Your Liver Transplant Guide

We're glad you have chosen University of Washington Medical Center (UWMC) as your transplant center. Our Transplant Team is here to support you every step of the way. We are committed to listening, respecting your needs, and providing care that includes your whole family. Please let us know how we can help you.

University of Washington Medical Center is one of the top multi-organ transplant centers in the United States.

About This Guide

Your Liver Transplant Guide is a reference tool for you to use before, during, and after your transplant surgery. Please talk with your nurse coordinator if you have any questions or concerns.

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Your Referral and Transplant Evaluation

Referral to the Transplant Program

Your local healthcare providers referred you to the UWMC Liver Transplant Program. The Transplant Team reviewed your medical records and decided to schedule you for a health assessment.

- Our financial department will work with your health insurance company to make sure transplant benefits are covered by your insurance policy.
- We will schedule an appointment to see if a liver transplant evaluation is needed.
- You will have some lab tests before you meet with the transplant physician.

Your First Consult

At your first consult visit, the Transplant Team will:

- Review your health history
- Give you a physical exam
- Review your mental, emotional, and nutritional health

Based on your lab results and health review, the team will work with you to create your care plan. This plan may or may not include a transplant evaluation.

You will have time to talk with the Transplant Team about any of your questions or concerns.

Your first consult will include a full physical exam.

Liver Transplant Evaluation

The evaluation process is different for each patient. Before each test, your Transplant Team will explain why it is needed and what will happen.

After your health assessment, labs, and tests are done, the team will review your test results and decide if the benefits of a liver transplant are greater than the risks for you.

Your transplant evaluation has 2 parts:

- Medical appointments and testing at UWMC
- Testing with your local primary care providers

Your transplant nurse coordinator will talk with you about your required tests and what to expect.

Going Forward

If our liver transplant specialists (hepatologists) decide that a transplant may be right for you:

- You will meet with your transplant nurse coordinator to talk about the process.
- You will need to sign required policy forms that will be kept in your UWMC records.

Your Health Assessment

The goal of your health assessment is to find out:

- If a liver transplant is the best treatment for you
- If you are healthy enough for transplant surgery
- If other treatments may work instead of a transplant

Exams and Tests at UWMC

Your exams and tests will most likely be done over 3 to 4 full days in UWMC outpatient clinics. Your scheduling coordinator will schedule and coordinate these.

During your assessment:

- You will have tests to check your heart, lungs, liver, kidneys, and other important organs.
- You will meet with many members of your care team, including a transplant dietitian, financial coordinator, and social worker.

We will try to complete your assessment as quickly as possible. If you have serious health problems during this time, you may be admitted to the hospital. This will help us finish your tests quickly and list you for transplant sooner.

After your UWMC tests, you will meet with the transplant surgery and pre-anesthesia teams.

Other Important Details

- Your nurse coordinator will give you a list of other tests to schedule with your local healthcare providers. **These tests are in addition to the ones we will schedule for you at UWMC.** You must complete these tests within 30 days.
- It is important to talk openly and often with your nurse coordinator so we can keep your assessment process moving forward.
- Your support team and caregivers must be involved in scheduling your appointments. This will be very important if the process feels overwhelming.
- Your test results may show that you have health problems that need treatment before we can decide if you are a candidate for liver transplant. We will help you schedule more tests and treatment, if needed.
- Some patients may not be able to have a transplant for medical, social, or financial reasons.
- Our goal is to decide within 60 days if you are a candidate for transplant.

The Evaluation Process

During your evaluation, you may need some or all of these tests and appointments. If you have questions about any of these terms or tests, please ask your care team for more information.

- **Abdominal imaging:** Images of your liver and blood vessels to check for tumors and other abnormalities.
- **Blood tests:** Include complete blood chemistry, tuberculosis screening, blood type, arterial blood gas, HIV, hepatitis, and screening for other viruses.
- **Blood typing:** This is the most important step in finding a donor, because it shows if a donor's liver can safely be in your body. You must have this test done 2 times to be listed for transplant.
  - There are 4 blood types: A, B, AB, and O. Type O is the most common, and the next most common is type A. Only a few people have type B or AB blood.

These tests will help your team make the safest care plan for your transplant.

- **Bone density study:** Checks your risk for *osteoporosis* (bone thinning). *Schedule with your local care provider***.**
- **Chest X-ray:** Checks your lungs and breathing health.
- **Colonoscopy**: Looks inside your large intestine for cancer. *Schedule with your local care provider.*
- **Consultations:** You may meet with doctors who specialize in the heart, kidneys, lungs, infectious diseases, and perhaps other specialties.
- **Dental exam:** *You will need to schedule a visit with your dentist to find out if you need to have any dental work done.* Your dentist must confirm that you do not have cancer or infections in your mouth.
- **Gastrointestinal endoscopy:** Checks your esophagus, stomach, and the first part of your small intestine. *Schedule with your local care provider.*
- **Heart tests:** You will have an echocardiogram, electrocardiogram (ECG), and cardiac stress test.
- **Immunizations:** You must be up to date with vaccines for influenza (flu), pneumonia, hepatitis A and B, tetanus, and shingles, and we encourage a COVID vaccination. Your care team may require additional vaccines.
- **Mammogram:** This is an X-ray exam of the breasts to check for cancer. *Schedule with your local care provider.*
- **Nutritional evaluation:** Meet with a UWMC dietitian to discuss eating habits and liver disease nutrition. Bring a support person to this meeting. (See "Nutrition" section, page 23.)
- **Pap smear:** Checks for cervical cancer. *Schedule with your local care provider*.
- **Pre-anesthesia consultation:** Meet with an anesthesiologist to talk about anesthesia risks

- **Pulmonary function testing:** Checks how well your lungs and breathing system work.
- **Social work evaluation:** A UWMC social worker will talk with you about your personal, family, and financial situation, including any drug and alcohol history. Please bring a support person to this meeting. (See "Social Work Services" section, page 18.)
- **Surgeon's consultation:** Meet with a transplant surgeon to review your test results, discuss your surgery, and ask questions. (See "Liver Transplant Surgery" section page 27.)
- **Toxicology screening:** Transplant patients must **NOT** use illicit drugs or alcohol. You may use pain medicine if it is prescribed by your doctor and you take limited doses. We will do random drug screenings throughout the pre-transplant phase.
- **Urine tests:** A 24-hour urine collection will check your kidney function.
- **Financial review:** Meet with your UWMC financial coordinator to review your insurance benefits, insurance coverage, and costs. (See "Financial Planning" section, page 14.)
- **University of Washington Transplant Policies (regulatory required documents):** You will need to sign many forms about the transplant process. You will be given copies for your records.

Lab Tests

The UWMC lab is on the 3rd floor (main level) of the hospital.

- The lab is open weekdays from 6:30 a.m. to 6 p.m.
- Please allow 60 minutes to have your blood draw done.

Liver Transplant Educational Series

You and your caregiver(s) must complete the liver transplant education and medication video series on YouTube. Topics include:

- Overview of liver disease and our liver transplant program
- What to expect while waiting for liver transplant surgery
- Details of transplant surgery and follow-up care
- Transplant medicines and side effects
- Insurance and prescription drug benefits for transplant surgery
- Living donor liver transplant program information

Patient Education Handouts

UWMC has patient education handouts for many of the tests in your evaluation.

- You can read these online on the Health Online website: *healthonline.washington.edu.*
- You may also ask your Transplant Team for printed copies.

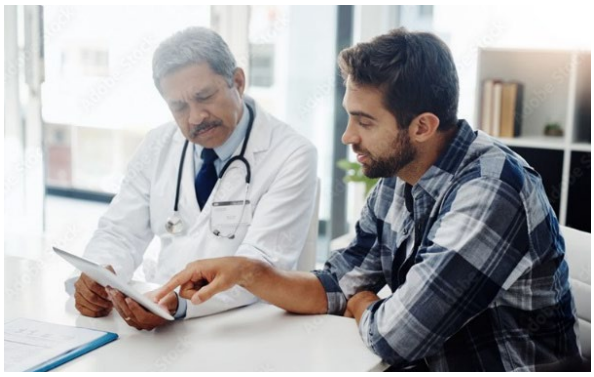
Your Liver Transplant Team

Who is on your transplant team?

Your team includes:

- You, the transplant recipient
- Your caregiver
- Your family and friends
- A group of specially trained healthcare providers

This section of *Your Liver Transplant Guide* explains what each person does to help make your transplant a success.



As the transplant recipient, you play a very active and vital role in your care.

You, the Recipient

As the patient, you are a very important part of the team. You can:

- **Keep Communication Open:**
  - Ask questions about your care and treatment.
  - Share any information that may affect your health.
  - Write down all your health changes and daily progress in a notebook. Share this with your healthcare providers.
- **Take Responsibility for Your Health:**
  - Follow all instructions from your Transplant Team.
  - Learn about all your medications: their names, what they do, why you take them, when you take them, and the dose (amount) you take.
  - Do as much as you can for yourself and stay as independent as you can.

Your Caregiver

Your **caregiver** helps take care of you before and after your transplant. A strong support system is very important. Choose a caregiver who can help with things like:

- Helping you with transportation
- Going with you to your clinic appointments
- Giving you emotional support
- Providing physical care

- Helping you take and keep track of your medications
- Watching for health changes and symptoms
- Calling and talking with your healthcare providers, when needed
- Sharing updates with family and friends

Transplant Hepatologist

The **transplant hepatologist** is a doctor who specializes in liver diseases and manages your care during the transplant process. They will:

- Be your main contact person on our transplant program
- Do a complete health exam to see if transplant is a good option for you
- Work with your primary providers to make sure you're getting the right care
- Make a plan for your follow-up care
- Stay involved in your care after your transplant surgery and for the rest of your life

Transplant Residents and Fellows

Residents and fellows are important members of your Transplant Team:

- **Resident:** a doctor who has finished medical school and is now training for a specific type of medicine or surgery
- **Fellow:** a doctor who has finished medical school and residency, and is now training for a special area such as hepatology or transplant surgery

While you are in the hospital, these doctors will:

- Visit you every day
- Examine you
- Write care orders
- Assist the Transplant Team with your care
- Be available at any time of the day or night while you are in the hospital

Physician Assistant or Advanced Nurse Practitioner

A **physician assistant** (PA) is a licensed medical provider who works with your doctor. They will:

- Examine you
- Write prescriptions
- Help manage your care while you are in the hospital

Clinical Transplant Nurse Coordinator

Your **clinical transplant nurse coordinator** is a registered nurse (RN) who organizes all events in your transplant process. You will meet this nurse during your first visit to UWMC.

- Your transplant nurse coordinator will be your main contact **during your transplant evaluation and after you leave the hospital.**
- Your main contact **during your hospital stay** will be the inpatient Physician Assistants.

Your transplant nurse coordinator will:

- Teach you about liver transplants
- Share your questions and concerns with your Transplant Team before your transplant and after you leave the hospital
- Help set up and manage your follow-up care
- Keep your spot on the transplant waiting list up to date

Transplant Social Worker

During your evaluation for transplant, the **transplant social worker** will:

- Ask you and your caregiver questions about your mental, physical, and emotional health. This *psychosocial history* helps the social worker create a care plan that will work best for you.
- Help you create a care plan.
- Recommend treatments and support for *substance use disorder* (problems with drugs or alcohol).
- Answer your questions about staying in the hospital and your care after you go home.

You can meet with your social worker any time. Please see the "Social Work Services" section (page 18).

Scheduling Coordinators

Your **scheduling coordinators** work with your transplant nurse coordinator. They will:

- Schedule all appointments for your evaluation, follow-up, and care after transplant
- Help coordinate your appointments in different UWMC clinics
- Answer your questions about how to prepare for tests
- Confirm your insurance for your appointments
- Make changes to your schedule, if needed

Transplant Financial Counselor

Your **financial counselor** will help you with questions about paying for your transplant care. They work with your scheduling coordinator to check your insurance and help solve insurance coverage issues. They can also talk with you about payment plans.

Transplant Dietitian

Your **transplant dietitian** is an expert in nutrition who will work with you during the entire transplant process. There are different types of dietitians:

- During your evaluation, an **outpatient dietitian** will check your nutrition and give you recommendations to help you prepare for surgery. They will also keep track of your nutrition after your surgery.
- During your hospital stay, an **inpatient dietitian** will make sure that you receive the right nutrition. They will talk with you about how your nutritional needs will change after transplant and help you make a diet plan.
- A dietitian will also help your caregivers understand how to support your nutrition and diet needs.

You will meet with transplant dietitians before and after your surgery.

Transplant Pharmacist

Transplant pharmacists are medicine experts who will:

- Teach you about the medications you will take after surgery.
- Work with your Transplant Team during your hospital stay to monitor your medication plan.
- Check that your new medications are safe to take with your regular medications.
- Meet with you after you go home to review your medication plan and answer your questions.

Transplant Surgeon

The **transplant surgeon** has special training in surgery and caring for transplant patients. They will:

- Meet with you and your caregivers before surgery
- Visit you every day during your hospital stay
- Review your lab tests and X-rays
- Check your incisions to make sure you are healing well
- Check your recovery progress before you leave the hospital
- Order tests, treatments, or changes to your medicine

Ask your transplant surgeon any questions you have about your surgery, your incisions, or other issues related to your care.

Critical Care Nurses

After your transplant, you may go to the critical care unit (also called the ICU or Intensive Care Unit). **Critical care nurses** are specially trained nurses who will:

- Monitor you closely after surgery
- Check how well your new liver is working
- Take care of your incisions and drains
- Help you move and recover

Transplant Unit Primary Nurses

A **transplant unit nurse** will be assigned to you daily during your hospital stay. This nurse will:

- Provide nursing care
- Talk with the rest of your team about your needs and concerns
- Include you and your family in decisions about your care
- Teach you and your family how to care for your health
- Help plan your discharge and next steps at home

Physical Therapy

Physical therapy helps you build strength and movement after surgery. Your Transplant Team will set this up for you if needed. Most transplant patients begin physical therapy when they move to the transplant unit, but you may see a **physical therapist** while you are still in the critical care unit. Your physical therapist will:

- Check your strength, flexibility, and endurance (stamina)
- Work with you to create a daily therapy plan
- Create a home exercise plan
- Work with an occupational therapist, if needed

Occupational Therapy

Occupational therapy helps you safely get back to daily activities like bathing, moving around, and taking care of yourself. Your Transplant Team will set this up for you if needed.

Your **occupational therapist** will recommend supplies and equipment for you to use during your recovery. They will also create a plan of activities to increase your strength, endurance, and independence during and after your hospital stay. These activities may include:

- Self-care
- Moving into or out of a car, bathtub, or bed
- Home safety strategies
- Ways to save your energy and make tasks easier
- A home exercise program

Your Transplant Candidacy

Who decides if I am a candidate for transplant?

Before your name can go on the liver transplant waiting list, your medical history and current health condition need to be checked. You can only be listed for a liver transplant after:

- the Liver Transplant Team completes your health assessment (also called *medical evaluation* or "work-up")

  and:

- the Liver Transplant Selection Committee approves you.

How are transplant recipients chosen?

Patients must meet the requirements in the "Selection Criteria Policy" to be chosen for a liver transplant. You should have received a copy of this policy at your first clinic visit.

After you complete all your tests and appointments, your information goes to the Liver Transplant Committee. This group meets with the Liver Transplant Team to review your results and make a decision.

You must have a complete health assessment before you can be listed for transplant.

To be listed for transplant, you must:

- Have severe (end-stage) liver disease that cannot be cured by other treatments
- Not be using alcohol or harmful drugs
- Have a safe and stable home, and support from family or friends
- Understand the transplant process
- Be able to follow medical instructions before, during, and after transplant
- Have a history of going to all follow-up appointments with your providers
- Have no active infections
- Have no active cancer (certain liver tumors may be okay)
- Not have other serious health problems that will make transplant surgery or recovery difficult (like heart or lung disease)

After the committee reviews your case, you will find out your status as a liver transplant candidate. Here is what each status means:

- **Accepted:** You meet the criteria for transplant. You will be listed for liver transplant as soon as we have financial clearance from your insurance company.
- **Accept-Pending**: You meet the criteria for transplant, but you need to complete more tests. If you are still a candidate after these tests, we will ask for insurance approval and list you for transplant.
- **Approved-Pending Timing:** You meet the basic criteria for transplant, but your liver disease is not yet severe enough to need a transplant. We will continue to check your health and list you for transplant if your liver disease gets worse.
- **Deferred:** You do not meet the criteria for transplant right now. However, the Transplant Team can work with you to help you qualify. You may need more medical or mental health tests or treatment, or you may need counseling or treatment for past alcohol or drug use. If you follow the care plan in the required amount of time, we will review your case again.
- **Denied:** You do not meet criteria to receive a liver transplant. This can happen for many reasons, including health problems that make surgery too risky, or not following the committee's instructions.

If the committee asks you to have more tests, treatments, or counseling, your team will help you with scheduling and support. The Transplant Team expects you to come to all scheduled appointments and to complete all the recommendations from the committee.

Your MELD Score

After your insurance gives financial approval, we will ask you to get a blood test. You can do this at UWMC or at your local lab, whichever is easiest for you. This test will give us your *MELD* (Model for End Stage Liver Disease) score.

Your MELD score shows how severe your liver disease is. This score can range from 6 (less severe) to 40 (very severe).

There are not enough donated livers for everyone who needs one, so people with the highest MELD scores are offered livers first.

The MELD blood test measures:

- **Bilirubin** - checks for jaundice
- **INR** (*international normalized ratio*) - checks how well your blood clots
- **Creatinine** - checks how well your kidneys are working
- **Albumin** - checks your nutrition
- **Sodium** - checks your body's fluid or electrolyte balance

Your MELD score changes over time. The higher it is, the more likely you are to get a liver transplant.

How often do I need to have blood tests?

To stay active on the transplant list, you must get regular blood tests. This is required by UNOS (the United Network for Organ Sharing).

Here is how often you need tests, based on your current MELD score:

If Your MELD Score Is:	You Must Have Blood Tests:
6 to 18	Every 90 days
19 to 24	Every 30 days
25 or higher	Every 7 days

Make sure we get your test results!

Ask your lab and doctor to send your blood test results RIGHT AWAY to your transplant coordinator. They must receive results **within 24 hours** of your blood draw.

If you miss your blood tests or if we do not get your results on time, it will affect your place on the waiting list. This could mean missing a life-saving transplant.

Make the Most of Your Waiting Time

If you are listed for transplant:

- Take care of your health and nutrition.
- Make a plan for who will care for your pets during your hospital stay.
- Have a transportation plan to and from UWMC (including flights or rides with friends, family, or taxis)
  - If you are flying to Seattle, learn the schedule for all flights to Seattle-Tacoma International Airport, at all times of the day or night.
  - If you are on Medicaid and live more than 2 hours from Seattle, contact your Medicaid Transportation Broker for help getting an open-ended ticket.

While waiting for surgery, keep all your plans up to date.

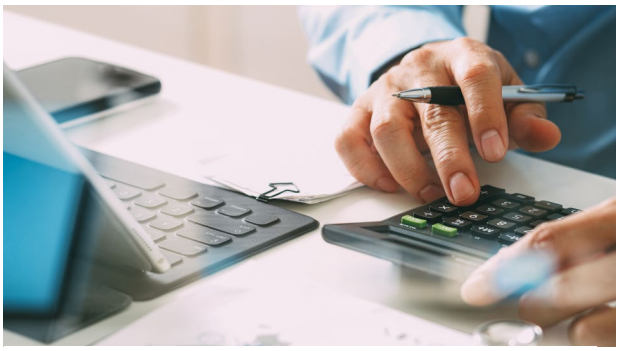
- Make a housing plan if you live more than 2 hours away from UWMC. Ask your insurance case manager if they can help with travel costs. Plan how you will pay for meals and lodging.
- Make sure you have a working cell phone with voicemail.
- Talk with your doctor about any worries or questions you have. All your questions and concerns are important!
- Ask your scheduling coordinator to set up your follow-up appointments on days when the liver transplant support group meets. Ask your social worker for the schedule of group meetings.
- Be careful with information you find online, because it is not always correct or up to date. Your doctor is the best source for answers. Read everything you can but talk with your doctor about all your medical decisions.

Financial Planning

This section covers:

- Health Insurance: What to learn and think about
- Medicare, Medicaid, and Apple Health
- Medication costs and planning
- Replacing income while off work
- Financial assistance resources
- Planning worksheet

If you have questions about this section, please contact your transplant financial coordinator at **transplant-tfc@uw.edu**. We are here to help!



Plan ahead – there are many costs to think about during and after your transplant.

Health Insurance: Understanding Your Coverage

Most private insurance plans cover liver transplants, but the details can be different. It's important to:

- Talk with your UW Transplant Financial Coordinator before changing insurance plans.
- Learn more about your insurance plan including:
  - Hospital stay coverage
  - Pre-approval
  - Your out-of-pocket maximum
  - Your co-pays, deductibles, and co-insurance
  - Prescription drug benefits
- Check if your plan covers care outside your home state or outside your network, especially if you do not live in the Seattle area.

Medicare and Supplement Plans

Medicare covers transplants for people 65 and older, and for some under 65 with certain disabilities.

- Part A and Part B may cover hospital and provider fees.
- As of 2023, some transplant patients can get lifetime coverage of immunosuppressive (anti-rejection) medications through Medicare. However, you may still have deductibles and 20% coinsurance unless you have supplemental insurance (Medigap).

Washington Apple Health (Medicaid)

If you qualify based on income or disability, Apple Health can give you full transplant coverage.

- Rules and benefits can be different depending on your plan.
- Your social worker can help you apply.

Managing Medication Costs

You will need important medications after your transplant. These can be expensive. To lower cost:

- Review your insurance plan's prescription coverage, including for brand-name medications.
- Ask about mail-order pharmacies to reduce co-pays.
- Look into patient assistance programs from medication companies.
- If you don't have insurance, these medications can cost $12,000 – $15,000 per year. Planning ahead is very important.

If you're not sure about your medication coverage, your transplant team can guide you step by step.

Planning for Time Away from Work

You may need weeks or months off work. Learn about:

- Short- and long-term disability benefits from your employer
- Social Security Disability Insurance (SSDI) if your condition will last at least 1 year
- Supplemental Security Income (SSI) if you have limited work history and income

Talk to your employer and your transplant financial coordinator about the options as soon as possible.

Financial Assistance and Fundraising

Some patients explore crowdfunding or charitable support to help with costs. Look into:

- Help Hope Live: helphopeLive.org
- Children's Organ Transplant Association (COTA), for patients under 21
- GoFundMe (this can impact your taxes and/or Medicaid eligibility)

Your transplant social worker can help you find the right tools and resources to begin fundraising with confidence.

Common Financial Mistakes to Avoid

As you plan for the costs ahead, **do not**:

- Let insurance lapse (pause or stop) during your transplant process
- Assume all medications will be covered automatically
- Wait too long to apply for disability benefits or Apple Health

Remember to:

- Budget for temporary lodging, transportation, or caregiver costs.
- Use mail-order options that can lower your medication co-pays.
- Keep track of all co-pays and deductible payments.

Financial Planning Worksheet

Use this worksheet to estimate your out-of-pocket costs and plan your budget.

Category	Estimated Cost	Notes
Health Insurance Premiums		
Hospital/Surgery Costs (co-pays/deductibles)		
Post-Transplant Medications (monthly)		
Temporary Housing (in Seattle)		
Transportation (flights/gas/parking)		
Follow-up Visits		
Lost Income (during recovery)		
Caregiver Costs or Support		
Other Expenses		

Medication Co-Pay Estimate Worksheet

Use this worksheet to estimate your monthly and yearly out-of-pocket costs for the medications you will need after your transplant.

Call your insurance company with this list to get accurate co-pay estimates. This is especially helpful if your insurance charges co-pays based on medication type (generic vs. brand name) or tier levels.

Medication Name	Dosage/Frequency	Generic or Brand	Monthly Co-Pay	Annual Co-Pay (Estimate)
Tacrolimus (Prograf)				
Mycophenolate mofetil (Cellcept)				
Prednisone				
Antibiotic (e.g., Bactrim)				
Antiviral (e.g., Valcyte)				
Antifungal (e.g., Nystatin)				

Checklist of Tasks:

- ☐ Confirm transplant coverage with insurance provider.
- ☐ Review out-of-pocket costs (hospital, medications, travel).
- ☐ Apply for Washington Apple Health (if eligible).
- ☐ Review medication coverage (Part D, copays, generics).
- ☐ Explore short- or long-term disability insurance.
- ☐ Contact social worker about fundraising support.
- ☐ Start an emergency savings plan or budget worksheet.

Social Work Services

The transplant journey is a mixed experience, for you and for your family. On one hand, the transplant offers the hope of extending your life, improving your quality of life, or both.

On the other hand, transplant also involves some risks and changes. You and your family will face some major challenges both before and after your transplant. Your transplant social worker is trained to help you and your family understand and talk about the stresses that are part of the transplant journey.

What does a social worker do?

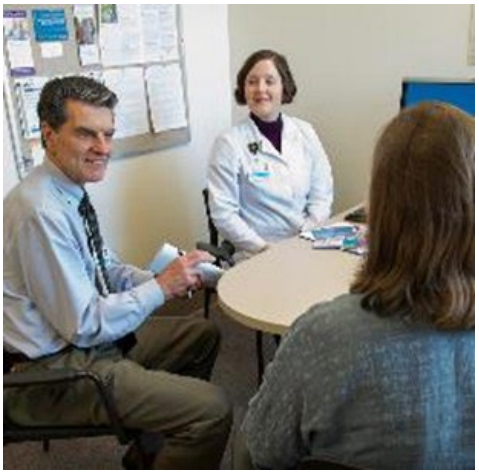
The transplant social worker is a member of the Transplant Team, and an important resource for patients and families. You and your caregiver(s) will meet with your social worker for a *psychosocial assessment* early in the transplant process. Your social worker will also provide ongoing case management and referrals throughout the transplant process.

Psychosocial Assessment

This important consult is usually the first time you meet your transplant social worker. You and your support person will talk with the social worker about different aspects of your life. This will help the social worker support you and your caregiver(s) as you prepare for transplant.

This assessment process may take more than one meeting to complete. And, you may have many of these meetings before you are ready to be listed for transplant. Here are some of the topics you will talk about when you meet with your social worker:

- **Social situation:** Your social worker will ask you about your family history. This includes your family of origin, any cultural or religious beliefs, your current family structure, and your education, financial, and employment history.
- **Your care plan before and after transplant:** Your social worker will explain what plans you need to make before you can be listed for transplant. You will be provided with an outline that you will use to address each step of your plan. You will need to fill out and return this care plan before you can be listed.



Your transplant social worker is an important resource for you and your family.

Some of the plans you will need to make include:

- **Your caregivers.** You will be asked to name a primary caregiver who will help you through the transplant process. This may be your spouse, partner, family member, or long-time friend. You must also name a back-up caregiver who will assume care if your primary caregiver becomes unavailable or needs assistance.

  Your caregiver will need to attend appointments with you before and after transplant. They will also need to come to the hospital for teaching on how to take care of you after your surgery. Once you are home, they will help you with managing your medications, meal preparation, and daily household tasks.

- **Your transportation to and from UWMC**, for scheduled appointments before and after transplant, as well as a plan to travel to UWMC as quickly as possible when you are called in for the surgery.

- **Where you will stay after transplant.** For 3 months after discharge, you and your caregiver must stay within 2 hours of UWMC. Most people either stay with family and friends in the area or rent a furnished apartment during this time. Some people bring an RV or travel trailer and stay in a local RV park. Your social worker can give you resources to help you make these plans.

- **Housing and transportation costs.** Some health insurance plans may help pay or reimburse you for housing and transportation costs. You may also want to try fundraising to help with these costs.

- **Mental Health:** If you have a history of mental health issues, your social worker may refer you for more evaluation and/or recommend mental health counseling. The goal of this is to provide you with the support you need for emotional stability during the transplant process.

- **Substance Use:** Your social worker will also ask you about your use of various substances:

  - **Alcohol and recreational drugs:** You must make a lifelong commitment to never use alcohol or recreational drugs. If you have a history of substance use disorder, you may be asked to have more evaluations and meet other requirements before you can be listed for liver transplant.

  - **Prescription pain medication and benzodiazepines:** If you are taking prescription pain medication, are using sedatives like Valium or Xanax, or are on a methadone maintenance program, you will be asked to meet other criteria before being considered for transplant.

  - **UWMC Substance Abuse Policy:** All transplant patients are asked to read and sign UWMC's Substance Abuse Policy. If you violate this policy at any time, you cannot be a transplant candidate or a re-transplant candidate at UWMC.

Case Management and Referrals

Your social worker can help you with many things both before and after transplant, including:

- **Coping:** You will deal with many lifestyle changes and stresses before, during, and after transplant. Your social worker can talk with you about the psychological, emotional, or social aspects of being a transplant recipient. If needed, your social worker can provide you referrals to agencies, community resources, or mental health professionals to help you cope with these changes.
- **Support Group:** At any point in the transplant process, you may attend the Liver Transplant Support Group. This group is open to UWMC patients and caregivers. Meetings are led by transplant social workers. The group usually includes people who are waiting for transplant and patients who have already had their transplant. It is an excellent way to hear from fellow patients about their experience, and gain support from others facing challenges that are similar to yours. Ask your social worker for the current support group meeting schedule.
- **Care plans:** Your social worker will help you solve problems on issues that come up as you create your care plan both before and after transplant. While you are in the hospital, your social worker may also help arrange services for your discharge home, such as home health physical or occupational therapy.
- **Legal forms:** Your social worker will provide you with forms to create these legal documents for your medical record:
  - A **Healthcare Directive** (also known as a "living will"), which tells doctors your choices for end-of-life care.
  - A **Durable Power of Attorney for Healthcare**, which names a spokesperson(s) who would help make your medical choices if you were unable to communicate.

  A more complete explanation of each document is included with the form. You may already have documents like these, or you might choose to work with your family attorney to create your own. Or you can use the forms as they are. The choice is yours.

  Keep your originals of these forms in the same place you keep other important legal papers. Give copies of them to your social worker so that they can be placed in your UWMC medical record.
- **Leave paperwork:** Your social worker can help you and/or your caregiver with paperwork for taking time off work or school for your transplant surgery and recovery. This may include FMLA, Washington state PFML, and excuse letters. Talk to your employer and your social worker to explore your options.

Life After Transplant

Our goal is for your life after transplant to be fulfilling, productive, and as normal as possible. For most people, this includes returning to work. Of course, a successful return to a job can help your financial situation and fill your health insurance needs. Patients who return to work also feel better about themselves and do better physically.

Returning to Work

Most transplant patients can return to work after their surgery. Some patients can continue working while they await transplant. Other patients have already been receiving Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI) benefits due to disability caused by their health problems. Still other patients apply for these benefits after their need for transplant has been confirmed.

Your doctor can help you decide when it is safe to return to work.

The legal definition of "disability" under the SSDI and SSI programs is important to note. Disability is defined as:

> "The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or has lasted or can be expected to last for a continuous period of not less than 12 months …"

Sooner or later after transplant surgery, most patients are no longer considered "disabled." This means that you will probably lose your disability benefits after your transplant.

We encourage transplant patients to go back to work, but it is very important that you give yourself plenty of time to recover from your surgery. If you have a job that involves:

- **Only deskwork/remote work:** You may be able to go back to work on a part-time basis as early as 8 weeks after transplant.
- **Any physical effort or lifting objects that weigh 4 or more pounds:** You may not be able to return to work until 3 or 4 months after surgery, or as determined by your transplant doctor.

Before you return to work, please talk with your transplant doctor about getting a *medical release*. This is a form that says it is medically safe for you to return to work.

Health Insurance

It is important for transplant patients to have active health insurance coverage for the rest of their lives. Many people have health insurance through their jobs. This makes it very important for transplant patients to have a plan for returning to work. If you don't plan to return to work, it is important to make other plans for your health insurance coverage.

Writing to Donor Families

Many patients ask about writing to the family of their organ donor. Most families appreciate hearing from transplant recipients.

It is your choice whether to write to the donor family. If you do write, it is helpful to talk about yourself, your family situation, your job or volunteer work, your hobbies and interests, and your transplant experience and how it has changed and improved your life. And don't forget to thank the donor family for their gift.

To maintain confidentiality:

- Please include your **first name only** in your letter.
- Do **not** include your address, phone number, email address, or other contact information.
- Place your letter or card in an unsealed envelope.
- On a separate piece of paper, write your full name and the date of your transplant. This information will be used to find your donor family, but it will not be given to them.

You can give your letter to your social worker, who will mail it to LifeCenter Northwest. This nonprofit organization manages organ donations in Alaska, Montana, Northern Idaho, and Washington. LifeCenter Northwest will forward your letter to the donor's family.

Or you can send your letter directly to the organization. (Remember to include your full name and date of your transplant on a **separate** piece of paper from your letter.) Send your letter to:

LifeCenter Northwest

Attn: Family Services Coordinator

3650 131st Ave. S.E., Suite 200

Bellevue, WA 98006

Nutrition During and After Transplant

It is very important to eat the right foods as you get ready for surgery, during your recovery, and for the rest of your life. To help you learn about good nutrition, you will meet with transplant dietitians before and after your surgery.

Nutrition Before Transplant Surgery

Before transplant, follow all the dietary guidelines your dietitian gives you. Eating the right foods will help you be in the best health possible. This will help your body handle the surgery and heal afterward.

Nutrition After Transplant Surgery

After transplant, good nutrition will help you:

- Heal and fight infection
- Keep your desired weight
- Reduce some of the side effects of your transplant medications

Your dietitian will monitor your food intake after surgery and teach you how to meet your nutritional needs. This will include tips to help you choose foods from the hospital menu.

After transplant, your most important diet goals are to:

- Eat enough calories and protein to support healing and build muscle
- Drink enough fluids
- Follow food safety guidelines

Eating well helps your body handle surgery and recovery.

Your Weight

During the first few weeks after transplant, do not worry about your weight. It will be hard to know your actual weight, since you may *retain* (hold onto) water after surgery. When you are eating well and meeting your protein needs, your dietitian will talk with you about long-term goals for your weight.

Controlling Side Effects

Your medicines may cause side effects. Some of these can be lessened by eating the right foods and avoiding others. Here is a list of some side effects and how you can help control them:

Side Effect	Caused by	What to Do
Fluid retention	Prednisone	• Do not add salt to foods • Do not eat salty foods • Choose more fresh foods and fewer processed foods
High blood pressure	Tacrolimus Cyclosporine	
Loss of muscle mass	Prednisone	• Eat high-protein foods • Exercise
High blood sugar	Prednisone Tacrolimus Cyclosporine	• Control carbohydrate intake • Control portion sizes • Exercise
High potassium	Tacrolimus Cyclosporine	• Limit high-potassium foods (this is usually short-term)
Low magnesium	Tacrolimus Cyclosporine	• Right after transplant, your care team will likely recommend a magnesium supplement and encouraged magnesium through food sources.
High levels of medicine in your blood	Tacrolimus Cyclosporine	• Avoid grapefruit, starfruit, pomegranate, and pomelo.
Not absorbing enough calcium and phosphorus	Prednisone	• Eat 3 servings from the dairy group each day • You will be prescribed calcium and vitamin D supplements
High blood cholesterol	Prednisone Tacrolimus Cyclosporine	• Follow a Mediterranean diet, which is high-fiber and low in saturated fats.
Increased appetite and weight gain	Prednisone	• Choose high-fiber and high-protein meals • Eat small frequent meals and snacks • Exercise

Your Food Choices After Transplant

What you eat affects your health after transplant. Before you leave the hospital, your dietitian will talk with you about your dietary needs and any concerns you have about nutrition. To help you, we will give you nutrition education handouts with important information, food lists, and cooking ideas.

In the weeks after transplant surgery, you will come to the clinic often. During these visits you can talk with the outpatient dietitian about your questions or concerns.

Many patients eat in the hospital cafeteria when they come to the clinic. There are many healthy options in the cafeteria, but there are also unhealthy foods available. It might help to bring your own breakfast or lunch to help you avoid eating foods that are not in your nutrition plan. You can bring a lunch cooler with protein snacks and shakes.

Weight Gain

Once you have fully recovered, you may gain weight. This happens because:

- Your diet is less strict
- You feel better
- You have more opportunities to eat rich foods

Losing muscle before and after transplant can also cause weight gain. Lean muscle boosts your metabolism and protects your body from extra weight gain. It is important to get plenty of physical activity after transplant to build muscle. Gaining weight can increase your risk for:

- High blood pressure
- High blood cholesterol
- High blood sugar

Your dietitian can help you make choices that will help you stay at the best weight for you.

Dietary Guidelines

We recommend following a heart-healthy Mediterranean diet after transplant. Here are basic dietary guidelines to follow after transplant:

- **Sodium:** If you are retaining fluids and your blood pressure is high, you will need to follow a low-sodium diet.
- **Potassium:** Cyclosporine and tacrolimus can cause your blood potassium to be higher than normal. This is a short-term side effect, but if it happens, you will need to follow a low-potassium diet.
- **Fat and Cholesterol:** Your medicines may raise your blood cholesterol and triglyceride levels, which increases your risk of heart disease. A diet low in saturated fat with and emphasis on heart-healthy unsaturated fats from plants may reduce this risk. It will also help you avoid gaining weight, if that is a concern for you.
- **Carbohydrates:** Because your medicines can increase your blood sugar levels, you may need to watch how many simple carbohydrates you eat. Focus on complex fiber containing carbohydrates and limit simple sugars in beverages and desserts.

Food Safety

Food safety is important to help prevent infections after transplant. Follow these tips:

- Wash your hands in warm soapy water before you eat or prepare food.
- Keep raw and cooked food separate in the refrigerator, and when you are preparing a meal.
- Refrigerate leftovers within 2 hours after cooking.
- Get a food thermometer and cook food to the right temperature.
  - You can find about safe food temperatures at *www.foodsafety.gov.*

A food thermometer will help you check that foods like meat and eggs are safe to eat.

Unsafe Foods

These foods are **not** safe to eat after transplant:

- Raw or unpasteurized juices, ciders, milk, and cheese
- Raw sprouts: bean, alfalfa, radish, and others
- Raw or undercooked meat, like rare hamburger or steak
- Undercooked eggs, like over-easy or in Caesar salad dressing
- Raw seafood, oysters, sushi, and sashimi

To Learn More

Visit these websites to learn more about food safety:

- **FoodSafety.gov** has food safety information from the United States government. Visit *www.foodsafety.gov.*
- **Fight Bac!** gives tips on how to keep food safe from bacteria. Visit *www.fightbac.org.*

Your Liver Transplant Surgery

What to expect

Liver transplant is usually done for people with end-stage liver disease and for people who have liver cancer. In liver transplant surgery, doctors replace a diseased liver with a healthy liver from a donor.

Most times, donated livers are given first to recipients who are sicker and who have a high *Model for End-Stage Liver Disease* (MELD) score.

Your wait for transplant could last days, months, or years. Sadly, up to 10% of patients on the wait list in the U.S. get worse or even die before they receive a transplant. This is why it is very important that you work with your doctor to prevent health problems that could prevent you from receiving a transplant..

Waiting for Your Transplant

Keep in Touch

- After you are accepted and listed for transplant, we need a reliable way to contact you at **any** time of the day or night. **You MUST have a reliable cell phone and other source of contact.**
- If you plan to be out of town, give your transplant coordinator the phone number(s) where we can call you. Please do not miss a life-saving opportunity because you cannot be reached!
- If your contact information changes, tell your transplant coordinator immediately so that we have your updated numbers.

Always keep your cell phone fully charged and nearby.

Know Your Transplant Travel Plan

Be sure to have your travel plan to UWMC decided ahead of time. This may include:

- Arranging for a person who can drive you to Seattle in the middle of the night
- Finding out when flights leave your nearest airport for Seattle
- Having your bag packed and ready

Be Ready

When we call you for your transplant, we'll give you time to arrive at UW Medical Center quickly but without rushing. Most patients have about 6 to 10 hours of notice. When we call you, we will give you a specific time to arrive at UWMC for check-in.

Be Flexible

Certain situations can affect when we call you for transplant, and what happens next:

- We may call you as a backup candidate for another transplant recipient.
- After you are called in for transplant, your surgery could be cancelled if we find that the donor liver is not of good quality.
- Your transplant could be cancelled after you arrive at the hospital if we determine that there are changes in your health condition that make the transplant surgery too risky. If this happens:
  - You will need to have more tests to clear you again for liver transplant. We want to make sure you are in the best condition to have a liver transplant as safely as possible.
  - You will **not** lose your place in line on the list for a new liver as long as your condition allows for a safe operation.

We realize that being called for transplant and not having the surgery happen as planned can be very stressful and may cause a financial burden. But even if you do not receive a transplant the first time we call you, being called means you are very close to receiving a transplant. Please be patient.

Day of Transplant

When you arrive at UWMC, check in at Admitting on the main level (3rd floor) of the hospital. After you are done with registration, you will be given the number of the room where you will stay. After you are admitted:

- Nurses will draw more than 10 tubes of blood. These will be used for both testing and storage.
- A member of your Transplant Team will ask you about your medical history and give you a physical exam.
- You will be sent to the radiology department for a chest X-ray.
- You will take a shower with an antibacterial soap.
- You will sign a consent form that gives us permission to do your transplant surgery.

When we are sure about the timing and quality of the donor liver, you will be moved to the pre-op room on the 2nd floor of the hospital close to the operating room (OR). Your family can come with you as you are moved. When you are moved to the OR, your family will be directed to the surgery waiting room. Family members are not allowed in the OR.

Your surgical team will include:

- Attending transplant surgeon
- Liver transplant surgery fellow
- Nurses
- Anesthesiologist
- Other medical providers as needed

Soon after you arrive in the OR, the anesthesiologist will give you medicine that will make you sleep. The anesthesiologist will then place the many lines needed to safely monitor you throughout the surgery. Some of these lines include special *intravenous tubes* (IVs) placed in your neck and arms.

The next thing you will be aware of is waking up in the intensive care unit (ICU) after your transplant.

The Liver Transplant Operation

A liver transplant operation can last 5 to 8 hours. You may be in the OR longer than that, depending on how complex the operation is. This includes the time it takes the anesthesiologist to prepare you for your operation and moving you to the ICU after the operation.

The operating room nurse will update your family during the operation. Your surgeon will also talk with your family in person when the surgery is done.

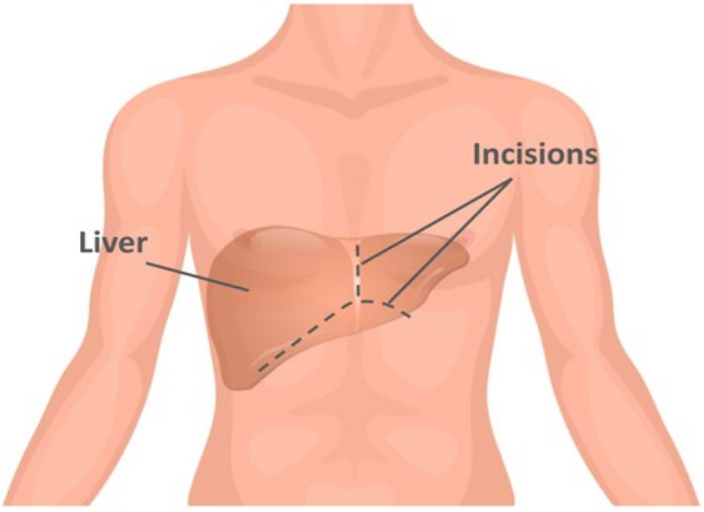
Your surgery may take a long time, but we will keep your family updated.

What happens during the surgery?

The liver transplant involves many steps:

Incision

The liver is in the right upper part of your abdomen, beneath your lower ribs. To do a safe transplant, we need to make a large incision beneath your ribs and up to the breastbone (see drawing).

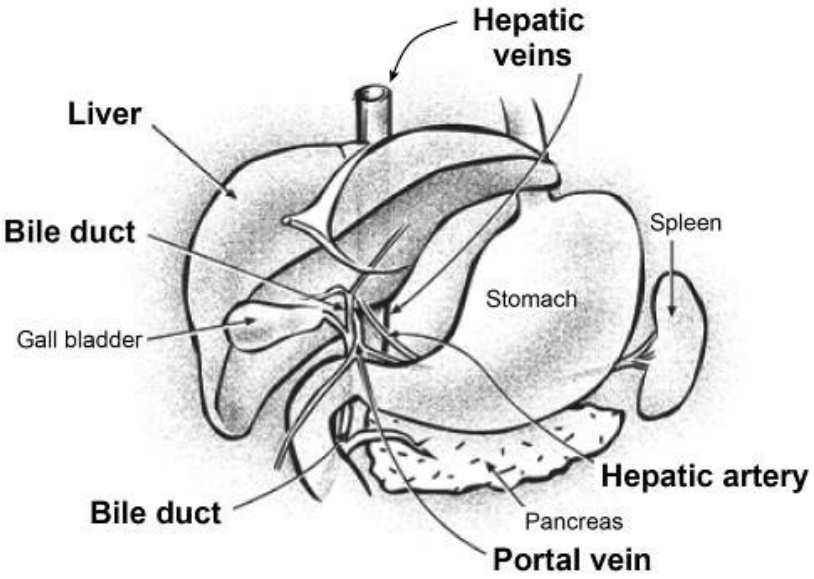


Incisions for liver transplant

Dividing the Liver

The liver has 4 connections that must be cut before it can be removed. These include:

- The **hepatic veins**, blood vessels that carry filtered blood from the liver to the *inferior* (lower) *vena cava*. The inferior vena cava is the large vein that carries blood to the right atrium of the heart.
- The **portal vein**, which collects blood from your bowels, pancreas, and spleen, and carries it through your liver before returning it to your heart. This is the main blood supply to your liver. It provides almost 80% of the blood supply to the liver cells.
- The **hepatic artery**, a very small vessel that supplies only 20% of the blood entering your liver. This artery is very important because it supplies blood to the bile ducts in your liver.
- The **bile duct**, which carries bile from your liver to your bowel to help absorb fat in the food you eat.



This drawing shows the connections to the liver that must be cut during transplant

Veno-Venous Bypass

A *veno-venous bypass* is used in some operations. In this procedure, we make 2 extra incisions over 2 large veins in your right or left groin and left armpit. A tube is placed in these 2 veins and connected to a pump. This bypass allows blood to flow around the site where we are working, and it returns a normal blood volume back to the heart.

Connecting the New Liver

Then we sew your new liver in. First the hepatic veins and the portal vein are reconnected, which restores blood flow to your liver. Then we reconnect the hepatic artery and, finally, the bile duct.

At the end of the operation, 1 or more tubes (drains) are placed near your liver and brought out through the sides of your abdomen. These drains remove any blood or fluid that collected in your abdominal cavity during surgery. The drains are removed a few days after surgery.

What happens after surgery?

When the transplant surgery is done:

- The surgeon and anesthesiologist will help move you to the ICU on the 5th floor of the hospital.
- You may have the breathing tube removed in the operating room or after a few hours in the ICU after the surgical team is satisfied that there is no bleeding problem, your new liver is working well, and you are breathing well on your own.
- We will then remove some of the other tubes and monitors that were placed for your operation. Some will stay in place for a while during your recovery.
- You will then go back to the regular hospital floor on either 7 SA (Montlake Tower) or 7 North (Pacific Tower).

Your Hospital Stay

While you are recovering in the hospital, your care will be managed by your Transplant Team of doctors, residents, and nurses. You will have daily blood tests to monitor your electrolytes, blood counts, liver function tests, and medication levels. We will do ultrasounds to check how well the new liver connections are working. Most transplant patients are in the hospital for about 7-14 days. If you have any complications, your stay will likely be longer.

During your stay, we will work with you on several things that are very important to your recovery and to the success of your transplant:

- **Getting up and moving:** After a major surgery, it is very important to start moving as soon as you can, and as much as you can. Moving helps your body get rid of the effects of anesthesia and return to normal more quickly. Walking helps prevent pneumonia and blood clots in your legs. It also helps your digestive system work better. Nurses and physical therapists will help you until you are comfortable walking on your own.
- **Your medicines:** Pain control is important for your healing. Right after transplant, your pain will be managed with pain medicine in your IV. Once you are eating well, you will start taking pain pills. Most patients can stop taking all pain medicine by 3 to 4 weeks after transplant.

  After your transplant, you will start taking 10 to 15 new medicines. The nurses and the pharmacists will teach you to identify your medicines and will help you set up a *mediset* (a box that holds your medicines) to organize your daily doses.

Follow-up Clinic Visits

- During the first 3 months after your transplant, the Transplant Team will take care of all your medical care. If you have a health problem, you can call us 24 hours a day, 7 days a week.
- After you leave the hospital, you will return to the Transplant Clinic and have your blood drawn for blood tests at least 2 times a week for the 1st month.

- During the 1st and 2nd months, you may need to come to clinic once a week and have a blood draw 1 or 2 times a week. By the end of the 2nd month, we may only need to see you every other week.
- About 3 months after your transplant, if things are going well, we will transition your care from the Transplant Clinic to your primary care provider.

Your Long-Term Care

When you have "graduated" from the Transplant Clinic, you will go back to your primary care provider for your healthcare needs. But you may consult with us sometimes. You will also have follow-up visits with one of our hepatologists:

- 6 months after transplant
- 1 year after transplant
- Each year after that, for the rest of your life

These follow-up visits are very important. They help us keep your transplant stable long-term.

Timeline After Surgery

The ideal: This timeline gives the **ideal** hospital stay and clinic follow-up after transplant surgery:

Day 0	Liver transplant operation
Day 7 - 14	Discharge from hospital
Day 15+	Clinic visits (You will have a varying number of visits between Day 11 - Day 90)
Day 90	Transfer care to primary care provider
6 months	Follow-up visit with UWMC hepatologist
1 year, then yearly	Follow-up visit with UWMC hepatologist

The actual: In **real life**, this is what often occurs:

- About 40% of all liver transplant recipients (40 out of 100 recipients) follow this ideal plan.
- About 10% of transplant recipients (10 out of 100 recipients) have a very difficult time.
- About 50% of all liver transplant recipients (50 out of 100 recipients) have at least 1 major complication.

The good news is that even if there is a complication, it is usually found, treated, and fixed for most patients. Often, by 3 months after transplant, these patients have caught up to those who have had no issues at all and then continue on the same "ideal" course.

Complications from Surgery

A liver transplant operation is a complex procedure. It requires hundreds of steps, and each one is important. There are many possible complications, but the good news is that most are very rare. Problems range from the most severe (dying) to more common problems like rejection or coming back to the hospital for fever.

One of the reasons you must have so many tests before your surgery is to reduce the risk of having a severe complication like heart attack, stroke, or death. However, even with careful testing, problems can still happen.

For the first 24 hours after transplant, our main concerns are bleeding and making sure that your new liver is working well. Some transplants can be done with almost no blood loss, while others require 10 or more units of blood. If you have a lot of bleeding after transplant, we may need to do another surgery to stop the bleeding.

For a small number of transplant recipients (about 1% to 2%, or 1 to 2 out of 100), a liver may not work well. We call this *primary non-function*. If the liver does not work well, we will need to do another transplant. We will do everything we can to get you a new liver as quickly as possible.

Any of the 4 connections of the new liver can develop a complication. But the most common problems occur with the bile duct and the hepatic artery:

- The **hepatic artery** supplies blood to the bile ducts. If this artery "clots off" so that no blood flows through it after surgery, the bile will not be healthy and may *atrophy* (waste away). This can lead to poor liver function, infection, or even a need for re-transplant. Very soon after your transplant surgery, we will check your hepatic artery by ultrasound to make sure the blood is flowing well. If there is a concern, we will take you back to the OR to remove the clot and repair the artery. If the artery becomes narrow (smaller) after transplant, you may need a procedure through your groin to open it back up with a balloon.
- The **bile duct** can sometimes become narrow (which blocks bile flow) or leak (which lets bile spill into the abdomen). Most bile duct problems can be fixed without surgery. Your doctor may do an *endoscopy*, where a thin, flexible tube with a camera is passed through your mouth into your stomach. This allows the doctor to place a balloon or stent to open or repair the bile duct from the inside.

Rejection

Your immune system helps fight off infections. It does this by knowing what is ***self*** (your own body) and what is ***non-self*** (things that are foreign/not your body). Your immune system will attack and destroy anything it sees as non-self, like a virus or bacteria.

It is natural for your immune system to see a transplanted organ as non-self and attack it like it would any other invader. This is called *rejection*.

Medicines to Control Rejection

To control rejection, we must slow down your immune system. This is done with 3 main *immunosuppressive* medicines:

- Tacrolimus (FK-506)
- Steroids or prednisone
- Mycophenolate mofetil (MMF)

Your Transplant Team will decide what immunosuppressive medicines you need to take. These medicines can have major side effects that need to be controlled with other medications. Your Transplant Team will continuously check your health and adjust your medications as needed.

- Most transplant patients take about 10 to 15 medicines, from 1 to 4 times a day. Right after transplant, this can be a handful of pills every few hours.
- Your doctors will review your medicines and taper (slowly decrease) them over time, usually at 3 months and again at 6 months after transplant.
- You **must** take immunosuppressive drugs for the rest of your life. If you stop taking them, your immune system will reject your gift of life, your liver transplant.

You will need to take many medications to protect your new liver.

Complications of Immunosuppression

Infection Risk

Immunosuppression helps your body accept your new liver, but it also makes it easier for you to get infections. You may get sick from bacteria, viruses, and fungal infections that do not affect other people.

We cannot completely protect you from these complications. But there are things you can do to reduce your risk of infection. You will learn more about these topics:

- Certain bacteria are carried on raw or uncooked food. Your dietitian will teach you about foods to avoid and how to safely handle, store, and cook foods.
- Certain jobs or hobbies can expose you to fungal spores (cells) in the air. Our occupational health services will help you find ways to lower this risk.
- You are more likely to get infections from animals. At discharge, your nurse coordinator will review pet safety guidelines with you.
- Good hand washing is very important for preventing infections. Wash your hands with warm soap and water several times during the day, for 20 seconds each time. This is the best way to reduce your exposure to germs.
- Be careful when you are with people who may be sick. If your friends and family are sick, take extra steps to protect yourself from germs, like washing your hands. Avoid inviting guests who are sick into your home.

Cancer Risk

The immune system also helps to fight tumors. With a suppressed immune system, you will be at a greater risk of developing some types of cancers, such as skin cancer, *sarcomas*, or a blood cancer called *post-transplant lymphoproliferative disease* (PTLD).

Only 1% to 2% of transplant recipients (1 to 2 out of 100 recipients) develop one of these cancers in their lifetimes. But because there is a risk, stay in close contact with your primary care provider and your transplant team. If you have any unusual new skin bumps or masses, your doctor will need to biopsy or remove them.

Survival After Transplant

End-stage liver failure gets worse over time. Without transplant, end-stage liver failure is 100% fatal.

Your chances of survival with a good quality of life are greatly increased with a liver transplant. The Scientific Registry of Transplant Recipients (SRTR) has the most current statistics on our liver transplant program. These statistics are updated 2 times a year at the website *srtr.org.*

In general:

- 1 year after liver transplant, 92 to 95% of transplant recipients (92 to 95 out of 100) are still alive.
- 3 years after liver transplant, 87 to 91% of transplant recipients (87 to 91 out of 100) are still alive.

When a recipient dies after transplant, it is usually because they:

- Had other diseases before the transplant, such as heart disease, that got worse
- Had complications related to immunosuppression
- Had a high risk of developing liver cancer

Many liver transplant recipients are doing well 10 or more years after their surgery. No one knows how long a transplanted liver can last, but worldwide there are a small number of patients who are still doing well 30 years after their transplant.

Communication

The transplant process is very complex. As you prepare for surgery, you will go through a long series of tests and interviews. Some of these can be physically or emotionally painful. At times, the relationship with your Transplant Team may even feel one-sided. Please remember, our goal is to guide you through this process safely and give you the best chance at a better quality of life.

You and your Transplant Team will be partners in your care for the rest of your life. Clear and open communication is the key to success. It is very important that you, your transplant coordinator, and your doctors can speak freely. If you or your family ever feel frustrated, let us know so we can help.

We know this journey can feel overwhelming at times, but you are not alone. Your Transplant Team is here to support you every step of the way.

Your Liver Transplant Medications

After transplant, you must take medications for the rest of your life. You will need to learn why you take them, how to take them, how they work, and what their side effects are. You will also need to plan how you will pay for them.

What medications will I take after transplant?

The medications you take after transplant are very important for your recovery and the success of your transplant. They will include:

- **Immunosuppressive medications** to help prevent your immune system from rejecting your new liver. You will take these medications for the rest of your life.
- **Anti-infective medications** to prevent infection. Immunosuppressive medications increase your risk of infection. You will take anti-infective medications for 3 to 6 months after your transplant surgery.
- **Antacids** to help prevent stomach upset or injury for 3 months after transplant.
- **Laxatives** and **stool softeners** to help prevent constipation.

You may also need to take:

- **Low dose aspirin**, to prevent blood clots
- Antihypertensive medication to lower blood pressure
- **Diuretics** (water pills) to help decrease swelling
- Medication to lower blood sugar which may include insulin
- **Multivitamin** to help with general wellness and healing
- **Calcium** and **vitamin D** to help prevent osteoporosis (weak bones)
- **Magnesium** supplements for low magnesium levels

You will need to learn how to organize your medications and take doses on time.

Getting Started

Where can I get my prescriptions filled?

After your transplant, you will receive your first fill of your new medications from the University of Washington Outpatient Pharmacy.

After that, you can fill your prescriptions at a local pharmacy or use a mail-order pharmacy.

It is important to:

- **Always** carry your prescription insurance card with you
- **Always** carry a list of your medications with you

What medical equipment will I need?

You will need to monitor the effects of your medications. To do this, you will need to buy these supplies:

- Blood pressure machine that also measures your heart rate
- Scale
- Thermometer
- Blood glucose meter (only if you have diabetes or elevated blood sugar)
  - If you prefer to avoid finger sticks, consider asking your primary care doctor or endocrinologist about transitioning to a Continuous Glucose Monitor (CGM).

At the Hospital

What to Bring

When you are called in for transplant, bring with you:

- **Your current medications** and a list of their names and dosages. Include any vitamins and supplements
- Your transplant guide (this manual)
- Any **equipment** you were asked to buy (see above)

Learning About Your New Medications

After surgery, you and your caregiver will begin to learn about your medications. You will meet with the transplant pharmacist before discharge and carefully review all the new medications. **Your primary caregiver must join you for this meeting.** We will also give you a new pillbox before discharge to help organize your medications. To keep track of your medication plan:

- Use your **pillbox** to organize your medications
- Use **alarms** to remind you when it is time to take each dose.

After Discharge

- Keep an up-to-date list of all your medications with you, along with the directions for taking them. Remember to update your list as doses change, and use the most recent version to refill your pillbox.
- **Refill your medications early.** Do not let your supplies run out.
- **When you come for clinic visits,** bring your pillbox, your prescription bottles, and your medication list.
- **If you have problems or questions about your medications** after discharge from the hospital, call your transplant nurse coordinator.
- Go to **all** your follow-up appointments.

Taking Your Medications

Basic guidelines for taking medications:

Talk with your care team if you have any questions about your medications.

- Take **ONLY** the medications your doctor prescribed for you.
- **Take your medications exactly as they were prescribed.** Do **not** increase or decrease your dose or stop taking a medication without talking with your doctor or transplant nurse coordinator.
- **Do NOT take any new medications** without talking with your doctor, transplant nurse coordinator, or pharmacist.
- Tell all your healthcare providers that you are a transplant patient and are taking immunosuppressant medications. This includes your dentist, optometrist, and all other providers.
- Keep all medications out of reach of children and pets.
- Do **not** let anyone else take your medications.
- **Do not take herbal, natural, or nutritional supplements** without talking with your transplant providers. These products:
  - May have hidden ingredients that can cause side effects or damage your transplanted liver
  - Might interact with your transplant medications and harm you
- Do **NOT** eat or take any of these after transplant:
  - Grapefruit, pomegranate, or star fruit
  - Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil, Motrin), naproxen (Aleve), and full-dose aspirin
  - Herbal or “natural” medications, or natural supplements

Immunosuppressant Medications

These medications help prevent rejection by lowering your immune system. You will take these medications for the rest of your life after transplant.

Immunosuppressants may make it easier for you to get infections. This means you may get colds and the flu more easily. You can also get infections from germs that usually would not cause illness. These are called *opportunistic* infections. Immunosuppression also carries a risk of developing certain types of cancer, such as skin cancer.

How many immunosuppressants will I take?

Your transplant team will prescribe 2 to 4 immunosuppressant medications for you to take. Your transplant surgeon will talk with you about the specific immunosuppressants you will need to take. Each medication affects the immune system in a different way.

How well do immunosuppressants work over time?

Even if you take your immunosuppressive medications as prescribed, rejection can still happen. Your blood test results will tell us if your body is rejecting your new liver. Do **not** skip any appointments or blood tests.

Induction Immunosuppression

Induction immunosuppressants quickly lower your immune system right after the transplant surgery. You will take 1 or more of these immunosuppressants while you are in the hospital, depending on your care plan. You will get these through your IV line.

Antithymocyte globulin (Thymoglobulin)

- ***Purpose:*** Antithymocyte globulin (ATG) is a strong anti-rejection medication. It destroys white blood cells.
- ***Possible side effects:*** White blood cells release chemicals as they are destroyed. These chemicals can cause allergic or flu-like symptoms. You will receive medications before each dose to lower the risk of these side effects.

  Side effects of ATG include:

  - Flu-like symptoms, like fever and chills
  - Nausea
  - Headache
  - Shortness of breath
  - Low or high blood pressure
  - White blood cell count getting too low
  - Low platelets and red blood cells
  - Increased chance of infection

Basiliximab (Simulect)

- ***Purpose:*** Basiliximab is an antibody that blocks white blood cells. This helps prevent your immune system from trying to destroy your transplanted liver.
- ***Possible side effects:*** This medication has a very low risk of side effects. Allergy or flu-like symptoms, such as fever and chills, are possible.

Methylprednisolone (Solumedrol)

- ***Purpose:*** This medication is a steroid. It blocks the response of many types of immune cells.
- ***Possible side effects:*** High doses of steroids can cause:
  - Higher blood sugar
  - Slower wound healing
  - Blurred vision
  - Muscle aches
  - Mood swings
  - Insomnia
  - Swelling

Maintenance Immunosuppression

These are the medications you will take for the rest of your life to prevent rejection.

Tacrolimus (Prograf, Envarsus)

- On clinic days, do **not** take your dose of tacrolimus until after your blood is drawn.
- ***Possible side effects:*** The most serious side effects of tacrolimus are injury to the kidney and nervous system reactions such as tremor and headache. These side effects may be lessened by adjusting your dose (remember to **never** change your dose unless your provider tells you to).

  Tacrolimus has many medication interactions and some food interactions (grapefruit, pomegranate, and star fruit) that can increase these side effects.

  Some side effects include:

  - Lower kidney function
  - Higher blood sugar
  - Higher blood pressure
  - Higher blood potassium
  - Lower blood magnesium
  - Shakiness or tremor
  - Headache
  - Convulsions (seizures)
  - Nausea or vomiting
  - Hair loss
  - Higher cholesterol
  - Greater chance of infection

Mycophenolate (CellCept, Myfortic)

- ***Possible side effects (more common):***
  - *Leukopenia* (white blood cells getting too low)
  - Nausea or vomiting or abdominal pain
  - Diarrhea
  - May cause birth defects. Should not be taken if you are pregnant or planning to become pregnant.

Prednisone (Deltasone)

- ***Possible short-term side effects (at high doses):***
  - Stomach upset, heartburn, stomach ulcers
  - Emotional changes, mood swings
  - Problems sleeping
  - Weight gain and swelling
  - Slower wound healing
  - Increased appetite, feeling hungry
  - Higher blood sugar
  - Blurred vision
- ***Possible long-term side effects:***
  - Muscle weakness
  - *Osteoporosis* (bones become brittle and can break more easily)
  - High blood sugar (*diabetes*)
  - Vision changes, cataracts
  - Higher cholesterol

Anti-infectives

When your body's immune system is suppressed, you have a higher risk of getting infections.

Clotrimazole Troche (Mycelex) or Fluconazole (Diflucan)

- ***Purpose:*** You will take these *antifungal* medications for 3 months after transplant to prevent fungal infections.
- ***Possible side effects of clotrimazole troche:***
  - Bad taste in your mouth
  - Dry or chalky mouth
  - Nausea
- **Possible side effects of fluconazole:**
  - Nausea
  - Rash
  - Diarrhea
  - Abdominal pain

Acyclovir (Zovirax)

- ***Purpose:*** Antiviral medication to prevent the herpes simplex virus. You will take this medication for 3 months after transplant. It does not treat other viruses like cold and flu.
- ***Possible side effects:***
  - Nausea
  - Headache

Trimethoprim/ Sulfamethoxazole (Bactrim)

- ***Purpose:*** Antibiotic to prevent pneumonia after transplant
- ***Possible side effects:***
  - Rash
  - Nausea
  - Lowered white blood cell count
  - Sensitivity to the sun

Care After Your Liver Transplant

You will most likely be excited to leave the hospital after transplant, but you may also feel anxious about taking over most of your care needs. Starting a new phase of life can cause anxiety, especially when it involves learning how to care for your new organ. You have been through a profound experience, and all these feelings are normal.

Many patients return to some of their regular routines within days after they get home. When you see how well you handle life outside the hospital, you will start to feel less anxious.

One of the biggest problems you may have after you leave the hospital is learning to be patient and slow down. A liver transplant is a life-changing procedure, and the recovery journey can be filled with both emotional and physical highs and lows.

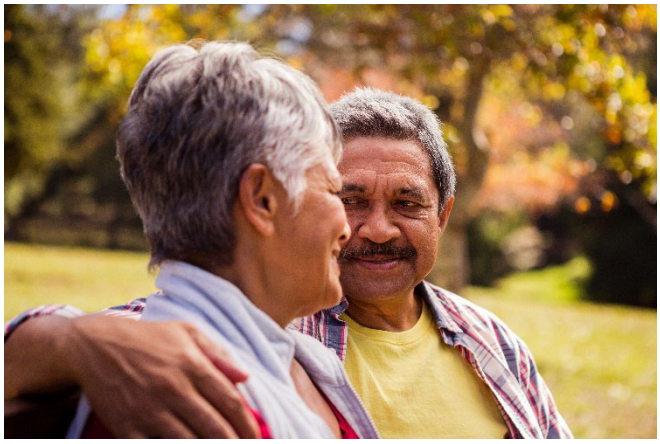
Remember to take it one day at a time. In time, you should be well enough to return to work or resume other activities or roles that may have been limited because of your liver disease. Focus on making progress in your recovery and be patient with yourself.

Life After Transplant

Adjusting to life after transplant takes time and requires close follow up and monitoring It is normal to get tired of the weekly clinic visits, blood draws, and medicines once the newness of your transplant has worn off, but this monitoring is crucial to the success of your recovery.

You may also get tired of answering questions from curious friends about your transplant. Some people may not be able to fully understand what you have been through. Our monthly support group can help offer support and connect you with others who can relate to your shared experience.

Once you have had your transplant, we hope that you will not think of yourself as a "patient," but as a healthy person with a special appreciation for life. Still, there are some important aspects of your healthcare that will always play an active role in your life.



When you leave the hospital after transplant, you may feel both excited and anxious about your new life.

Clinic Visits

- For the first 2 months after you leave the hospital, you will need to return to the Transplant Clinic 1 or 2 times a week to have blood drawn in the lab. By the end of the 2nd month, we may need to see you only every other week.
- For the first 3 months after your transplant, the Transplant Team will take care of all aspects of your healthcare. If you have a health issue, you can reach us by phone 24 hours a day, 7 days a week.
- About 3 months after your transplant, if things are going well, your care will be transferred to your primary care provider and our team of *hepatologists* (doctors who specialize in liver care).
- During this transition time, your transplant nurse coordinator will be your direct link to your Transplant Team members. Call your transplant nurse coordinator weekdays during clinic hours if you have any questions or concerns.

Self-Monitoring

Before you are discharged from the hospital, you will learn how to monitor your progress at home. Your nurse coordinator will review how to take your vital signs at home and review any signs or symptoms that you should report.

For the first 3 months, you will need to record your weight, blood pressure, and temperature every day. If you do not already have one, you may need to buy a blood pressure cuff, a thermometer, and a scale.

Lab Tests

Your blood draws for your lab tests must be done before you take your morning medicines. You will need to arrive at our lab between 6:30 a.m. and 7:30 a.m. for your blood draw, depending on your clinic appointment time.

The results of each blood draw will tell your Transplant Team how well your new liver is working.

Your immunosuppression level will also be checked with each blood draw. The test is based on the type of immunosuppression you are taking. Most patients are on tacrolimus (TAC) or cyclosporine (CYA).

Taking Your Medicines

Before you leave the hospital, the pharmacist will give you a box called a *mediset*. Use this box to organize your many new medicines and remember to take them.

You must carefully take all of your drugs as prescribed and your blood levels must be monitored to make sure the doses of your immunosuppressant medicines are at the right levels.

- Too little suppression of the immune system (low tacrolimus or cyclosporine level) will allow your body to reject your transplanted organ.
- Too much suppression of the immune system (high tacrolimus or cyclosporine level) can increase your risk of infection and side effects.

Your Transplant Team will decide and let you know if you need any changes in your doses.

Potential Long-Term Complications after Transplant

High Blood Pressure (Hypertension)

High blood pressure is a risk factor for both heart disease and stroke. Immunosuppressive medicines can cause high blood pressure in transplant recipients. Even if you do not have a personal or family history of hypertension, you may develop it after your surgery.

If you have high blood pressure, your transplant doctor will prescribe one or more *anti-hypertensive* medicines. A *diuretic* (water pill) may also be used to lower your blood pressure and remove extra fluid from your body.

To help keep your blood pressure under control:

- Check your blood pressure daily. Tell your transplant nurse coordinator or doctor if your numbers change.
- Take your anti-hypertensive medicines exactly as prescribed.
- Eat a well-balanced, healthy diet that is low in salt and cholesterol.
- Exercise every day. Walking is one of the best exercises to do after transplant.
- Do not smoke or drink alcohol.

Walking every day will help you recover and stay healthy after surgery.

Diabetes

Some transplant recipients may also develop *diabetes* (high blood sugar) after their surgery. Diabetes is one of the side effects of taking immunosuppressive medicines, especially prednisone and tacrolimus.

High blood sugars (greater than 200) may lead to wound infections and dehydration. If high blood sugar is not controlled, kidney and heart disease can occur over time.

Managing high blood sugar begins with making changes in lifestyle, following a meal plan, and getting regular exercise. You may need to take medicines in the form of pills or insulin injections (or both).

All transplant recipients who have high blood sugar are referred to a dietitian and a diabetes clinical nurse specialist for teaching and support. As their doses of immunosuppressive medicines are lowered, most patients are able to control their blood sugar without taking diabetes medicines.

Anxiety and Depression

Many transplant patients have anxiety and even some depression in the weeks after they return home from their transplant surgery. Pain, mood-swings from prednisone, unexpected complications, family concerns, or financial stress can all add to these feelings.

Talking about your feelings with trusted family and friends can help. But, if your feelings are causing you concern, talk with your transplant social worker or transplant nurse coordinator about support services you can use.

Remember that the Liver Transplant Support Group meets once a month. This group is a place for all liver transplant patients and their caregivers, both before and after their transplant surgery, to share their concerns with others who may have similar issues.

Cancer

Transplant recipients have a higher risk for developing certain types of cancer, including skin cancer. This risk is caused by the anti-rejection medicines you must take. It is important that you:

- Have regular cancer screenings, including yearly mammograms, pap smears, stool samples, and exams for skin, testicular, and prostate cancer.
- Check yourself regularly for any signs of cancer, including skin exams and monthly breast self-exams for women.
- Check for changes in your moles, birthmarks, and beauty marks. Tell your doctor if you have skin spots that change color or increase in size or thickness.
- Tell your doctor if you have any sores that do not heal within 3 weeks or that continue to itch, hurt, crust, scab, or bleed.
- Tell your doctor if you have swollen lymph nodes (glands) anywhere in your body, including your neck, groin, and underside of your arms.
- When you go outside, wear a hat and sunscreen with sun protective factor (SPF) rated at least 15 to 30.

Immunizations (Vaccines)

- You must never receive “live virus” vaccines for smallpox, measles, rubella, shingles, or any other illness. If you plan a trip to a country that requires any of these vaccines, call your transplant nurse coordinator. The Travel Clinic at UWMC can also help you plan for your trip.
- During your transplant journey, you will need many vaccines to help boost your immune system.
- If you are in the middle of receiving vaccines for hepatitis or HPV when you have your transplant surgery, you may finish the series after your transplant.
- Starting 3 months after your transplant surgery, we advise you to get yearly flu shots.
- We recommend that you get COVID vaccines yearly.

Diet

Follow the guidelines your dietitian gave you about a healthy diet. Also see the “Nutrition” section of this transplant guide (page 23).

Dental Care

- Good dental and mouth hygiene is very important after your transplant.
- Wait 3 to 6 months after transplant before you have dental work done. Bacteria in your mouth may cause infection if dental work injures your mouth or gum tissue.
- If you have any symptoms of a problem with your teeth or gums, see your dentist right away.
- Tell your dentist you are a transplant recipient. Your dentist will decide if you need antibiotics before having dental work done. We recommend that your dentist follow the American Heart Association guidelines.

Traveling

If you plan to travel away from home, either on vacation or on business, tell your transplant nurse coordinator before you leave to review travel recommendations and to assess if further review by the infectious disease team is needed.

Plants and Gardening

Dirt carries fungus and bacteria. After transplant, wear heavy gloves while you are working outdoors or with indoor plants. Avoid direct contact with the soil.

Pets and Your Safety

- **Be aware:** After transplant, you are more likely to get infections from animals because of your weak immune system.
- **Keep clean!** Wash your hands well with running water and soap after touching animals. Do **not** touch animal feces.
- **Pet care:**
  - Have your pet checked by a veterinarian (vet) before your transplant surgery. Make sure your pet is healthy and does not have any infections.
  - Make sure your pet has regular health checkups.
  - Talk with your vet about live vaccines. If your pet receives a live vaccine, you must avoid contact with your pet for about 1 week.
  - Have your pet spayed or neutered. Neutered animals are less likely to roam, so are less likely to come down with diseases.
  - If your pet gets ill or has diarrhea, take your pet to the vet for a checkup as soon as possible. Many illnesses that cause diarrhea in pets are easily transmitted to people who are immunosuppressed.
- **Getting a new pet:** If you are thinking about adopting a new cat or dog, choose one that is 1 year or older. Kittens and puppies are more likely to scratch and bite, and this can spread infections more easily.

Washing your hands well is one of the best ways to prevent infection.

Your Long-Term Care

When you have "graduated" from the Transplant Clinic, you will go back to your primary care provider for your healthcare needs. But, you may consult with us from time to time. You will also have follow-up visits with one of our hepatologists at:

- 6 months after transplant
- 1 year after transplant
- Yearly after that, for the rest of your life

These follow-up visits are very important. They help us keep your transplant stable over the long term.

This timeline gives the **ideal** hospital stay and clinic follow-up after transplant surgery:

Day 0……..	Liver transplant operation
Day 7 to 14……..	Discharge from hospital
Day 15+ ……..	Clinic visits (You will have a varying number of visits between Day 11 - Day 90)
Day 90……..	Transfer care to primary care provider
6 months……..	Follow-up visit with UWMC hepatologist
1 year, then yearly……..	Follow-up visit with UWMC hepatologist
Yearly after that……..	Long-term follow-up visit

In real life, this is what usually happens:

- About 40% of all liver transplant recipients (40 out of 100 recipients) follow this ideal timeline.
- About 10% of transplant recipients (10 out of 100 recipients) have a very difficult time.
- About half of all liver transplant recipients (50%, or 50 out of 100 recipients) have at least 1 major complication.

The good news for most transplant recipients is that even if they have a complication, it is found, treated, and resolved. Often, by 3 months after transplant, these recipients have caught up to those who have had no issues at all and then continue on the same ideal course.

Resources for You, Your Caregivers, and Donors

The resources in this section provide information that may be helpful to liver transplant patients, their caregivers and families, and living donors.

NOTE: Some internet sites may not have accurate or up-to-date information. Your doctor is the best person to answer your questions. Read sources that interest you but rely on your doctor for medical decision-making.

Information and Support

- **American Liver Foundation**

  Helps people learn about liver disease, get support, and find research and prevention resources.

  www.liverfoundation.org

  800.GO.LIVER (800.465.4837)

- **American Transplant Foundation**

  Offers education, emotional support, and financial help for living donors, transplant patients, and families.

  www.americantransplantfoundation.org

- **Medscape**

  A health website with information on many medical conditions and procedures, including liver disease and transplant.

  www.eMedicine.com

- **National Foundation for Transplants**

  Provides fundraising help and guidance so transplant patients can focus on recovery.

  www.transplants.org

  800.489.3863

  Email: info@transplants.org

- **Organ Procurement and Transplantation Network**

  Connects patients, families, and doctors in the U.S. transplant system. Works to make transplants safer and more available.

  www.optn.transplant.hrsa.gov

- **Organ Transplant Support, Inc.**

  Offers counseling, education, and support programs for patients and their families.

  www.organtransplantsupport.org

  630.527.8640

  Email: organtransplantsupport@gmail.com

- **Scientific Registry of Transplant Recipients (SRTR)**

  Tracks transplant outcomes across the U.S. and shares results with patients and the public.

  www.srtr.org

  877.970.SRTR

  Email : srtr@srtr.org

- **Transplant Living**

  A website with tips and support from patients, donors, and professionals to help you live well after transplant.

  www.transplantliving.org

- **United Network for Organ Sharing**

  Runs the U.S. organ transplant system. Provides information and resources for patients and families.

  www.unos.org

- **UWMC Support Groups**

  Ask your social worker for information about the support groups available at UW medical center.

Addiction Recovery

- **Recovery.org**

  If you have problems with drugs or alcohol, addiction treatment centers can offer treatment and support. You can search for locations near your home.

  www.recovery.org

- **Quitting Smoking and Using Tobacco**

  Websites with tools and support to help you stop using tobacco:

  - *smokefree.gov*
  - *www.cancer.org*
  - *www.cdc.gov/tobacco*
  - *www.heart.org*
  - *www.lung.org/stop-smoking*
  - *www.quitnet.com*
  - *www.quitsmokingsupport.com*

Financial and Fundraising Support

- **Medicare Hotline**
  800.MEDICARE (800.633.2273)
- **National Organization of Social Security Claimants' Representatives (NOSSCR)**
  www.nosscr.org
  800.431.2804; Fax: 201.567.1542
- **Northwest Justice Project**
  www.nwjustice.org
  Legal self-help materials and tools for non-criminal legal problems, including Copes, Medicaid, power of attorney, and much more.
- **Social Security: Disability Information**
  www.ssa.gov/disability

Medications

Our transplant financial coordinator will review your insurance to make sure your plan covers your prescription medications. If you have limited benefits there are programs available to help. Visit the U.S. Department of Health and Human Services website to learn more: *www.healthfinder.gov*.

If you lose your coverage or if your benefits change, talk with your transplant pharmacist about your options and programs that can help.

Transportation and Housing in the Seattle Area

Ask your social worker for a copy of "Patient Family Housing: Guide to Housing, Transportation, and Parking."

Medicaid Transportation for Liver Transplant Patients

If you live more than 2 hours from UWMC and you are a part of the DSHS Medicaid System, you may qualify for help with transportation and housing while you are in the Seattle area. This is very important when you must stay in the Seattle area after your surgery.

To use this service, you must tell the organization that you are a **liver transplant candidate at UWMC**, and that you are looking for help both before and after your transplant surgery.

The name of the transport service provider depends on the county you live in. Please see the table on the next page.

Transport Service Providers by County

Counties	Service Provider	Phone Number
Island, San Juan, Skagit, Whatcom	NW Regional Council	800.860.6812
Adams, Asotin, Ferry, Garfield, Grant, Lincoln, Pend Oreille, Spokane, Stevens, Whitman	Special Mobility Services	800.892.4817
Clallam, Jefferson, Kitsap, Mason-North	Paratransit	800.756.5438
Grays Harbor, Lewis, Mason-South, Pacific, Thurston	Paratransit	800.846.5438
Pierce	Paratransit	800.925.5438
Snohomish	Hopelink	855.766.7433
Clark, Cowlitz, Klickitat, Skamania, Wahkiakum	Human Services Council	800.752.9422
Benton, Columbia, Franklin, Kittitas, Walla Walla, Yakima	People for People	800.233.1624
Chelan, Douglas, Okanogan	People for People	800.233.1624
King	Hopelink	800.923.7433

Air Travel Assistance

If you live outside Washington state, you may be eligible for air travel assistance. Contact these organizations to learn more:

- **Life Flight**
  www.lifeflight.org
  888.883.9998
- **Angel Flight West**
  Free flights from volunteer pilots for patients with limited resources
  www.angelflightwest.org
  800.426.2643

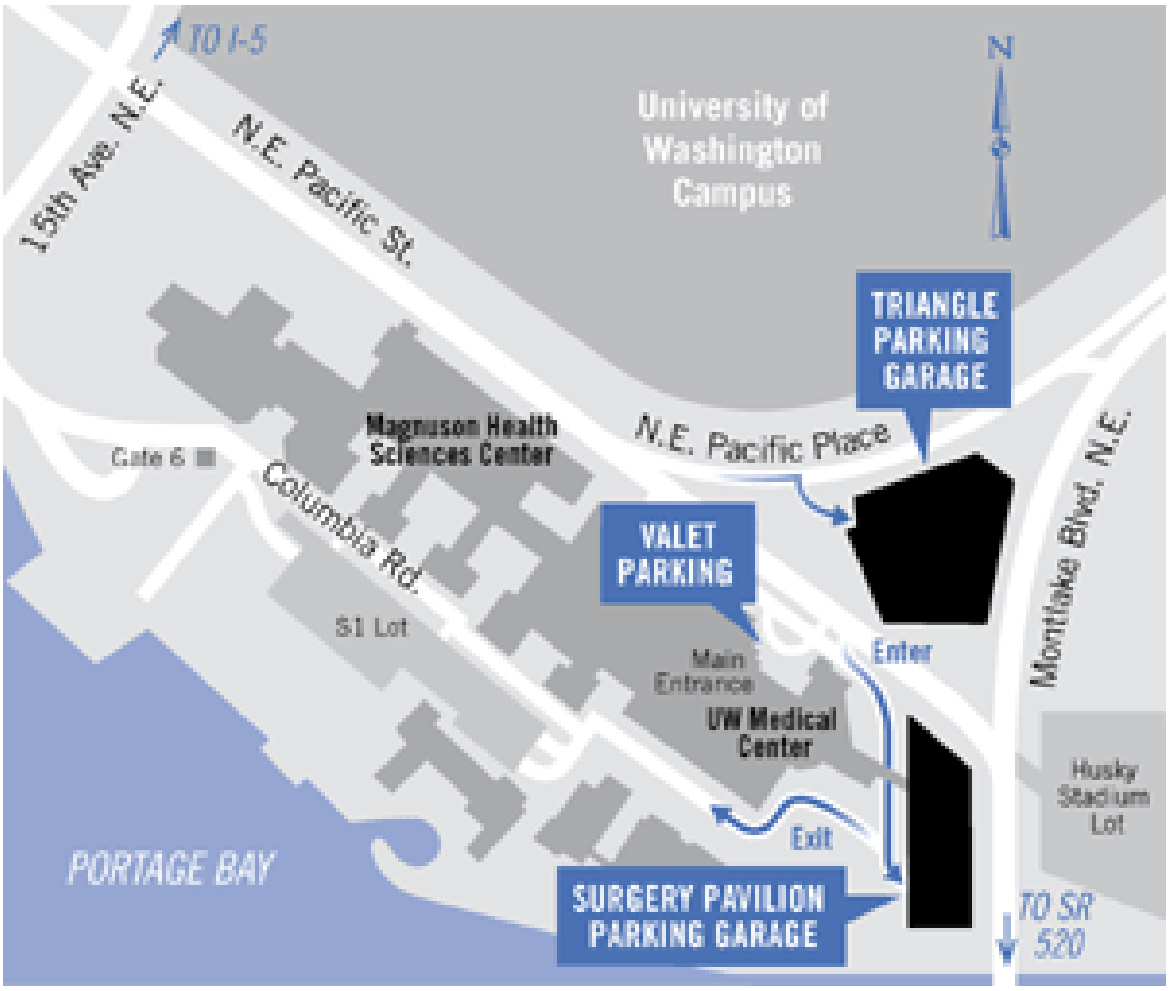
Ground Transportation from SeaTac Airport

- **METRO Transit:** *www.kingcounty.gov*
- **Port of Seattle:** *www.portofseattle.org*
- **Light Rail:** *www.soundtransit.org* (Light Rail stop across the street from UW Medical Center)

Getting to UW Medical Center

- **Main phone number:** 206.598.3300
- **Address**: 1959 N.E. Pacific St., Seattle, WA 98195

UWMC also has clinics in the Roosevelt buildings, just a few blocks northwest of the main hospital



UWMC is in northeast Seattle, south of the University of Washington main campus.

Driving Directions

To the Triangle Parking Garage from I-5 or WA-520 (heading west)

- Take Exit 168B onto WA-520 toward Bellevue/Kirkland. Continue onto WA-520 E.
- Exit onto Montlake Blvd. NE
- Turn left on Montlake Blvd. E, cross the bridge, then turn left onto NE Pacific St.
- Move to the right-hand lane. Turn right at the second “Patient Parking” sign onto NE Pacific Place.
- Turn right into the Triangle Parking Garage. This underground garage is connected to the medical center by a walking tunnel.

Hospital Parking

The Triangle and Surgery Pavilion Garages may **only** be used by patients and their visitors.

Triangle Parking Garage

This underground garage is across N.E. Pacific Street from UWMC. It is connected to the hospital by a walking tunnel.

- The Triangle Garage has:
  - **Valet parking**. The rates are the same as the rest of the parking garage.
  - **Disability parking** and wheelchair-accessible spots. The height restriction is 6'8".
  - **After-hours parking** available.
  - **Parking staff** available weekdays 6 am - 12 am, and Saturdays 7 am - 4 pm.
- Pay at the ticket booth in the garage as you leave. Parking in the Triangle Garage is free on Sundays and for a reduced rate on Saturdays.

Surgery Pavilion Parking Garage

- Located under the Surgery Pavilion, for surgery patients and visitors.
- Entrance: From NE Pacific St., just east of the hospital's main entrance. Pass the Emergency entrance, then turn left at the stop sign.
- Disability parking is available on all 3 levels. Level P1 has limited space for oversized vehicles.

  Maximum vehicle height is:
  - 9'6" on Level P1
  - 6'7" on Levels P2 and P3
- Hours: Open weekdays 6 am - midnight. Closed weekends and after hours. Hours may change if there are special events.
- Pay at the lobby machines before returning to your car or at the ticket booth in the garage.
- If you need to leave after the garage has closed, ask for help at the Information Desk (main entrance, 3rd floor).

Disability Parking

- Disability spaces are available in both the **Triangle Garage** and **Surgery Pavilion Garage**, including spots for wheelchair vans.
- Disabled patients who do not have adaptive vehicles may use **valet parking** in the Triangle Garage (same rates as the garage). Valet staff do **not** park adaptive vehicles.
- **Wheelchairs and escort services** are available. Ask at the Information Desk inside the main hospital entrance for details.

In/Out Parking Access Card

UWMC has an in/out access card for patients who plan to leave and return to the hospital on the same day. Ask for an in/out access card at any parking garage pay booth.

Parking Rates

- Reduced-rate parking is available for patients and their visitors. Ask your clinic or nurses' station for validation so you won't pay more than the daily set amount.
- If you have questions about current parking rates, call UWMC parking at 206.598.2801.

UWMC Floor Maps

To help patients, families, and visitors find their way around the hospital, UWMC has maps of all the hospital floors. Ask for directions and maps at the Information Desk (inside the main hospital entrance on the 3rd floor).

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