

Waiting for Your Liver Transplant

This guide will help you and your loved ones learn about the steps needed to get ready for a liver transplant. This guide will explain the process leading up to before you receive a liver transplant. After your transplant, you will get a second guide with information about recovery, self-care, anti-rejection medications, and possible complications. Members of the Liver Transplant Team are always available to talk with you about your concerns.

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Contents

Your transplant assessment	1
Team support	1
Coping.....	1
Advance care planning.....	2
Healthy eating	2
Exercise	3
Dental care	3
Planning for costs.....	3
Meal coverage.....	4
Common tests	4
MELD (Model for End-Stage Liver Disease) score.....	5
Assessment results	5
Waiting period	6
Research	7
Getting ready for the day a liver is donated.....	8
Getting “the call”	9
Before surgery	11
Surgery.....	11
After surgery	12
The Intensive Care Unit (ICU)	12
The Transplant Unit	14
Possible long-term complications	14

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Your transplant assessment

- You may find that the assessment needed to get ready for a liver transplant can be very stressful and tiring. You must have a family member, friend, or designated support person with you during your appointments. They can give comfort, support, and help remember the information that you are given. The Transplant Team will be giving you a lot of information.
- Our team members will support you during your assessment. The Recipient Transplant Coordinator will guide you through this process as many tests and appointments will be arranged for you.
- The Team will also be asking you to give them a lot of information. This is to find out about your health, the type of liver disease you have, the stage of your liver disease, and what you can do to become as healthy as possible.

Team support

During your assessment, the Team will help with the following:

Coping

- A psychologist will meet with you to talk with you about how you are feeling about your health, and help you work through any worries or concerns you may have. They help us to determine if you have the support and mental health resources to go through a transplant. The psychologist will learn more about your coping abilities by talking with:
 - › your family member, friend, or designated support person.
 - › your family doctor.
 - › you.
- The psychologist may make suggestions about how to improve your coping skills.
- If you are depressed or anxious about the transplant, or because of some other stressful event, the psychologist may suggest counselling. They will offer to counsel you or refer you to a counsellor in your community.

- A social worker will work with you in Halifax or in your community. They are also available to give emotional support and counseling to you and/or your family while you wait for your transplant.
- They will help you with practical concerns (like how you will get to the hospital, where your family will stay, how to find coverage for your medications after your transplant, help connect you to financial resources, help you plan to get your home ready). They will help you think about advance care planning (also known as advance directives or living wills).

Advance care planning

- There may be a time in the future when you are not able to make decisions about your medical care and treatment. This situation may be temporary or permanent. It could happen suddenly or over time. Advance care planning helps to make it clear how you wish to be cared for and gives someone you trust the authority to act on your wishes. This person is known as a Substitute Decision Maker (SDM). This is the person we would ask to make decisions, in the event that you are not able to do so.
- **If you are not able to make decisions for yourself, there are 2 important things we need to know:**
 1. What are your specific wishes about your health care?
 2. Who would you want to make decisions for you?
- It is important to answer these questions now, while you are capable of making decisions. 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 always happy to answer any questions you have about advance care planning.

Healthy eating

A dietitian will meet with you to learn about your eating habits. They will make a healthy eating plan for you. Your dietitian will review how to cut down on salt and help you choose foods with the recommended amounts of protein, so you will be healthier for your transplant.

Exercise

A physiotherapist will meet with you. They will help you design a home exercise program that will help you get ready for surgery. Being in good shape and staying active will help you to be ready for your transplant and help you recover faster after surgery. Exercise can also lower stress as you wait for a transplant.

Dental care

It is very important to keep your gums and teeth healthy. Rotten teeth and diseased gums can cause infections. Visit your dentist to make sure that your teeth and gums are in the best shape possible before your transplant and to check there are no teeth or gums that need repair.

Planning for costs

- It is important to prepare for all costs related to a liver transplant. Your social worker will connect you to resources that can help you during this process. Financial planning done before your transplant can make your recovery less stressful. We encourage you to ask friends and colleagues to help with fundraising. Worrying about money can take away from the joy of your new liver.
- You and you family may be caught off guard when you get “the call” from the Recipient Transplant Coordinator. Many people have said, “I never really thought it would happen so I never prepared.”
- During your transplant assessment process, you may be asked to come to the Transplant Clinic in Halifax to see the Team or have testing done.
- If you live outside of Nova Scotia or farther away than 50 km (one way) from the Victoria General Hospital, you may be able to stay at off-site patient accommodations. Your Transplant Coordinator will review this with you if you meet the criteria.

Meal coverage

If you meet the criteria to stay in off-site patient accommodations, you will get meal tickets to help with meal costs. If you do not meet the criteria, your Transplant Coordinator will suggest places to stay that offer lower rates for patients and families. If you are told to stay in Halifax for follow-up care after your transplant, all costs will be covered. The Post-transplant Nurses will talk about this with you.

Newfoundland

- If you live in Newfoundland, the government does not cover the costs of any health care outside of the hospital before surgery. You will need to keep records of all accommodation and food expenses while in Halifax so that you will be reimbursed (paid back) in your own province.
- If you are on social assistance, a social worker will contact an income assistance worker for you.
- We strongly encourage anyone who is waiting for a liver transplant to save money for their surgery. Please prepare far in advance so you are ready when you get “the call”.

Common tests

- During the work-up process, you will have most, if not all of the following tests to find out if this is the right time for you to be placed on the transplant wait list. The tests will also help us find out if you are healthy enough for a transplant.
- **You may have some of these tests:**
 - › Abdominal (stomach area) ultrasound
 - › Abdominal MRI scan
 - › Arterial blood gases
 - › Blood tests (including HIV testing)
 - › Chest X-ray
 - › Colonoscopy
 - › Echocardiogram
 - › Electrocardiogram (ECG or EKG)
 - › ERCP/MRCP
 - › FIT Test (colon cancer screening)
 - › Gastroscopy
 - › Liver biopsy
 - › Pulmonary function test
 - › Triphasic abdominal CT scan
- These tests are explained on pages 14 to 17 of this guide.

MELD (Model for End-Stage Liver Disease) score

A MELD score is a number that ranges from 6 to 40, based on lab results. It measures your liver function (how well your liver works), which shows how much you need a liver transplant. The higher the number, the more urgent your case is.

Assessment results

- After the assessment phase is done, the Transplant Team will:
 - › review your test results.
 - › find out the risks and benefits of a transplant for you.
 - › decide if this is the right time for you to go on the liver transplant wait list.
- Some patients are too sick for a transplant, and they will be reassessed if their condition changes. For example, these health conditions make a transplant too high risk:
 - › Severe (very bad) heart disease
 - › Large tumours
 - › Severe obesity (very overweight)
- If a transplant is recommended or not, the Recipient Transplant Coordinator will tell you the Team's decision. They will also contact your primary health care provider (family doctor or nurse practitioner) and referring doctor.

Please ask the Transplant Team any questions or concerns you have as you are going through this process.

Waiting period

- It may be a few months to several years before a new liver is found for you. The length of time you wait for a liver transplant depends on:
 - › When a healthy donor becomes available
 - › Your blood type
 - › Your body size (weight and height)
 - › Your health status (how sick you are) including your MELD score
 - › How long you have been on the wait list
- Most people are able to stay at home while waiting for the call that a liver has been found. Others may have to stay in the hospital for a long time, to make sure they are watched closely during this time.
- You may be placed “on hold” temporarily if you have an infection or any other problem that needs to be treated. A person may be taken off the list if they get too sick while waiting.
- Waiting for a transplant can be very stressful. You may feel anxious, depressed, confused, or have other strong emotions. These feelings are all normal reactions to your illness or the wait time. Sharing your thoughts and feelings with supportive family members and friends can be very helpful. You can contact the Transplant Team if you need extra support.
- While you wait for your transplant:
 - › **Do not** smoke
 - › Take your medications as prescribed by your doctor
 - › Exercise regularly
 - › Follow your healthy eating guidelines
 - › **Do not** drink alcohol
 - › **Do not** use recreational drugs
 - › Tell the Recipient Transplant Coordinator of any changes in your health or if you are admitted to the hospital for any reason
 - › Keep all Clinic appointments
 - › Have your blood work taken monthly or as ordered by your doctors
 - › Visit your primary health care provider each month
 - › Tell the Recipient Transplant Coordinator if your address or phone number changes

- **You may be taken off the list if you do not try to keep yourself in the best shape possible.** 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 after your surgery.
- If you do not have voice mail or an answering machine, please consider buying or borrowing one from a friend. The Transplant Coordinator needs to be able to reach you about health issues if you are not at home.
- For privacy, we will ask you beforehand if it is OK to leave a message on your voice mail or answering machine to let you know the call is from the Pre-Liver Transplant Clinic. The Transplant Coordinator will ask you if it is OK to leave a message with the person who answers the phone at the number(s) you have given us.

If there is an emergency, call your primary health care provider or go to the nearest Emergency Department (ED).

- Please call the Pre-Liver Transplant Office if you went to the ED and tell them of any new health changes.
- Call your Recipient Transplant Coordinator from Monday to Friday (7:30 a.m. to 3:30 p.m.). If there is an emergency after hours, please call your Recipient Transplant Coordinator and listen to the message for instructions.

› Phone: _____

Research

- The QEII is the major referral centre in the Atlantic provinces. 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 placed on the wait list for a liver transplant, you may be asked to take part in a research study. Your decision will not affect your wait list status or the care you receive. If you do choose to take part in a research study, you can stop at any time.

Getting ready for the day a liver is donated

Make sure you have an answer for each of these questions:

- › How will I travel to Halifax? (Be sure to have more than one plan).
- › Who will travel with me?
- › How long will it take to travel to Halifax?
- › Who will look after my children, home, or pets when I am in the hospital?
- › What will I pack in my suitcase?
- › Where will my family stay while I am in the hospital?
- › Have I 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 when you get “the call”:

- All of your medications in their original containers
- Your provincial health card
- Private insurance card
- Unscented toiletries (like deodorant, hair products, shaving foam)
- Slippers (non-skid soles)
- Pajamas
- 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 glucometer, pens, lancets, if needed
- CPAP machine, if you use one
- Walking aids (walker, cane), if needed

Getting “the call”

- A Recipient Transplant Coordinator is on call 24 hours a day to make the arrangements when a liver becomes available.
- **Do not call the on-call Recipient Transplant Coordinator if you have a health problem.**
- When a liver becomes available, the on-call Recipient Transplant Coordinator will call you.
 - › If you are admitted to the hospital at the time, a member of the Transplant Team will let you know that a liver is available
- **The Recipient Transplant Coordinator will ask you:**
 - › How will you get to the hospital?
 - › When do you expect to arrive at the hospital?
 - › How are you feeling right now?
 - › Do you have a fever?
 - › Are you on antibiotics for a new infection?
- **They will tell you:**
 - › **Do not** eat or drink anything (not even water)
 - › Where to check in when you arrive at the hospital
 - › The type of donor (see information below) and if you are willing to accept a high risk organ
- **When you get “the call”, you must come to the hospital safely as soon as possible. Do not rush or break any speed limits.**
- Go to the 6th floor, Unit 6B, of the Centennial Building at the Victoria General (VG) Hospital site. Enter the hospital using the Dickson Building entrance.

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

- › **A donor after cardiac death (DCD):** This donor has had an irreversible (permanent) brain injury and may be close to dying, but does not meet formal criteria for brain death. There is a 50% chance that these types of donors may not be suitable, but you need to be waiting in the hospital and ready to go to the Operating Room (OR). The time after life support stops is a major factor in determining whether the organ donation can go ahead or not. Organs from these types of donors may be a little slow to start working. Your hepatologist (liver doctor) and surgeon agree that DCD organ transplants are still good quality organs that should be used.
- › **A neurological determination of death donor (NDD):** This is a donor who has permanently lost all brain function (their brain stops working) because of a severe (very bad) brain injury or trauma.

Exceptional Distribution Donor (EDD)

- Exceptional Distribution Donors, also known as high risk donors, are becoming more common. These types of donors may be at a higher risk for infectious diseases (like HIV, hepatitis, and West Nile Virus).
- They can be grouped as a high risk donor if there is not a full medical and/or social history on the donor. The organs are usually of good quality, but may come with certain risks.
- Your hepatologist and surgeon will review these cases and approve these organs before offering them to you. You are allowed to turn down an EDD organ. **This means you will be waiting for another donor to become available for an unknown amount of time.** There is no guarantee that the next donor will be as good or better than the EDD organ.
- If you decide to accept an EDD organ:
 - › NAAT (Nucleic Acid Amplification Testing) will be done. This is a blood test used to find out if a donor has infectious diseases. This test will be done on the donor before a transplant. We will make sure it is negative for infectious diseases before you receive your transplant. A negative NAT test does not rule out all infectious risks, but lowers the risk to very low (less than 0.1% in most cases).
 - › The Transplant Team will also do follow-up testing after your transplant.
- The Transplant Team will explain why the organ is EDD once you are admitted to the hospital. The Transplant Team will not offer you an organ if they do not feel it is safe.

Before surgery

- When you get to Unit 6B, you may feel that the health care team is rushing you. Many things need to be done in a short period of time:
 - › You will be asked to sign your consent for surgery
 - › You will have tests done (like an ECG, chest X-ray, blood work)
 - › A nurse and then a doctor will examine you
 - › A research nurse may visit with you
 - › Unit nurses will give you instructions about your surgery
- Your support person and/or family will be able to stay with you in your room before you go to the OR.
- While you are getting ready for surgery, the Transplant Team will be retrieving the donor liver. If the donated liver is not suitable, the surgery will be cancelled. If this were to happen, you would go home and wait until another liver is donated. Although this would be disappointing, it is done for your safety. You want to get a liver that will work well.

Surgery

If the liver is suitable for transplant, you will be taken to the OR. The anesthesiologist will give you anesthetic (medication to put you to sleep before surgery). The surgery will take about 4 to 8 hours. Although every effort will be made to cut down on blood loss, you may need a blood transfusion.

While your family waits

- Once you are in the OR, the wait for your family/support person(s) can be very long. This is a great time for your family to find a place to stay, if they have not already made plans.
- The social worker is available to talk and offer support Monday to Friday (9 a.m. to 5 p.m.).
- Your family can also check in with the Intensive Care Unit (ICU) staff to give them a contact number to call once your surgery is over and you arrive in the ICU.

- There is a waiting area on the 10th floor, Victoria Building. Monday to Friday (8 a.m. to 4 p.m.) there is a Surgical Liaison Nurse who visits the waiting area on the 10th floor to give families an update on how things are going during the surgery.
- If you are having your surgery outside of these hours, there is no one who can directly give your family any information.
- The nurses in the ICU may not have any information about you until just before you come back to that unit.

After surgery

- It is important that you and your family know what to expect right after surgery. The second guide, *After Your Liver Transplant*, will explain your care after you are moved to Unit 6B.
 - › <https://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/0411.pdf>
- A person who has a liver transplant is usually in the hospital for 4 to 6 weeks.

The Intensive Care Unit (ICU)

- You will be closely observed and monitored in the ICU for many days after your surgery. The time spent in the ICU varies from person to person. The average stay is 24 to 48 hours (1 to 2 days), but this depends on how well your surgery went, how fast you recover from the anesthetic (medication used to put you to sleep before surgery), and how sick you were before the transplant.
- The ICU nurses receive 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 tube in your mouth connected to a breathing machine. This is needed until you can breathe on your own. The nurse will suction the breathing tube to remove any sputum (phlegm). When the tube is inserted, you will not be able to talk, eat, or drink.
- After the tube is removed, an oxygen mask is placed over your mouth and nose. You will probably have a sore throat for a few days after this tube is taken out.

- Later, a small tube (nasal prongs) may be used to give you oxygen through your nose. **Take deep breaths and cough often to clear your throat and expand your lungs – this is very important.**
- You will also have a lot of tubes connected to parts of your body to help monitor your organs and vital signs (like 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, and scared. These are all normal reactions.
- Nights and days may feel like they blend together. You may find 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 medication for your pain. Well managed pain will help you take deep breaths and help with moving after surgery.
- Your nurse will teach you how to move around the right way so that you have less pain and/or 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 bed exercises.
- We want you and your family to know about your condition and your care. Family members can get a full update from the nurse on each shift. Please choose one family member to get and share information with other family members. This keeps everybody updated and gives the nurse more time to care for you.
- The nurse in the ICU can plan for your family to meet with the doctors at any time.
- The attending ICU doctors direct your care while you are in the Unit. They work very closely with your surgeons, liver specialists, and other team members. They will review your progress every day and adjust your plan of care.
- Once your condition is stable and you can breathe on your own, you will leave the ICU.

The Transplant Unit

- After leaving the ICU, you will be moved to either the Intermediate Care Unit (IMCU) or if the team feels you are well enough, directly back to Unit 6B.
- The IMCU is a 4-bed unit where two nurses care for 4 patients. You will be here until the team feels your condition is stable enough for you to move back to Unit 6B. People of different genders may need to share a room in this area.
- On the unit, your care focuses on helping you get ready to go home. For example, you will be expected to do more of your daily care, learn about your medications, and work with the physiotherapist. The team will be working closely with you during this time.
- You will meet the Post-liver Transplant Clinic nurse. They will work with you during your hospital stay and for the life of your new liver.
- After you have been discharged home, you may need to stay in the Halifax area to learn about your medications, how to care for yourself at home, and get follow-up care.

Possible long-term complications

Osteoporosis

- Osteoporosis makes your bones weak and thin. Some of the medications needed after a transplant, such as prednisone, may place you at higher risk for this problem. Exercise, such as walking, lowers the risk of osteoporosis.
- It is important to have enough calcium in your diet (1200 to 1500 mg every day). Milk and milk products are good sources of calcium. We may also suggest taking vitamin D (800 IU a day) and calcium pills (such as TUMS®). Never take more calcium than your primary health care provider recommends.

Diabetes

- Diabetes can be a short or long-term complication of a transplant. Some anti-rejection medications raise your blood sugar levels. This is more likely to happen if you had high blood sugar before your transplant.
- Diabetes can affect many parts of your body. It is important to keep your blood sugar under control (see page 20).

High blood pressure

- This is a very common problem after a transplant. It can be caused by the anti-rejection medications, but may also have other causes.
- If not treated, high blood pressure can hurt your heart, blood vessels, and even your new liver.
- A healthier lifestyle may help control your blood pressure. This includes keeping a healthy weight, not eating salty foods, exercising, and not smoking.
- You may also need medications to control your blood pressure. A medication that works well for one person may not work well for another. Your doctor will adjust and change your medications and doses to find the best treatment for you. All blood pressure pills can have side effects. Always tell your doctor if you notice any side effects. **Never stop or change blood pressure pills on your own.**

High cholesterol

- Cholesterol has many useful roles in your body, but too much cholesterol can clog your arteries.
- Anti-rejection medications can raise your cholesterol levels. If your cholesterol was high before your transplant, it may be even higher after.
- Eating foods low in cholesterol and saturated fat, losing weight, and exercising may help to lower your cholesterol. Medication may be needed to make sure your cholesterol is as low as possible. If your cholesterol is high for a long time, you have a higher chance of having a stroke or heart attack.

Cancer

- Liver cancer is more common in people with cirrhosis (scarring of the liver). After your transplant, this risk is lower. But, anti-rejection medications may increase your risk of cancer. People who have had cancer before are at higher risk and need to have regular check-ups.

