

## Care After You Leave the Hospital

### *For liver transplant patients*

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 of these feelings are normal.

Most patients return to many 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. You may feel so good that you expect to be able to return to work and other activities right away.

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. You may have an emotional let-down after you have been home for a while and the newness of your transplant has worn off. It is normal to get tired of the weekly clinic visits, blood draws, and medicines.

You may also get tired of answering questions from curious friends about your transplant. You may need to tolerate some odd questions and judgments. Some people may not be able to fully understand what you have been through.



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

Now that 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.

## 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. For the first 3 months, you will need to record your weight, blood pressure, and temperature every day.

- Buy a notebook or use your smart phone or tablet to record your vital signs (weight, blood pressure, pulse, temperature, and maybe blood sugar).
- If you do not already have them, you may need to buy a blood pressure cuff, scale, thermometer, and blood glucose meter.
- Measure and record your vital signs twice a day, at 8 a.m. and 8 p.m.

## Blood Pressure

High blood pressure can cause poor health. Blood pressure readings include 2 numbers:

- *Systolic* (upper number) is the pressure created by the heart when it squeezes blood into your circulatory system.
- *Diastolic* (lower number) is when the heart relaxes between beats.

Normal blood pressure is 120/80. Your transplant surgeon or transplant coordinator will tell you what blood pressure is best for you.

- The best times to take your blood pressure are in the early morning and again in the evening, right before bedtime.
- Always check your blood pressure **before** you take your blood pressure medicines, if your doctors have prescribed these.
- Always record your blood pressure readings in your notebook, smart phone, or tablet.
- Buy a machine that records both blood pressure and pulse.
- You will need to make sure someone brings your blood pressure machine to the hospital on your discharge day. Your hospital nurse will check it to make sure it gives accurate readings.

### **Pulse**

Your pulse rate (heartbeat) is measured in beats per minute.

- Use your blood pressure machine to monitor your pulse.
- You can also check your pulse by lightly pressing on the inside of your wrist, below your thumb. Your inpatient nurse can show you how to do this. Use your watch or cell phone and record your pulse for one full minute.
- Always record your pulse results in your notebook, smart phone, or tablet.

### **Temperature**

Take your temperature twice a day **and** any time you feel ill with chills or fever. Normal body temperature is 98.6°F (37° C). Always record your temperature results in your notebook, smart phone, or tablet.

Call your transplant coordinator or your local doctor if you have:

- A fever higher than 100.4°F (38° C) that lasts longer than 24 hours.
- Any fever higher than 101°F (38.3°C). **Call right away.**

### **Weight**

We will check your weight at each Transplant Clinic visit. We may need to make changes in your care plan if you have sudden weight gain or loss:

- Sudden weight gain can mean your kidney function has decreased and you are retaining fluid.
- Rapid weight loss can be a sign of dehydration.

Call your transplant coordinator or doctor if:

- Your abdomen is swollen

- You have a lot of swelling in your legs or ankles
- You are short of breath

## **Symptoms**

Right after your transplant, also record any unusual symptoms or feelings you have. Call your transplant coordinator if you have:

- Flu-like symptoms
- Redness, warmth, or a change in drainage from your incision
- Pus or a bad smell from your incision
- Swelling, warmth, and tenderness over incision area
- Body rash
- Nausea or vomiting
- Shortness of breath that causes you concern
- Headaches
- Changes in vision
- Stomach cramps
- Muscle aches or pains
- *Jaundice* (skin or whites of eyes are yellow)
- Changes in your stool (clay colored)
- Swelling of your ankles or legs
- Decreasing amounts of urine
- Burning feeling when you urinate
- Change in color or odor of urine

## **Severe Symptoms**

Go to the Transplant Clinic **right away** if:

- Your wound opens so that you can see your internal organs
- You have seizures
- You are so short of breath that you cannot lie flat
- Your incision is red and hot to the touch
- You have a fever higher than 101°F (38.3°C)
- Your heart is racing (pulse is higher than 120)
- Your blood sugar is higher than 300

## Who to Call

- **If you think you may be having a life-threatening emergency, call 911.**
- If you are having an urgent need that is not life-threatening:
  - During clinic hours, call your transplant coordinator.
  - After clinic hours and on weekends or holidays, call 206.598.6190 and ask for the liver transplant medical provider on call to be paged.
- If you cannot reach anyone, go to the emergency room.

## 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.

If your blood draw cannot be done on a clinic day, you can schedule a draw for 8 p.m. the evening before your clinic visit. Please call your transplant coordinator to arrange this evening blood draw.

The results of each blood draw will tell your Transplant Team how well your new liver is working. These lab tests will be done each time you have a blood draw:

- *Comprehensive metabolic panel (CMP)*
- *Complete blood count (CBC)*
- *Prothrombin time and international normalized ratio (PT/INR)*
- Cytomegalovirus (CMV)
- Magnesium (Mg)
- Phosphate (P)

## Immunosuppression Level Check

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).

## Test Results

Results of your lab tests should be ready by the time you have your clinic visit, except for the immunosuppression level results. Ask your transplant nurse coordinator if you have questions about these results.

You can view your lab results online, on the patient portal (eCare). If you are not signed up for eCare, please ask your transplant nurse coordinator

for a copy of your labs at each clinic visit. You can also ask your transplant nurse coordinator how to sign up for eCare.

After your transplant surgeon has reviewed your test results, your transplant nurse coordinator will call you to tell you if there are any changes to your medicine doses.

## **Taking Your Medicines**

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

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 if you need any changes in your doses.

It is important to know and keep track of your medicines. The best way to do this is to keep a written list. The pharmacy will give you a medicine profile list at the time of discharge. Always bring this list with you to your clinic visits, along with your mediset. You may want to keep your medicine list on your computer, tablet, or smart phone so that you can update it easily and have it with you at all times. Your doctor may make changes in your medicines during your clinic visit.

Do **not** take any medicines, including non-prescription medicines, herbal remedies, or dietary supplements that were not prescribed by your doctor or your Transplant Team. These products may cause harmful and life-threatening interactions with your transplant medicines.

Also remember that some foods can interact with your medicines. **Do not eat grapefruit, pomegranate, star fruit, or products containing these fruits.** Be sure to read the labels on all food items you buy.

For more details about your medicines, please see the “Medicines” section of this manual.

## **Blood Draws and Tacrolimus or Cyclosporine**

Your tacrolimus or cyclosporine level is checked at each blood draw. This draw should be done about 12 hours after your last dose of this medicine.

On your blood draw days:

- Do **not** take your morning dose of tacrolimus or cyclosporine. Wait until after your blood is drawn. Taking your last dose 12 hours before lab work is very important.
- You may take your other medicines at the usual times.
- Please be at the lab no later than 8 a.m.
- Bring your tacrolimus or cyclosporine with you and take it after your blood is drawn. **Do not skip a dose.**

## Activity

Now that you have had a transplant, you are not a sick patient but a healthy organ recipient. You can resume your usual activities. You may even feel well enough to add some new ones.

You may need extra rest the first day or two after leaving the hospital. After that, a daily exercise program will improve your strength and help maintain your health.

Follow these guidelines so that you do not damage, hurt, bump, or strain your new liver:

- For **3 months** after transplant:
  - Avoid heavy lifting, straining, and doing anything that pulls on your abdominal muscles, such as sit-ups.
  - Do not lift anything that weighs more than 5 pounds (a half-gallon of milk weighs a little more than 4 pounds).
- For at least **6 weeks** after surgery, do not drive. Wait until your transplant doctors tell you it is OK. You may travel as a passenger. Always wear your seatbelt.
- Walking is the best exercise right after transplant. You may also have outpatient physical therapy to make sure that you keep making progress. After about 3 months, you will be able to add more activities to your exercise routine, such as swimming, bike riding, and more.

If you have any questions about whether you should or should not do a certain activity, ask your transplant nurse coordinator or doctor.

## Sexual Activity

Once you feel well enough, you may resume sexual activity any time after transplant. Make sure that you are ready, both physically and emotionally, before you have sex.

Potency and sex drive usually return to at least the level they were before surgery. But, they may be affected by some of the medicines you are taking. Ask your doctor if you have questions.

Remember, you can get infections more easily, so take precautions and practice “safe sex.” If you are with a new partner, ask if that person has or has had any infections. We advise you to use condoms to lower your risk of getting sexually transmitted infections and other diseases. We advise women to avoid pregnancy during recovery time.

## Staying Healthy

To help prevent infections and illnesses:

- **Wash your hands often with warm running water and soap.** Proper hand washing is one of the best ways to keep from getting infections and disease.
- Avoid contact with anyone who is ill or might be ill. Do not be afraid to ask about someone’s health!
- **Especially** avoid being around anyone who has a contagious disease such as measles, mumps, or chicken pox. **If you are exposed to these or any other contagious diseases, call the Transplant Clinic right away.**
- **Do not smoke.** It is bad for your health and will harm your liver.
- Avoid being around people who are smoking (secondhand smoke).
- **Do not drink alcohol.** It will harm your liver.

**Important:** If you violate the UWMC Transplant drug, smoking, and alcohol policies, you will **not** be eligible for re-transplantation, if needed.

## Infections

Infections are a possible complication after surgery. You are more likely to get infections because of your anti-rejection medicines.

Know the signs of infection. Call the Transplant Clinic **right away** if you have any of the signs in this section.

### Fever

A fever is a sign that your body is trying to fight something. **Call your transplant nurse coordinator or your local doctor right away** if you have:

- A fever of 100.4°F (38°C) or higher for more than 24 hours
- A sudden fever of 101°F (38.3°C)

### Cough

A cough could mean that you have an infection in your lungs. Call your transplant nurse coordinator or your local doctor if you have a cough that lasts longer than 24 hours.

## Wound Infections

Call your transplant nurse coordinator or local doctor if you have any of these signs of infection around a wound:

- Drainage
- Redness
- Swelling
- Tenderness

## Viral Infections

The common cold, the flu, cold sores (*herpes simplex I*), genital herpes (*herpes simplex II*), shingles (*herpes zoster*), and chicken pox (*varicella zoster*) are all viral infections. Avoid direct contact with people who have active infections:

- Do **not** kiss someone who has a cold sore.
- Do **not** have sex with someone who has active genital herpes.
- Delay a visit with someone who has the flu or a cold.

If you do get painful, red fluid-filled blisters (herpes sores), call your transplant nurse coordinator **right away**. You will need treatment.

## CMV Infection

*Cytomegalovirus* (CMV) is a virus. Most people have been exposed to the CMV virus at some point in their lives. The virus is usually spread through bodily fluids such as saliva, blood, urine, semen, vaginal fluid, and breast milk.

CMV can cause serious illness in some people. This includes people who are taking immunosuppressive drugs after organ transplant, people who have AIDS, and newborns.

Before your transplant, we tested you for CMV. If your test was positive, you have been exposed to CMV. To prevent CMV complications after transplant, we will watch your CMV levels at your weekly blood draws and check you for signs of CMV. We will treat you as needed.

The common symptoms of CMV infection are:

- Fever, fatigue (feeling tired and run down), muscle pain, joint aches, and flu-like illness
- Abdominal pain or discomfort, nausea, vomiting, diarrhea
- Cough, shortness of breath
- Blurry vision, eye pain, or any other new eye symptom

If you have any of these symptoms, call your transplant nurse coordinator or local doctor **right away**. You will need to be evaluated and treated, if you have CMV. If you live outside the Seattle area, your local doctor can call your hepatologist or transplant coordinator so that they can work together to evaluate you.

To check for CMV, your doctor:

- ◆ Will do a blood test that screens for CMV
- ◆ Can do other blood tests such as liver function tests or a complete blood count (CBC)
- ◆ May also do a chest X ray or *endoscopy* (a test that examines the inside of your gastrointestinal tract)

If you have a CMV infection, you will:

- ◆ Receive treatment with IV or oral antibiotics
- ◆ Have your blood tested for CMV every week while you are being treated

## Other Common Infections

Here are some other common infections and their symptoms. **Be sure to tell your doctor if you have these symptoms so that you can be treated:**

- **Oral thrush:** This is a yeast infection (Candida) that causes white patches on the tongue. These patches cannot be brushed away and may be painful.
- **Urinary tract infection:** Symptoms may include pain or burning when urinating, having a hard time starting your urine stream, a feeling of urgency, or having to urinate often.
- **Vaginal infection:** This is a yeast infection (Candida). Symptoms include vaginal discharge, odor, itching, and pain.
- **Gastrointestinal (GI) infection:** Nausea, vomiting, diarrhea, and abdominal pain may mean you have a GI infection. If these symptoms last longer than 24 hours, call your transplant nurse coordinator. You will need to take your oral immunosuppressive medicines in a different form. Your doctor will also try to find the cause of your symptoms.

## Other Complications

### 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.

## **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.

And remember that the Liver Transplant Support Group meets twice 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.

## Constipation

You may have constipation after transplant. Some reasons for this may be that you are less active, have muscle weakness, eat a low fiber diet, do not drink enough liquids, or are not in the habit of having regular bowel movements. Constipation can be a serious problem if it is not treated.

Here are some tips to prevent and treat constipation:

- Try to keep your stools soft by using the stool softener prescribed for you.
- Be active and exercise as much as possible.
- If it has been at least 3 weeks after your transplant, start eating more fresh fruits and vegetables.
- Drink plenty of fluids.

**Never go longer than 48 hours without having a bowel movement.** If your constipation lasts longer than 48 hours, call your doctor or transplant nurse coordinator.

## Wound Care

The staples holding your wound closed will be removed about 3 weeks after surgery. While your wound is healing:

- Keep the area around your wound dry and clean. Clean with soap and water only. Shower every day and gently pat the incision area dry.
- Do not apply any lotions, antibacterial creams, or oils to your wound.
- Wear loose clothing to keep from irritating your incision.
- Call your transplant nurse coordinator or doctor if you have any of these signs that your wound may be infected:
  - Fever
  - Redness or swelling
  - Drainage

### **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.
- You may receive vaccines for polio (IPV only, **not** OPV) and for diphtheria/tetanus (as booster).
- You may have a TB test, since these vaccines use dead organisms.
- If you are in the middle of receiving vaccines for hepatitis 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 *pneumovax* vaccines every 5 years to protect you against viral pneumonia.

### **Diet**

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

### **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.
- When you travel, carry all your medicines with you. Do **not** check them with your baggage.
- Before you leave home, find the transplant center that is nearest to your destination. Ask your nurse coordinator for help. Write down the center's phone number and address, and keep it with you on your trip.
- See the "Immunizations (Vaccines)" section for information on getting vaccines that are needed for travel.

## **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 handling 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.
  - After your transplant surgery, 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, and therefore 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.

## 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 10 .....Discharge from hospital  
 Day 11.....Clinic visits (Your number of clinic visits between Day 11 and Day 90 will depend on your unique needs)  
 Day 90.....Return to care of primary care provider  
 6 months .....Long-term follow-up visit with Transplant Hepatology  
 1 year .....Long-term follow-up visit  
 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.

