-up appointment with our care team. You might be asked to come to the clinic more often if we have concerns about your HPN.
- see your family doctor regularly. You might also need to have regular appointments with other specially trained doctors.

Space: You need enough space at home for your HPN supplies, including an extra refrigerator for HPN solutions. This refrigerator is provided by our supplier and delivered to your home before you are discharged from St. Paul’s Hospital.

Strength: HPN solutions and equipment are heavy. On average, the solution and equipment together weigh about 10 pounds. You will need to lift and move the solutions or have someone at home to help you do this.

Things to consider, *continued*

Ordering: You must keep track of your solutions and supplies. You have to order your solutions and supplies every two weeks. Our supplier sends your solutions and supplies to your home.

Complications: HPN has some risks. You will learn what those risks are, how to prevent them and how to spot them early so you can get treated. Some of the complications can be life threatening if not treated in time.

Who is the HPN care team?

The HPN care team includes:

- Medical director
- Medical associates
- Nurse (patient educator)
- Dietitian
- Pharmacist
- Secretary
- Program coordinator

The team works together to manage your HPN care while you are at St. Paul's Hospital and once you are at home.

Note that while you are at St. Paul's Hospital you will not see a doctor every day unless you become unwell.

How do I get into the BC HPN Program?

Not everyone who is on PN is appropriate for the BC HPN Program. You need to qualify for the program.

Step 1: Your doctor completes an application on your behalf. The HPN application can be found on our website: www.bchomenutrition.org.

Step 2: The BC HPN Program care team reviews your application. This includes a thorough review of your:

- Medical and surgical history
- Medications
- Current illness
- Mobility
- Nutrition status
- Living situation

As part of our review, we might make some recommendations to the doctor referring you to our program. These recommendations might include:

- changing your medications
- changing your diet
- trialing enteral nutrition (tube feeding)
- teaching on care unrelated to HPN such as ostomy, fistula, wound and diabetic care (if needed)

Step 3: If the BC HPN Program care team thinks you need HPN, then our patient educator does a "trainability assessment". This assessment takes about 45 minutes and we usually do it by phone. The goal of the assessment is to make sure you and your caregiver are able to be safe with HPN.

Step 4: If you are accepted into the BC HPN Program, then our coordinator plans for you to come to St. Paul's Hospital for training.

What is the wait time for coming to St. Paul's Hospital?

There is usually a wait time for coming to St. Paul's Hospital. The wait time depends on:

- your medical and nutritional status
- your medications
- your ability to be independent at home with or without the help of a caregiver
- how many other patients are on the wait list
- if there is a bed available at St. Paul's Hospital

To find out what the wait time is for you, call the HPN program coordinator at 604-806-9808.

How do I get to St. Paul's Hospital?

All patients in BC and the Yukon who need HPN must come to St. Paul's Hospital in Vancouver for HPN assessment and training. This is because St. Paul's Hospital is the provincial centre for HPN care. Most of the time, patients referred to our program are patients at other hospitals in BC or the Yukon. This is how the hospital-to-hospital transfer process happens:

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Transfer process, continued

1. A transfer date is selected by the BC HPN Program care team.
2. The HPN program coordinator will arrange for you to come to St. Paul's Hospital by ambulance through the BC Patient Transfer Network.
3. The transfer might be delayed if there is no bed at St. Paul's Hospital or if there is no ambulance to transfer you. This can sometimes happen because of urgent (critical care) transfers or bad weather.
4. If the transfer is delayed, then the HPN program coordinator talks every day with the "sending" hospital until the transfer happens.

If you are currently at home, and not in hospital, the HPN program coordinator will speak with you about coming to St. Paul's Hospital for HPN training.

How does my spouse or family member get to St. Paul's Hospital?

If your spouse or a family member is coming to St. Paul's Hospital to be trained on HPN, they need to find their own way to Vancouver. Sometimes, the transfer ambulance will let a spouse or family member travel in the ambulance with the patient if there is space. Extra space is not guaranteed because the transfer ambulance might be moving more than one patient. This is not known in advance. You need to ask the ambulance attendant at the time of transfer if your spouse or family member can come with you.

Your spouse or family member must have a plan for finding their own way to St. Paul's Hospital.

Is there funding for my spouse or family member to come to St. Paul's Hospital?

Unfortunately, the BC HPN Program is not funded to cover the cost of travel or accommodations for your spouse or family member. The HPN program coordinator, however, can write a letter for medical expense reporting on your taxes or for third party coverage depending on your situation (Persons with Disabilities, First Nations & Inuit Health Benefits, ICBC, etc.).

What happens when I arrive at St. Paul's Hospital?

When you arrive at St. Paul's Hospital, you will be:

1. taken to your bed and met by your bedside nurse
2. seen by a doctor on the gastroenterology ("GI") team, who will write orders for blood tests, diet, medications, etc.
3. started on PN in the evening, if you were on PN before coming to St. Paul's Hospital
4. given time to rest; the HPN assessment and training usually starts the morning after you arrive

Can I stay in a private or semi-private room at St. Paul's Hospital?

There are a small number of private and semi-private rooms at St. Paul's Hospital. These rooms are often occupied by patients who are very sick and at high risk of spreading or contracting an infection. We cannot guarantee these rooms will be available for HPN Program patients.

Where does my out-of-town family stay?

Unfortunately, your spouse or family member being trained with you cannot stay at St. Paul's Hospital. There are many hotels near the hospital that offer a discounted medical rate. Ask the HPN program coordinator for a list of hotels.

How long do I have to stay at St. Paul's Hospital?

You and/or your caregiver need to plan to be at St. Paul's Hospital for 2 to 3 weeks for HPN training and ongoing assessment by the HPN care team. During this assessment, the HPN care team:

- makes changes to your hospital PN prescription and ensures it is safe for home
- monitors your blood work
- keeps track of your "ins and outs"
 - "ins" include food and fluids you put into your body by mouth or by intravenous (IV) access
 - "outs" include bowel movements, ostomy output, fistula output and urinary output

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Assessment process, *continued*

- assesses your diet and provides recommendations if needed
- reviews your medications and makes changes if required

You might be at St. Paul's Hospital longer if you:

- need to have a new CVC put in
- have an HPN prescription that needs to be changed
- have any extra or unplanned medical tests
- become unwell and the HPN training is put on hold

How is the HPN training scheduled?

There are 1 to 2 HPN training sessions daily from Monday to Friday during daytime hours. The training schedule can vary day-to-day. The schedule depends on what topic you are learning, if the patient educator is training other patients at the same time, if the HPN care team is seeing patients in the outpatient clinic or if the team is in a care-planning meeting.

Here is a list of topics you will learn about during the training:

- Learning more about the BC HPN Program
- Finding out about the different types of CVCs (central venous catheters)
- Caring for your CVC and CVC complications
- Having good hand hygiene and using aseptic (sterile) technique
- Adding vitamins and medications to your HPN solution
- Connecting your CVC to your HPN bag
- Using the infusion pump
- Un-hooking your CVC from your HPN bag
- Using the gravity method of infusion for extra fluids
- Ordering your HPN solutions and supplies
- Going for regular blood tests
- Coming to our outpatient clinic

What if I am unable to complete the HPN training?

If you or your caregiver are unable to complete the training or are unable to be safe with HPN skills, then we will transfer you back to the hospital that referred you to us. This hospital will have to make a new plan.

The training is done – how is my discharge home organized?

When the HPN training is close to finishing and the prescription for your HPN solution has been sent to our supplier, we work with you to identify a discharge date. Once the discharge date is known, we make sure your first order of HPN solutions and supplies are delivered to your home. This first delivery also includes a refrigerator for your HPN solutions.

We usually arrange for your first delivery to happen the day before or the day of discharge. We let you know if you need to have a family member, friend or neighbour be at your home to accept the delivery on your behalf.

You are responsible for getting home once you are discharged from St. Paul's Hospital. We suggest you arrange for a family member or friend to take you home.

Who pays for my HPN solutions and supplies?

Your HPN solutions and supplies are 100% paid for by the BC HPN Program.

Please note that the BC HPN Program does not pay for or provide any non-HPN supplies. For example, we do not pay for supplies you might need for your ostomy, fistula and non-HPN medications requiring a needle or syringe for administration.

Questions

Call the HPN program coordinator:

- Phone: 604-806-9808
- Toll-free: 1-877-806-9353 ext. 6

Visit our website and check our video for more information about the BC HPN Program:

www.bchomenutrition.org

Visit the Oley Foundation for more information about HPN in general:

www.oley.org



How you want to be treated.

www.providencehealthcare.org