Patient & Family Guide

2025

Waiting for Your Liver Transplant

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Contents

Waiting for Your Liver Transplant

- This pamphlet will help you get ready for your liver transplant.
- After your transplant, you will get another pamphlet with information about:
  - Recovery
  - Self-care
  - Anti-rejection medications
  - Possible complications
- If you have any questions, please ask a member of your health care team.

Your transplant assessment

- Before your liver transplant, you will have a health assessment to check if you are ready for a transplant. The Transplant Coordinator will guide you through this process.
- It is common to find the assessment stressful and tiring. For this reason, **you must have a support person with you during your assessment**. This can be a family member, friend, or a caregiver.
- We also recommend that your support person come with you to your other appointments. They can support and comfort you, and help you remember important information from the Transplant Team.

Team support

- During your assessment, the Transplant Team will ask you a lot of questions to learn about:
  - Your health
  - The type of liver disease you have
  - The stage of your liver disease

They will also go over how to get ready for your liver transplant.

The Transplant Team will help you with:

Coping

- If needed, our social worker can help you:
    - plan how to get to the hospital.
    - find a place for your support person to stay while you are in the hospital.
    - find possible medication coverage.

  They can also offer emotional support and counselling to you and your support person while you wait for your transplant.

- A psychologist may meet with you to talk about your health and any worries or concerns you may have. They:
    - will check if you have the support and mental health resources to have a liver transplant.
    - will talk with you and your support person to learn about your coping skills. They may also help you learn new coping skills.
    - may suggest counselling, if you are depressed or anxious about the transplant or other things in your life. They may offer to meet with you again or refer you to a counsellor in your area.

Advance care planning

- There may be a time when you are not able to make decisions about your medical care and treatment. This may be only for a short time, or for the rest of your life. This may happen suddenly, or slowly over time.
- Advance care planning lets you share your wishes with your health care team about:
    - Your health care
    - Who you would like to make decisions about your care if you are not able to. This person is called a **Substitute Decision Maker (SDM)**.
- It is important to think about your wishes and appoint an SDM. This helps to make sure that your wishes guide your care.
- Please talk about your wishes with your family, your SDM, and anyone else who might make decisions for you in the future. We are happy to answer any questions you may have.

- For more information, please use the QR code or the link below, or ask a member of your health care team for pamphlet 2327, *Making Health Care Decisions for Someone Else: Acting as a Substitute Decision-Maker (SDM)*
  - www.nshealth.ca/patient-education-resources/2327

Scan the QR code above on your device (open the camera on your device, point the camera at the code, and tap the banner or border that appears).

Healthy eating

- A dietitian will meet with you to learn about your eating habits. They will:
  - work with you to make a healthy eating plan.
  - show you how to eat less salt and more protein.
  - help you choose foods with the recommended amounts of salt and protein, so you will be healthier for your transplant.

Exercise

- You will meet with a physiotherapist to make a home exercise program that will get you ready for surgery. Staying active will help you get ready for your liver transplant and recover faster after surgery. It can also help to lower stress as you wait for a transplant.

Dental care

- It is very important to keep your gums and teeth healthy. Decaying (rotting) teeth and diseased gums can cause infections. Visit a dentist before your transplant to make sure your teeth and gums are healthy.

Planning for costs

- It is important to be ready for all costs related to your liver transplant. A social worker will help you find resources that may help.
- We encourage you to ask people you know to help you fundraise. Worrying about money can take away from the joy of having a new liver.

- During your assessment, you will be asked to come to the Transplant Clinic in Halifax to see the Transplant Team and have tests.
  - If you live outside of Nova Scotia or farther than 50 km (1 way) from the Victoria General (VG) site of the QE II, you will have to stay in Halifax. You may be able to stay at off-site patient accommodations (places to stay for QE II patients).

Out-of-province reimbursement

- **If you are not a Nova Scotia resident**, you may be able to be reimbursed (paid back) for costs related to your transplant. Some provincial governments will reimburse the health care costs outside of the hospital before surgery.
  - Keep records of all accommodation and food expenses while you are in Halifax. The social worker and a provincial liaison nurse (if you have one) will help you with this.
  - If you are on social assistance, the social worker will contact your income assistance worker to plan for your costs.

Common tests

- Before being added to the liver transplant waitlist, you must be healthy enough for a transplant.
- You will have many tests to find out if this is the right time for you to be put on the transplant waitlist. These tests may include:
  - MRI of your abdomen (stomach area)
  - Ultrasound of your abdomen
  - Arterial blood gases
  - Blood tests (including an HIV test)
  - Chest X-ray
  - Colonoscopy
  - Echocardiogram
  - Electrocardiogram (ECG or EKG)
  - F.I.T. Test (colon cancer screening)
  - Gastroscopy
  - Liver biopsy
  - Pulmonary (lung) function test
  - Triphasic abdominal (stomach area) CT scan
  - Other tests

- Your test results will tell us your **MELD (Model for End-stage Liver Disease)** score. This is a number from 6 to 40. It measures your:
    - Total bilirubin
    - INR (International Normalized Ratio)
    - Creatinine
    - Sodium
- This score tells us how well your liver is working. The higher the score, the sooner you need a liver transplant.

Assessment results

- After your assessment, the Transplant Team will:
    - review your test results.
    - talk with you about the risks and benefits of a liver transplant.
    - decide if this is the right time for you to be added to the liver transplant waitlist.
- If the Transplant Team finds that you are not healthy enough for a transplant, you will be reassessed when your condition changes.
- **A transplant is not safe for people with**:
    - Severe (very bad) heart disease
    - Large tumours
    - Severe obesity (very overweight)
- The Transplant Coordinator will tell you what the Transplant Team decides. They will also update your primary health care provider (family doctor or nurse practitioner) and the doctor that referred you.

What are your questions?

Please ask a member of your health care team. We are here to help you.

Waiting period

- It may be months to years before a liver is found for you. How long you will wait for a liver transplant will depend on:
  - When a donor is available
  - Your blood type
  - Your body size (weight and height)
  - Your health condition (how sick you are), including your MELD score
- Most people can stay at home while waiting for a liver transplant. Others may have to stay in the hospital, so they can be watched closely.
- You may be put “on hold” for a short time if you have an infection or any other problem that needs treatment.
- You may be taken off the waitlist if:
  - Your condition changes (your health gets worse)
  - You do not follow the Transplant Team’s advice
  - You do not take part in your own care
- Waiting for a transplant can be stressful. You may feel anxious, depressed, or confused, or have other strong emotions. This is common.
  - It can help to share your thoughts and feelings with family members, friends, and/or support persons. If you need more support, please tell your Transplant Team.
- **While you wait for your transplant**:
  - **Do not** smoke.
  - Take your medications as prescribed by your health care team.
  - Exercise regularly.
  - Follow your healthy eating plan.
  - **Do not** drink alcohol.
  - **Do not** use recreational drugs (like cannabis).
  - Tell your Transplant Coordinator if there are any changes in your health or if you are admitted to the hospital for any reason.
  - Keep all Transplant Clinic appointments.
  - Have blood work done each month, or as told by your health care team.
  - Visit your primary health care provider each month, if you can.
  - Tell your Transplant Coordinator if your address or phone number changes.

- **You may be taken off the waitlist if you do not try to keep yourself as healthy as you can be**. **Your physical and mental health at the time of your transplant is very important**. If your body is not strong enough, it can affect your recovery.
- **If you do not have voicemail or an answering machine, please think about buying or borrowing one**. Your Transplant Coordinator needs to be able to reach you.
- For your privacy, we will ask you if it is OK to say that we are calling from the Transplant Clinic when leaving a message:
  - on your voicemail or answering machine.
  - with the person who answers the phone at the number(s) you gave us.
- We will also ask if it is OK to email you and ask you to sign a consent form.

If it is an emergency, call 911 or go to the nearest Emergency Department (ED) right away.

If you go to the ED:

- Please call the Transplant Clinic and tell them of any new health changes.

Research

- We are always looking for better ways to care for our patients. Research is an important part of the Multi-Organ Transplant Program.
- If you are put on the waitlist for a liver transplant, you may be asked to take part in a research study. Your decision will not affect your waitlist status or the care you receive. If you choose to take part in a research study, you can stop at any time.

Getting ready for the day of your transplant

- Make sure you know:
    - How you will travel to Halifax (be sure to have more than 1 plan)
    - Who will travel with you to Halifax
    - How long it will take to travel to Halifax
    - Who will look after your children, pets, or home while you are in the hospital
    - What you will pack in your suitcase
    - Where your support person will stay while you are in the hospital
    - That you have left all valuables (like jewelry, money, and credit cards) at home. The hospital is not responsible for the loss of any item.

Bring these items to the hospital with you:

☐ Your provincial health card

☐ Private insurance card, if you have one

☐ All of your medications (including prescription and over-the-counter products, inhalers, creams, eye drops, patches, herbal products, vitamins, and supplements) in their original containers

☐ Unscented toiletries (like deodorant, hair products, shaving foam). Nova Scotia Health is scent-free.

☐ Slippers (with non-skid soles)

☐ Pyjamas

☐ Robe or housecoat

☐ Underwear

☐ Socks

☐ Loose-fitting pants (like sweatpants)

☐ Shirts that are easy to get on and off

☐ Books, magazines, or other things to pass the time

☐ Diabetes supplies (like a glucometer, pens, lancets), if needed

☐ CPAP machine, if you use one

☐ Walking aid (like a walker or cane), if needed

Getting the call

- A Transplant Coordinator is on call 24 hours a day to make arrangements when a liver becomes available. They will call you when a liver is available for you.
  - If you are already admitted to the hospital, a member of the Transplant Team will tell you that a liver is available.
- **The Transplant Coordinator will ask you**:
  - How will you get to the hospital?
  - How are you feeling right now?
  - Do you have a fever (temperature above 38 °C or 100.4 °F)?
  - Are you on antibiotics for a new infection?
- **They will tell you**:
  - **Do not** eat or drink anything (not even water), if applicable
  - What time to arrive at the hospital
  - Where to check in when you arrive at the hospital
  - The type of donor (see page 10)
- **When you get the call, you must come to the hospital as soon as you can. Do not rush or break any speed limits**.
- When you arrive, go to:
  Unit 6A, 6th floor
  Centennial Building, VG site
  - Enter the hospital through the Dickson Building entrance.
  - Take the elevator to the 6th floor.
  - Walk through the Dickson and Victoria Buildings to reach the Centennial Building, Unit 6A.

You may be called to the hospital for 2 types of donors:

- **A donor after cardiac death (DCC)**: This donor has had a permanent brain injury. They may be close to dying, but they do not meet the criteria (standards) for brain death.
  - There is a 50% chance that a DCC donor is suitable for a transplant. **You must be in the hospital and ready to go to the Operating Room (O.R.)**.
  - Whether the donor's liver is able to be transplanted or not will largely depend on how long it has been since they were taken off life support.
  - Organs from DCC donors may be slow to start working. Your hepatologist (liver doctor) and surgeon agree that DCC organs are still good quality and should be used.
- **A neurological determination of death donor (DNC)**: This is a donor who has permanently lost all brain function (their brain stops working) because of a severe brain injury or trauma.

Exceptional distribution donor (EDD), also called an increased risk donor

- EDDs are becoming more common. These donors may be at a higher risk for infectious diseases (like HIV, hepatitis, West Nile Virus).
- A donor may be considered an EDD if the health care team does not have their full medical and/or social history. Although organs from EDD donors are usually of good quality, they may come with risks.
- Your liver doctor and surgeon will review the donor and approve the liver before offering it to you.
  - **You can choose to turn down a liver from an EDD. This means you will stay on the waitlist**.
  - There is no guarantee that the next liver that becomes available for you will be as good or better than the EDD donor's liver.
- **If you decide to accept a liver from an EDD donor**:
  - The donor will have a blood test called a NAAT (nucleic acid amplification test). This is to check that they do not have any infectious diseases. A NAAT means that **the risk is very low** (less than 0.1% in most cases). It **does not** mean that there are no infectious risks.
  - You will have follow-up tests after the transplant.
- The Transplant Team will explain why the donor is EDD once you are admitted to the hospital. **They will not offer you an organ if they do not think it is safe**.

Before surgery

- When you arrive at Unit 6A, many things will need to be done in a short amount of time:
  - You will be asked to sign a consent form for your surgery.
  - You will have tests done (like blood work, a chest X-ray, an ECG or EKG).
  - A nurse and a doctor will examine you.
  - A research nurse may talk with you about research studies you may choose to take part in.
  - Unit nurses will give you instructions about your surgery.
- Your support person will be able to see you before you go to the O.R.
- While you are getting ready for surgery, the Transplant Team will be getting the donor liver ready for transplant.
  - If the liver is not suitable, your surgery will be cancelled. This is for your safety and to make sure you get a healthy liver.
  - If this happens, you will need to stay on the waitlist until another liver becomes available.

Surgery

- If the liver is suitable, you will be taken to the O.R.
- The anesthetist (a doctor who puts you to sleep for surgery) will give you medication to put you to sleep.
- The surgery will take about 6 to 8 hours. Although every effort will be made to cut down on blood loss, you may need a blood transfusion.

While your support person is waiting

- Once you are in the O.R., your support person may need to wait a long time. They may choose to use this time to find a place to stay, if they have not already made plans.
- There is a waiting area on the 10th floor of the Victoria Building.
  - A Surgical Liaison Nurse is available from 8 a.m. to 4 p.m., Monday to Friday. They visit the waiting area to tell your support person how your surgery is going.
  - If your surgery is outside of these hours, there is no one who can give your support person this information.

- A social worker can also talk with your support person and offer support from 9 a.m. to 5 p.m., Monday to Friday. To talk with a social worker, your support person can ask a member of your health care team.
- Your support person can also give Intensive Care Unit (ICU) staff a phone number to call when your surgery is over and you are in the ICU.
  - ICU staff may not have any information about you until just before you come back to the ICU.

After surgery

- After a liver transplant, you will likely stay in the hospital for 2 weeks (14 days).

ICU

- After your surgery, you will be closely observed and monitored in the ICU. The amount of time spent in the ICU is different for each person. The average stay is 24 to 48 hours (1 to 2 days). This will depend on:
  - How well your surgery went
  - How fast you recover from the anesthetic (medication used to put you to sleep for surgery)
  - How sick you were before your transplant
- ICU nurses have special training to care for patients who are very sick. Each nurse cares for 1 to 2 patients.

When you wake up from the general anesthetic:

- You may have a breathing tube in your mouth connected to a breathing machine. You will need this until you can breathe on your own. The nurse will suction (clean out) the breathing tube to remove any sputum (phlegm). You will not be able to talk, eat, or drink while the breathing tube is in place.
- After the breathing tube is taken out, an oxygen mask will be placed over your mouth and nose. You will probably have a sore throat for a few days after the breathing tube is taken out.
- Later, nasal prongs (a small tube) may be used to give you oxygen through your nose. **It is very important to take deep breaths and cough often**. This will help to expand (make bigger) your lungs and clear your throat.

- You will have a lot of tubes connected to your body. This is to help monitor your organs and vital signs (like your temperature, pulse, blood pressure, and breathing rate).
- You may feel overwhelmed by the noise and lights in the ICU. You may be mildly confused because of the anesthetic, anxious, or scared. These reactions are common.
- You may have trouble knowing when it is night or day. This can make it hard to sleep. This will go away as your medications are changed.
- **There will always be nurses close by to monitor and help you**.
- You will get pain medication. Controlling your pain will help you take deep breaths and start moving after surgery.
- Your nurse and a physiotherapist will teach you how to move so you have less pain and discomfort.
- Try to sit on the side of the bed the first day after your surgery.
- To prevent muscle and joint stiffness, your nurse will show you how to do gentle exercises in bed.
- We want you and your support persons to know about your condition and your care. They can get an update from the nurse on each shift. **Please choose 1 person to get and share information with your other loved ones**. This keeps everyone updated and gives the nurses more time to care for you.
- Attending ICU doctors direct your care while you are in the ICU. They work very closely with your surgeons, liver specialists, and other team members. They will check your progress every day and adjust your care plan.
- The ICU nurse can plan for your support person to meet with your doctors at any time.
- Once your condition is stable and you can breathe on your own, you will leave the ICU.

Intermediate Care Unit (IMCU)

- After leaving the ICU, you will be moved to:
  - The IMCU
    or
  - Back to Unit 6A, if the Transplant Team feels you are well enough
- The IMCU is a 4-bed unit where 2 nurses care for 4 patients. You will be here until the Transplant Team feels your condition is stable enough for you to move back to Unit 6A. You may need to share a hospital room with someone of the opposite sex on this unit.
- Your care will focus on getting you ready for discharge. For example, you will:
  - do more of your daily care yourself.
  - learn about your medications.
  - work with the physiotherapist.
- The Transplant Team will work closely with you during this time.
- When you are getting closer to discharge, the post-transplant nurses will meet with you. They will work with you during your hospital stay and for the life of your new liver.
- It is important that you and your support person know what to expect after surgery. You will get a copy of pamphlet 0411, *After Your Liver Transplant*. This pamphlet explains your care once you are back on Unit 6A. You may also view this pamphlet by using the QR code or the link below:
  - www.nshealth.ca/patient-education-resources/0411

Scan the QR code on your device (open the camera on your device, point the camera at the code, and tap the banner or border that appears)

- After you are discharged, you may need to stay in Halifax to:
  - Learn about your medications
  - Learn how to care for yourself at home
  - Get follow-up care

Possible complications

- You may have complications after your transplant and recovery. The Transplant Team will do their best to lower your risk of complications and will treat them quickly if they happen.
- **Possible short-term complications include**:
  - Bleeding
  - Wound infections
  - Bile leak
  - Biliary stenosis or stricture (a narrowing of the bile ducts)
  - Rejection (when your body sees your new liver as a threat to you and starts to fight against it). **You will always be at risk for rejection**.
  - Higher risk of common infections (like cytomegalovirus, yeast infection, pneumocystis pneumonia)
  - Kidney problems
  - Diabetes
  - Primary graft nonfunction (acute liver failure). **This is rare**.
- **Possible long-term complications include**:
  - Osteoporosis (your bones get weak and thin)
  - High blood pressure
  - High cholesterol
  - Cancer
- For more information about possible complications, ask a member of the Transplant Team for pamphlet 0411, *After Your Liver Transplant*.

What are your questions?
Please ask a member of your health care team.
We are here to help you.

Questions for my health care team:

Notes:

Find all patient education resources here:
www.nshealth.ca/patient-education-resources

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: https://811.novascotia.ca

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To be reviewed August 2028 or sooner, if needed.
Learn more: https://library.nshealth.ca/patient-education-resources