

# **After Your Liver Transplant: When You Have Questions**



Capital Health

# After Your Liver Transplant: When You Have Questions

## **Remember:**

- Stay calm and do not panic.
- Use common sense.

**These things are very serious. Go to the nearest Emergency Department for immediate attention if you have:**

- Severe shortness of breath
- Chest pain or bad dizzy spells
- Bleeding from belly or bowel
- Severe belly pain with throwing up and/or severe diarrhea
- Severe headache with high fever and/or stiff neck
- Trauma such as a fall or blow to the head, belly, back, or possible broken bones

**Report any signs of infection or rejection to your family doctor for his/her assessment. If your doctor's office is closed, follow your doctor's advice on how to contact a doctor on call for his/her family practice.**

**Call the Liver Transplant Clinic at (902) 473-5631 and tell us about the problem after you have been in touch with a doctor.**

# A quick review of infection and rejection

## Signs of infection:

- Fever
- Cough with sputum (phlegm)
- Shortness of breath
- Cold sores around your lips or mouth
- Headaches
- Changes in your eyesight
- A white coating on your tongue or the roof of your mouth, along with pain and difficulty swallowing
- Aching joints
- Burning or stinging when passing urine
- Passing urine more often than usual
- Fatigue or feeling tired for no reason
- More than your usual amounts of redness, swelling, drainage, or pain around an incision, sore, or cut

## **Signs of rejection:**

- Jaundice (your skin or eyes turn yellow)
- Fatigue or feeling tired for no reason
- Weakness
- Fever
- Feeling like you have the flu
- Nausea (sick stomach) or throwing up
- Lack of appetite
- New or different belly pain or tenderness
- Urine is dark yellow or orange
- Bowel movements are light-coloured
- Weight gain
- Swelling of your ankles, hands and/or belly

## **Tell the Transplant Clinic during normal office hours whenever:**

- You start on any new medications, either prescribed by other doctors or over-the-counter medication, including herbal remedies.
- You are admitted to a hospital, or visit an Emergency Department.
- You have questions about your anti-rejection medications.
- You have any other transplant-related questions.

## Anti-rejection medications

### Anti-rejection medications include:

- Cyclosporine (Neoral®)
- Mycophenolate Mofetil (CellCept®)
- Mycophenolate Sodium Enteric Coated (Myfortic®)
- Sirolimus (Rapamune®)
- Tacrolimus Extended Release (Advagraf®)
- Tacrolimus (Prograf®)

### If you live in Nova Scotia:

**The provincial government, through the QEII Pharmacy, provides your anti-rejection medications.**

- You do not pay for the medications. You will need to pay a dispensing fee for each of the prescriptions. The current dispensing fee is about \$10.90 for each prescription. You will get a bill in the mail for the dispensing fee(s).
- The anti-rejection medications are only available at the Outpatient Pharmacy, main floor of the Victoria Building, at the VG site in Halifax. This is the same building where you come to the Transplant Clinic. The doctor on the Liver Transplant Team will write a prescription on your chart, with enough refills to last for a year.
- When you have a **2 or 3 week supply left**, call the Outpatient Pharmacy at (902) 473-7986. A staff member will get your medications ready for pickup or to be mailed or bused to you.
- When there are no repeats left on your prescription, call the Transplant Clinic at (902) 473-5519 or (902) 473-4986 so the doctor can write a new prescription.
- The cost of mailing medications may change so ask the Outpatient Pharmacy to find out the current prices. If the medications are sent by bus, the cost is more.

**These medications are commonly used by NS transplant recipients but are not paid for or supplied by the Outpatient Pharmacy, VG site:**

- Acyclovir
- Blood pressure medications
- Diabetes medications
- Omeprazole
- Prednisone
- Ranitidine
- Sulfamethoxazole-trimethoprim (Septra® DS)
- Valgancyclovir (Valcyte®)

**If you live in Prince Edward Island, anti-rejection medications include:**

- Cyclosporine (Neoral®)
- Mycophenolate Mofetil (CellCept®)
- Mycophenolate Sodium Enteric Coated (Myfortic®)
- Sirolimus (Rapamune®)
- Tacrolimus Extended Release (Advagraf®)
- Tacrolimus (Prograf®)

**The provincial government, through the Provincial Pharmacy, supplies your anti-rejection medications.**

- They are only available at the Provincial Pharmacy, 16 Fitzroy Street in Charlottetown.
- The doctor on the Liver Transplant Team will write a prescription for you, with enough refills to last for one year and will send the prescription to the pharmacy.
- When you have at least a **2 week supply left**, call the Provincial Pharmacy at (902) 368-4947. The staff will get your medication ready for you to pick up or you can pay for it to be sent by courier.
- When there are no refills left on your prescription, call the Transplant Clinic at (902) 473-5519 or (902) 473-4986 to have the doctor write a new prescription.

**These medications are commonly used in transplant recipients but are not paid for or supplied by the PEI Provincial Pharmacy:**

- Acyclovir
- Blood pressure medications
- Diabetes medications
- Omeprazole
- Prednisone
- Ranitidine
- Sulfamethoxazole-trimethoprim (Septra® DS)
- Valgancyclovir (Valcyte®)

## **If you live in Newfoundland, anti-rejection medications include:**

- Cyclosporine (Neoral®)
- Mycophenolate Mofetil (CellCept®)
- Mycophenolate Sodium Enteric Coated (Myfortic®)
- Sirolimus (Rapamune®)
- Tacrolimus Extended Release (Advagraf®)
- Tacrolimus (Prograf®)

## **The provincial government supplies your anti-rejection medications.**

- Your family doctor or specialist will write the prescription for you. It may be for a year or for several months.
- The prescription is sent to St. John's and the medications are mailed to your home. The pharmacy sends out a 2 month supply at a time. They are only available from the Outpatient Pharmacy of the St. John's Health Sciences Centre.
- When you have at least a **2 or 3 week supply left**, order a new supply of medications. If there are more repeats left on your prescription, call the Provincial Pharmacy directly to have your medication prepared and sent to you. If there are no repeats on the prescription, contact your family doctor or specialist for a new prescription.
- Provincial Outpatient Pharmacy toll free phone number: 1-800-563-7077.
- Provincial Pharmacy fax number: (709) 777-8120.

## **These medications are commonly used in transplant recipients but are not paid for or supplied by the Outpatient Pharmacy, St. John's Health Sciences Centre:**

- Acyclovir
- Blood pressure medications
- Diabetes medications
- Omeprazole
- Prednisone
- Ranitidine
- Sulfamethoxazole-trimethoprim (Septra DS)
- Valgancyclovir (Valcyte®)

**If you live in New Brunswick, your anti-rejection medications may be paid for in a variety of ways:**

**Each person who has a transplant receives information on the New Brunswick Prescription Drug Program (PDP) Organ Transplant Plan (Plan R).**

- The NB Liaison Nurse in Halifax will meet with you to discuss the NB Program (Plan R), your eligibility, and assist you in applying for coverage. You will be provided with a Plan R brochure which will list criteria for eligibility.

**The following is a quick overview of Plan R eligibility:**

- If you have **private insurance** and it **does cover** anti-rejections medication, then you apply to your insurance company for coverage. You are **not eligible** for the NB Program (Plan R). Contact your insurance company with the list of medications and they will let you know if these are covered.
- If you **have private insurance** and it **does not cover** anti-rejection medications, then **you are eligible** to apply to the NB Program (Plan R).
- If you **do not have private insurance**, then **you are eligible** to apply to the NB Program (Plan R).
- If you **have a NB Department of Social Development (DSD) Health Card** (Income Assistance and Seniors Drug Program), **you are eligible** to apply for anti-rejection medication coverage under Plan R and will be issued a separate drug card for these medications. Your co-pay registration fee will be the same as you currently pay.

**If you are eligible** for the NB Program (Plan R), and **do not have a health card with DSD**, Plan R covers 80% of the anti-rejection medication cost (the maximum you will be charged per drug is \$20.00). There is an annual registration fee of \$50.00.

Your local pharmacist can order in and provide all medication you will require. Your pharmacist will be able to direct bill the 80% for the anti-rejection medication directly to NB Program (Plan R).

When you have a 5 day supply left, contact your pharmacy to have your medications prepared for you. When you receive your last prescription refill, make an appointment with your family doctor or specialist for a new prescription.

## **NB outpatient clinic follow-up: Immediately post transplant**

- You may be required to stay in Halifax post transplant for several weeks after discharge from the hospital. You will be booked into the Point Pleasant Lodge (PPL) by hospital staff.
- All rooms are semi-private and you will be sharing a room with another patient (unless you have someone to stay with you, and in that case, they would be responsible for half of the room cost).
- You will have a meal allowance of \$28.75 per day for the PPL cafeteria. Your room and meal bills will be direct billed to NB Medicare. The NB Liaison Nurse will talk about this in more detail when she meets you.

## Important Phone Numbers

**Emergency: 911**

**Post Liver Transplant Clinic (902) 473-5631**

**Open Monday-Friday, 7 a.m.-3:30 p.m.**

Closed weekends and holidays

**Your primary nurse:** \_\_\_\_\_

**Phone #:** \_\_\_\_\_

When the Liver Transplant Clinic is closed, your doctor may get advice by calling the QEII Health Sciences Centre locating and asking for the

**Liver Transplant Specialist on call: (902) 473-2222.**

**Your family doctor:** \_\_\_\_\_

**Your local drugstore:** \_\_\_\_\_

**Provincial Pharmacy for anti-rejection medications:** \_\_\_\_\_

**You can also visit the Multi Organ Transplant Program's (MOTP) website:**

[www.motphalifax.net](http://www.motphalifax.net)

If you have any questions, please ask.  
We are here to help you.

