



OREGON
HEALTH & SCIENCE
UNIVERSITY

Liver Transplant

A Handbook for Patients
& Their Families

Table of Contents

GENERAL INFORMATION	1
Contact Information	1
Transplant Emergencies	3
When to Call a Transplant Nurse	3
LABS AND VITALS	5
MEDICATION INFORMATION	7
Prescription Do's and Don'ts	8
Warnings	9
DIET AFTER TRANSPLANT	11
HEALTHCARE INFORMATION	15
Long Term Health Maintenance	17
Prevention of Infectious Disease	19
Dental Care	20
Drugs and Alcohol	20
Pets at Home	21
Health Concerns	22
LIVER COMPLICATIONS	25
Rejection	25
Treatment for Liver Rejection	25
Infection	26
Treatment for Infection	26
WRITING YOUR DONOR'S FAMILY	27
REFERENCES	29
Diagnostic Tests	29
Over the Counter Medications	31
Medications You May Be Taking	32
Food Safety	41
Diabetic Meal Planning	42
Foods with Magnesium and Phosphorus	51
Lab Values	53
Blood Pressure / Blood Glucose Tracking Sheets	56
Definitions	58
Web Resources	64

GENERAL INFORMATION

Contact Information

My Post-Transplant Liver Coordinator is _____

Local: (503) 494-_____

Toll-free: 800-452-1369 extension _____

My Social Worker is: Ashely Swift (503) 494-4999

Transplant Office local: (503) 494-8500
Monday-Friday 8:00 am to 4:00 pm
Toll-free: 800-452-1369 extension 8500
Fax: (503) 494-5292

Issues DURING Office Hours (503) 494-8500
Monday-Friday 8:00 am to 4:00 pm

Urgent Issues AFTER Office Hours Local: (503) 494-8311
Nights, Weekends, Holidays Toll-free: 888-222-6478

*Tell the operator you are a liver transplant patient and that you **need to speak with the Liver Transplant Coordinator on-call**. Please remember, the nurse is on-call for **EMERGENCIES ONLY**.*

OHSU Pharmacy (503) 346-3370
OHSU MyChart (503) 494-5252
OHSU Laboratory (503) 494-7383

Mailing Address Oregon Health & Science University
Clinical Transplant Services
Mail Code: L590 • 3181 SW Sam Jackson Park Road
Portland, Oregon 97239-3098



What to Do When You Go Home

We do not expect you to grasp all the important points of your health care immediately. Read this book through more than once, note any questions, and discuss them with the Transplant Team. *Always* feel free to have points clarified that you do not understand. Do not be afraid to ask questions.

Make your health care important to you! The Transplant Team is here to help you return to an active life in family, work and play.

Your care really begins once you are discharged from the hospital. All the things you have learned during your hospital stay will play an important part in your care at home. It will be your responsibility to take care of your new liver.

- 1. Take your medications:** One reason why transplants fail is because patients do not follow their medication routine. It is very important to take all your medications as prescribed
- 2. Get your lab work done:** every Monday and Thursday for the first month then as instructed by the Transplant Team.
- 3. If you are instructed to take and record your blood pressure:** Take your blood pressure in the morning and early evening, and record it every time. Know what your blood pressure should be before you leave the hospital. The self-reporting records section of the book has a blood pressure form that you can use.
- 4. If you are instructed to take and record your blood glucose:** Take and record your blood glucose before meals and at bedtime or as instructed by the transplant team. A blood glucose recording form is in the self-reporting records section of the book.
- 5. Bring your education book and any questions you have to clinic.**
After you discharge from the hospital, you will be seen in clinic by the transplant team once a week. The frequency of these visits will decrease as you continue to recover.

Clinic appointments are in the Physicians Pavilion, 2nd floor, Suite 220.

You will be given your first clinic date and time upon discharge from the hospital.

Clinic visits are a great opportunity to touch base with the transplant team about your ongoing care plan, as well as the following:

- Assess your incision and eventually have staples removed
- Discuss medication changes / issues

6. PLEASE CALL IF YOU HAVE ANY QUESTIONS



Transplant Emergencies

Call 911 if you experience

- Chest pain
- Loss of consciousness/pass out
- Bleeding

When to Call the Transplant Nurse

Call if you experience

- Temperature over 100° F
- Breathing problems – shortness of breath, problems catching your breath, pain when you breath in, problems breathing when you lay flat in bed
- Incision area - increased pain, redness, tenderness, swelling, and/or drainage
- Ongoing diarrhea (more than 4 loose stools in one day)
- Nausea and vomiting - if you can't keep your pills down
- Pain that does not go away after taking your pain medication
- Bleeding that will not stop
- Heartburn
- Tenderness or pain in the area surrounding your transplanted liver
- Anything that you are concerned about and think you need to see a doctor about, or things that can't wait until the office is open

The Transplant Office is open 8:00 am to 4:00 pm, Monday through Friday. Please call the office during these hours if a problem develops after you are discharged from the hospital. Please note the Transplant Office is closed on weekends and major holidays.

For **EMERGENCIES* ONLY** on weekends, holidays or after office hours, call the **Liver Transplant Nurse Coordinator on-call (503-494-8311/1-800-452-1369)**. If you need to see a doctor immediately, you will be sent to an emergency room.





LABS AND VITALS

Getting your blood tests done is one of your most important responsibilities. The test results help us diagnose rejection and side effects of the drugs.

- Your blood should be drawn in the morning so results are available the same day.
- You will be required to get your labs done at OHSU for the first month after transplant.
- Once you are released to do so, lab orders will be sent to a local lab of your choice that tells the lab what tests to run:
 - These orders give the lab permission to release the results to you and requests that they fax or telephone us with the results.
- You need to know what your blood test results are:
 - There are pages in this section of the Transplant Manual for that purpose, or you may sign up for MyChart.
 - **Your coordinator will not call you if your liver transplant numbers are normal** for you.
 - **Get to know what the numbers mean and what is normal for you.**

If you are taking Tacrolimus or Cyclosporine

- On the days that you have your drug level blood test you must take your medication 12 hours before blood draw with a ½ hour window before and after the 12 hours:
 - This means you must have your drug level drawn between 11 ½ and 12 ½ hours after you take the dose.
 - **Do not take your next dose until after the blood is drawn.**

If you are taking Rapamune

- On the days that you have your drug level blood test you must take your medication 20-24 hours before the blood draw.
- **Do not take your next dose until after the blood is drawn.**

**If your blood is not being drawn within the time frames designated above,
DO NOT GET A TACROLIMUS/RAPAMUNE/CYCLOSPORINE LEVEL DRAWN and notify your
Coordinator.**

If you use the OHSU lab

The lab at OHSU is located on the third floor of the Physicians' Pavilion. You may get the results of your blood tests by calling the lab **at 503-494-7383 after 2:00 pm** on the day of your lab work. You may also sign up for OHSU **My Chart** to get access to your labs online.
<https://mychartweb.ohsu.edu/mychart> or call 503-494-5252.

The lab has variable hours on holidays and weekends, so verify the hours with the lab staff.



If you use a non-OHSU lab

Call your lab in the afternoon and write the results in your book. Remember, it is essential that both you and the transplant team follow your lab work closely.

Routine lab schedule

Discharge-Month 3..... Monday, Thursday
Months 4-6..... Monday
Months 7-12..... Every other Monday
After 1 year..... Every 3 months

*All labs will be done at OHSU the first month post-transplant



MEDICATION INFORMATION

After you have received your new liver, you will be required to take a combination of medications each day for the life of your new liver:

- These medications are essential to prevent liver rejection.
- You can never stop taking or miss these medications; if you do you risk rejecting your new liver.
- It may also be necessary to take other medications.
- Before you go home, the Pharmacist will give you a medication list and dosing schedule.
- You will learn what the medications look like, what amounts to take, what they are for, and what side effects they may cause.

The doses of your medications will change frequently:

- After you are home, medication changes may be called to you over the phone.
- Write down any changes you are requested to make on your medication list.
- *Always* take your medication according to your medication list.
- When you are given new medication lists, be sure to destroy any old lists.

It is extremely important that you take your medications at the correct time each day.

- It is easy to forget whether you took your pills or not:
 - You may want to set your schedule around meals and bedtime.
 - You may find it helpful to use the medication pages in your transplant manual, or to set up a check system of your own.

The Transplant Office will manage your immunosuppression medications for life. If your Primary Care Physician wants to make any changes to your immunosuppressant medications, please have him or her contact the Transplant Office.

- At 3 months your Primary Care Physician will manage all medications **except** your immunosuppression.

Explanations of specific medications you may be taking are in the **reference section of your book**. It is important that you become familiar with common side effects that may occur from the medications you are taking.

It is also important for you to know that not all side effects or problems related to each medication are included. Only those that commonly occur in the transplant patient are listed. Please remember that you will not necessarily develop all of the side effects mentioned.



Feel free to call the Transplant Office to discuss any problems you feel you may be having with any of the medications you are taking.

Remember: Never change your dose of immunosuppressant's without discussing it with the Transplant Team.

Prescription Do's and Don'ts

DO'S

- ✓ Call your regular pharmacy for medication refills
- ✓ Keep the name and phone number of your local pharmacy handy
- ✓ Call the Transplant Office during office hours if you have a problem with your immunosuppression prescriptions
- ✓ Keep the Transplant Office up-to-date on your allergies
- ✓ Give your local pharmacist our telephone number for refills
- ✓ Ask for refills when you are seen in the Transplant Clinic

DON'Ts

- ✗ Go to the transplant floor for refills
- ✗ Run out of medication before getting refills
- ✗ Wait until the weekend or after 3:00 pm to call for refills



Warnings

- There can be many possible drug interactions between your post-transplant medications and herbs/over-the-counter dietary supplements. **Do not take herbs or dietary supplements without first consulting with your Transplant Physician.** Transplant patients should never take medications or herbs intended to “boost” their immune system.
- Do not take ibuprofen, Motrin, Aleve, naproxen or any other NSAID (Non-steroidal Anti-inflammatory Drugs), unless told to do so by the transplant team.
- Avoid grapefruit, grapefruit juice, mandarin oranges, orange marmalade, pomegranates and pomegranate juice; they will make the level of medication rise too high in your blood.
- If any of your other doctors want to make changes to your transplant drugs (immunosuppressive medications), please have them contact the Transplant Team.

See reference section on **Medication** for details.





DIET AFTER TRANSPLANT

Nutrition plays a key role in your recovery from transplant. As with any major surgery, the proper amount of calories, protein, vitamins and minerals are needed for proper wound healing. As you recover from your transplant your dietary requirements will change.

Short term dietary needs

In the first one to three months after your transplant it is important that you eat enough protein and calories to help with wound healing. During this recovery time you may not feel like eating “three square “meals a day, this is normal, poor appetite and feeling full after eating only a portion of a meal is common during this time period. If this happens try to eat smaller portions 4-6 times a day. Also quite common during this time period is the feeling of nausea, and abnormal bowel movements, talk to your transplant team about these issues.

Your diet will change after your transplant. As your new liver function improves, you will be able to enjoy much more variety. With normal liver function, you will need to drink 10 glasses (80 oz.) of fluid preferably water daily. Caffeinated beverages do not count towards your daily fluid requirement.

Calories

You should try to eat calorie rich foods such as dairy, whole grains and plant based foods, instead of “empty calories” (soda, chips and candy). Good caloric intake will help you to decrease muscle wasting (this is often present in pre liver transplant patients).

Protein

Protein is a very important component of your diet after your transplant. Protein helps to promote healing and muscle gain. You should eat some foods that are high in protein every day, meat and fish have the highest concentration of protein, there are also many vegetarian options that are also high in protein.

Please see references for additional information.

Sugar

Prednisone can decrease your body’s ability to manage absorption of sugar. This can cause your blood sugar (glucose) to rise, this condition is called hyperglycemia. Some patients will be sent home on insulin, this helps to lower your blood glucose.

You can help control your blood sugar by avoiding high sugar foods such as candy, soda and ice cream. High carbohydrate foods can also raise your blood sugar. It is important to remember that as your prednisone medication decreases your blood sugars will start to stabilize.



If you do develop high blood sugars the following guidelines may be helpful:

- Eat at least three meals a day at regular times, avoid skipping meals. You should have protein with each meal.
- When eating foods high in carbohydrates you should choose whole grains, legumes, vegetables instead of refined processed foods such as white breads and cereals.
- Limit the amount of fruit to one serving per meal.
- Remember to read the food labels when grocery shopping. Also many restaurants now have nutritional available to you, either on the menu or on line. If you need help with managing your blood sugars talk to your transplant team.
- Please see references for additional information.

Sodium (salt)

During the first three months post-transplant your body may “hold onto” (retain) sodium and water (edema). Your blood pressure may also be affected. This is due to the surgery itself as well as some of the medications that you have to take to keep your transplanted organs working properly. It is therefore important that you follow a “No Salt Added” diet. Try to keep your sodium intake to less than 3000 mg of sodium a day.

To do this you should limit salt when cooking.

Do not add salt after food is prepared.

And avoid/ limit processed Foods:

- Bacon, Deli Meats, and Sausages
- Prepackaged Meals
- Frozen Vegetables with Sauces
- Canned Juiced (V8, Kerns)
- Canned Soups (There are low sodium canned soups available, read the labels)

Please see references for additional information.



Food Safety

Because you have a suppressed immune system, avoiding food borne illness is a must:

- Always wash your hands in warm soapy water before handling/preparing any foods, especially after using the bathroom.
- Keep uncooked meats separated from all other foods. Use different cutting boards and utensils for raw meats/fish and vegetables.
- Always sanitize all of your utensils and kitchen surfaces (cutting boards, countertops, sinks, etc.) with a solution of ½ teaspoon bleach and 2 cups of water.
- Use a food thermometer to ensure that meats/fish are properly cooked before eating.
- Do not share utensils or food.

Do not eat any of the following:

- Raw eggs
- Unpasteurized (Raw) Milk
- Raw Seafood such as Oysters/Sushi
- Sprouts

Please see references for additional information on food safety.





HEALTHCARE INFORMATION

Activity Restrictions

Activity restrictions following transplant are few. We want you to resume your past level of activity and lead an active life. General restrictions include:

- Lifting
 - Do not lift anything greater than 10 lbs. until 6 weeks after transplant.
 - Do not lift anything greater than 20 lbs. from 6 to 12 weeks after transplant.
 - After 3 months post-transplant there aren't any lifting restrictions.
- Avoid activities, such as horseback riding, snowmobiling, and trail or cross country motorcycling, for 3 months after transplant.
- No tub baths and swimming until your incision has healed (approximately 6-7 weeks).

You may notice your muscles, especially leg and abdominal muscles, becoming weak. This is due partially to not using them, and to the side effects of prednisone.

Excellent ways to improve the strength of leg muscles include:

- Walking
- Stationary bike riding or bike riding

After 3 months, sit-ups and other abdominal exercises will improve the tone of your abdominal muscles.

Returning to Work

Depending on the kind of work you do, we encourage you to return to work as soon as possible after transplant. Some people are able to resume their previous employment at 4 to 6 weeks after transplant, unless they do manual labor. Patients may be eligible for up to 12 weeks of job protected leave via OFLA or FMLA, please check with your employer regarding this. We encourage you to return to work as early as three months. Our social worker can provide resources to assist you with vocational rehabilitation counseling if necessary.

Play

Use common sense as your guide to any activity after transplant. As you gain strength and endurance, your amount of physical activity will also increase. If you have any questions, please call the Transplant Office.

Sexual Activity

Your new organs are well protected; sexual activity will not harm your transplanted organs. As with any major surgery, wait six weeks before engaging in sexual intercourse, to allow the incision and muscles to heal. It is even more important to take precautions against sexually transmitted diseases after a transplant. Always practice safe sex.



Men Fertility

Some men are able to father children after transplant and regain sexual desire and function often lost during liver failure. The status of liver function and certain medications, such as those used to treat high blood pressure, will sometimes affect sexual function after transplant. If you notice a change in your sexual ability, do not hesitate to ask for advice about what might be done to improve the situation. Men should discuss family planning with their hepatologist. It is recommended that men do not father children while on certain immunosuppressive medications.

Women Fertility

The decision to have a child is a personal one, but we hope you will feel free to talk with us. We want you to make an intelligent choice based on all available information.

Most women are fertile after transplant. Menses (periods) resume anywhere from one to several months after transplant. You may be ovulating even though you do not have a regular period.

Many women have become pregnant and delivered healthy children after a transplant. Women on Cellcept or Myfortic, who are pregnant or considering pregnancy, must consult the transplant physician; **Cellcept/Myfortic increases the risk of birth defects.**

Regarding pregnancy:

- We recommend waiting at least 1 year after transplant before becoming pregnant.
- You should use a reliable form of birth control immediately after your transplant.
- You should not have other medical conditions that might add to the risk of the pregnancy.
- You will need more frequent lab testing.
- Your immunosuppression drugs will need to be adjusted.

Although the odds are with you for a successful pregnancy, there are some special risks to the mother and child:

- About 30 percent of mothers will develop high blood pressure with protein in their urine, and in approximately 10 percent of cases this can be accompanied by a decrease in kidney function.
- There is a 30 percent risk of premature birth and prenatal care is essential for successful outcome.
- The risk of major congenital malformations of the baby is approximately 5% if the mother has had a transplant, and about a 4% chance of an abnormal baby if the father has had a transplant.

Plan to have a routine gynecological exam every year, close to your birthday. It must include a Pap smear and a breast examination.



Long Term Health Maintenance

Sun Exposure

Transplant recipients have an increased risk of developing skin cancer. This risk is up to 65 times greater than in people who have not had a transplant. The medications that transplant recipients take to suppress their immune system cause this increased risk.

Skin and lip cancers are the most common cancers of transplant patients. Since the risk increases with time, you must always protect your skin and lips from the ultraviolet rays of the sun. Apply lotion and lip balm that has sunscreen with an SPF of 30 or greater every day.

- Avoid midday (10 am to 3 pm) sun, when ultraviolet rays are strongest.
- Wear a hat, long sleeves and pants when outdoors.
- Use a sunscreen lotion and lip balm (>30 SPF) every day (rain or shine) and apply often to exposed areas, especially face, neck and hands.
- Never use tanning beds.
- Use extra caution near water, snow and sand, they reflect the sun's damaging rays.
- Notice what is normal for your skin and report any changes to your doctor or dermatologist.

Remember that sunscreen lotions wash or wear off. Reapply the lotion as needed, especially after swimming.

Immunizations

You may receive injectable polio and a TB skin test. It is recommended that you receive the Influenza A & B or "flu" shot every year and pneumovax every five years.

You should not get live vaccines such as the nasal mist influenza vaccine (Flu-mist®), the live polio vaccine, the smallpox vaccine, the measles-mumps-rubella vaccine (MMR®), and the live varicella vaccine (Varivax®, Zostavax®). Receiving a live vaccine may cause serious health complications because transplant recipients could develop the virus that he/she is being immunized against.

It is best to avoid close contact with anyone who has had the oral polio vaccine for up to 2 weeks since the virus may shed in their stool and saliva. Do not change diapers of children that have received live immunizations, for 2 weeks. Transplant recipients who have infants should be sure that their child receives the Salk polio injection. It is also recommended to avoid close contact with a child who has received the chicken pox vaccine. However you do not need to avoid a child who has recently received an MMR.

Get a tetanus booster every 10 years. If you are injured and have not had a tetanus booster within the last 5 years, please contact your Primary Care Physician.



Travel

Before you plan a trip to a foreign country, contact a travel clinic; they are experts regarding appropriate vaccinations required for international travel and risks of infection. Please consult your Transplant Team with any questions. Remember, after transplant **you should never receive live virus vaccines.**

Bone Disease

All transplant patients suffer from some bone disease. Talk to your Primary Care Physician about preventative strategies, including diet and exercise.

Routine Cancer Surveillance

Always contact the Transplant Office with any diagnosis of cancer. Due to the immunosuppression you are receiving, the following tests are recommended:

Women

- All women need to have an annual pelvic exam and pap smear.
- Females over the age of 40 should have an annual mammogram.
- Females over the age of 30 who have a mother or other female relative diagnosed with breast cancer before menopause should have an annual mammogram.

Men

- You should have your first prostate-specific antigen test (PSA) at the age of 45 if you have a father or brother who has been diagnosed with prostate cancer or if you are an African American.
- If you are over the age of 50 you should have an annual PSA test.

Everyone beginning at the age of 50

- Colon-rectal cancer screening, including a rectal exam, every 2 years.
- Fecal occult blood test performed annually.
- Colonoscopy done every 5 years.



Prevention of Infectious Disease

Hand washing is the single most important way to prevent infection!

Wearing Masks and Gloves

Transplant patients should wear a mask for the first 3 months after transplant in the hospital, around active construction and farming areas, and in crowded places. Transplant patients should not garden during the first 3 months after transplant, and must wear a mask and gloves from 3 months to 1 year post-transplant. After 1 year post-transplant patients should always wear gloves when gardening.

Avoiding Infection

You need to consciously protect yourself from infection by taking the following precautions:

- Wash your hands often. This is the number one way to protecting yourself from infection.
- Keep your hands away from your face and mouth.
- Stay away from people with colds or other infections.
- Avoid close contact with people who have obvious illnesses such as colds and flu.
- Avoid crowded places like stores, movies, restaurants and churches in the first few months, particularly during cold and flu season or when you are highly immunosuppressed.
- Do not share eating utensils, cups, or glasses with others since many viral illnesses are spread through saliva and mucous. Do not share razors or toothbrushes.
- Ask friends to visit only when they are well.
- If you have a wound that requires dressing changes, wash your hands before and after changing the dressing.
- Avoid working in the soil for three (3) months after your transplant. Thereafter, wear gloves. Avoid compost piles, wet leaves, and rotting organic matter. These materials can carry mold that can cause significant respiratory infections.
- Wear a surgical mask if you are near a construction site or in a large crowd until your prednisone dose is down to 10 mg a day.
- Avoid handling animal waste and avoid contact with animals that roam outside. Do not clean birdcages, fish tanks, turtle tanks, or cat litter boxes. The cat litter box should be covered and taken out of your home before it is changed. Some types of pets should be avoided such as reptiles, turtles, amphibians (frogs), hamsters, and guinea pigs. These animals can carry infections that could cause you to become ill.

Dental Care

Seeing your dentist after transplant is very important. You must have a dental checkup every 6 months. Since your immune system is suppressed, infections could become serious problems. Be sure to follow the guidelines below:

- After a transplant, delay any routine dental care for 3 months.
- Inform your dentist that you have had a liver transplant and that you are on immunosuppressive medications.
- Pre procedure antibiotics for standard dental care is not recommended.
- If your dentist would like to prescribe pre procedure antibiotics we recommend that they follow the American Heart Association recommendations for dental prophylaxis.
- If your dentist has any questions regarding your dental care, please have them call the Transplant Office.

Drugs and Alcohol

Smoking

The following are strongly discouraged:

- Chewing tobacco can lead to neck and mouth cancers.
- Smoking increases your surgical risk, your risk of cancers, and causes atherosclerosis (fatty deposits in blood vessels).
- Smoking increases your risk of heart attack and stroke.
- Smoking marijuana can cause lung and brain fungal infections.
- Vaping.

If you need help quitting smoking or chewing tobacco, please contact the transplant nurse.

Alcohol

Do not drink alcoholic beverages. Do not drink “nonalcoholic” beverages including “near beers” and wine coolers. Alcohol is metabolized, or broken down, in the liver. Drinking any type of alcoholic beverages can harm your liver. Many of your medications are metabolized by the liver. Liver cells may be destroyed with the additional stress of breaking down alcohol as well as your medications.



Pets At Home

Most pets can remain in the household, the following are our recommendations:

- Dogs and cats vaccinations should be kept up to date and treated regularly for flea and tick prevention.
- Transplant patients cannot clean out a cat's litter box.
- Transplant patients cannot clean out a bird cage or chicken coop.
- Transplant patients should not handle any reptiles, which may carry salmonella. They are not recommended as pets.
- Always remember, good hand washing is important after working with or cleaning up after your pets.

Health Concerns

What happens after transplantation depends on the organ transplanted and the recipient's specific medical situation. Most patients recover fully, return to work and resume a normal, active life after receiving a new organ. However, there is a possibility of developing unrelated health problems after transplantation. It is important to work closely with your doctor concerning your overall wellness.

Anxiety and Depression

Patients and their families face a new lifestyle after transplantation that may cause them to feel nervous, stressed or depressed. Anxiety and depression post-transplant are considered normal. Because emotional and psychological support is a continuing process, ask your social worker about counseling services that can help you and your family deal with these changes. Common concerns are; mood swings; job planning; rehabilitation; family stresses, such as parent-child conflicts and marital conflict. Financial concerns are also common issues, such as questions about Medicare, disability or insurance. Your social worker can help direct you to the appropriate resources.

High Cholesterol

Many immunosuppressant drugs can contribute to high cholesterol. This condition therefore affects many transplant recipients. When a patient develops high cholesterol, blood vessels, including the ones attached to the transplanted organ become clogged, which may affect the flow of blood. This slowing of blood flow can affect the success of your transplant and may lead to heart disease. It is important to talk to your doctor about how to reduce the risk factors of heart disease, including controlling your cholesterol.

High Blood Pressure

High blood pressure (hypertension) is a common condition that is seen in the general population. After transplant, patients who have had high blood pressure may need to continue to be treated for this condition. Sometimes, high blood pressure occurs in patients who have never had any problem with their blood pressure. Hypertension after transplant can be a side effect of medications, particularly the anti-rejections medications. High blood pressure also may occur if the kidneys are not working well.

There are several medications that can be used to treat high blood pressure. They work in different ways to control hypertension. Sometimes patients are prescribed more than one blood pressure medication because the medications work together to control hypertension. Sometimes a diuretic (water pill) is needed to work with these medications. Your doctor will prescribe the blood pressure medications that are right for you to control high blood pressure and any complications you may have.

Diabetes

Diabetes is an increased level of sugar in your blood. Some of the immunosuppressive medications that you take may cause diabetes.

If you develop diabetes, you will receive specialized teaching and ongoing follow up about how to deal with this problem.



Symptoms of diabetes may include:

- Increased frequency of urination
- Increased thirst
- Blurred vision
- Confusion
- Extreme hunger
- Constant itching
- Irritability

What can you do to lower your risk?

- Improve your overall health through diet and exercise.
- If you are overweight, it is important to lose weight to reduce your risk for diabetes.
- Improve your nutrition with a balanced diet. Talk to your dietician, transplant coordinator, and/or physician about the best diet for you.
- Exercise is an important treatment, particularly when combined with a weight loss program and stress reduction.
- Try to reduce stress. You may feel comfortable talking with your social worker, transplant coordinator, and/or physician about any increased stress you are experiencing after your transplant. They can help or refer you for additional counseling and advice.

If left untreated or uncontrolled, diabetes is related to heart disease, stroke, high blood pressure, blindness, kidney disease, and kidney failure. Severe problems with blood flow in small blood vessels also may lead to amputation.

Recurrent Hepatitis C

Unfortunately the Hepatitis C Virus is found in the blood and not just the liver, so a liver transplant is not a cure. Most people transplanted because of hepatitis C will have a recurrence of the virus in their blood.

The rate of progression is variable. It is unclear what all increases the rate of progression of the disease, but it is known that treatment of acute rejection has been associated with faster progression. About 25% of patients will develop significant recurrence of hepatitis C (seen on liver biopsy) in the new liver. Some patients will develop symptoms related to the hepatitis C shortly after transplantation. Two things lead to the quick recurrence; a high level of the virus in the blood at the time of transplantation, and the body's inability to fight the virus because of the immunosuppression. Most people with recurrent hepatitis will develop cirrhosis within five years of their transplant. There are several new medications used to treat recurrent Hepatitis C disease. How well a person responds to treatment is dependent on the type of hepatitis C (the genotype), side effects during treatment and any complications during treatment. Typically hepatitis C treatment is not started within the first year after transplant. If you have questions about treatment please discuss them with your Transplant Team.



Cancer

The anti-rejection medications you take increase your risks of developing certain types of cancer. The most common cancers are: skin cancers, cancers of the genitals and urinary system and lymphoma (cancer of the white blood cells).

We recommend that all patients be seen by a dermatologist once a year. It is very important that you learn what your cancer risks are and report any new symptoms or concerns to your physician.

LIVER COMPLICATIONS

Transplant Organ Rejection

Rejection does not mean that you will lose your liver but early diagnosis and treatment is very important to avoid complications.

Rejection is detected by looking at your labs and with biopsies of the transplanted organ.

Rejection is the process by which your body recognizes your transplanted liver as a foreign protein (not a part of your (original body) DNA. The body responds with the immune system which is its natural defense against foreign proteins. The immune system is very complicated and made of many things including your white blood cells, which are your fighter cells in your body. In rejection, these cells can attack your transplanted liver. If rejection is not treated, your new liver can be damaged.

In spite of all precautions, rejection episodes can occur. Even while taking immunosuppressants, up to 10-30% of all liver-transplant recipients will have at least one rejection episode. The first episode often occurs within 3 months of surgery. Changing the dosages of your immunosuppressive medications or adding a new one usually controls rejection.

Treatment for Organ Rejection

Anti-rejection medications are used to prevent rejection. This class of drugs is called immunosuppressant medications and are discussed in the Medication section of your book. If you experience rejection, we use this same class of medications to try to stop organ rejection

Any injury to the liver can cause the release of liver enzymes into the bloodstream. An injury to the liver cells can be caused by rejection, infection, or side effects of medications. Measuring the liver function tests (LFTs) regularly and watching the pattern of the results can help your doctor decide what is happening to your liver.

How is rejection treated?

Mild to moderate rejection is treated typically by increasing your immunosuppression and/or your prednisone dose. Sometimes the IV form of prednisone is given for several days. Another way to treat rejection is by adding or combining other anti-rejection medicines.

Severe rejection requires admission to the hospital for IV administration of stronger agents.

The risk of rejection decreases over time but can occur at any time. Taking good care of yourself, taking your medications as prescribed, and having your blood tests done as requested will help decrease your risk of rejection.



Infection

When anti-rejection drugs (immunosuppressant drugs) are used, your body is not able to fight infection as well as before the transplant. The anti-rejection drugs weaken (or suppress) your immune system. If your immune system is weakened you are at greater risk for infection. There are certain things you can do to help prevent infection including washing your hands regularly, limit visits from sick family or friends, wear a mask when in crowds or around construction sites, and take your infection-fighting medications (antibiotics). You will be on these prophylactic medications for at least the first 6 months after transplant.

Treatment for Infection

You will need to have the exact type of infection diagnosed before the proper treatment can start. This may include having your blood, urine and possibly stool cultured to see where the infection might be.

If the infection proves sensitive to antibiotics, you will be treated with the appropriate antibiotics.

You should get medical advice for symptoms of infection such as: fever, chills, new onset diarrhea, new or unexplained pain, cough, tiredness for unknown reason, concerns of not feeling well, and for problems with urination such as: frequent urination, painful urination, cloudy urine.

We also monitor and treat patients when indicated for viral infections, such as Cytomegalovirus (CMV), Epstein Barr virus (EBV) and BK virus.

CMV

Cytomegalovirus (CMV) is a member of the herpesvirus family; it is a very common viral infection. CMV infection is usually asymptomatic in non-transplant patients. Transplant patients are treated prophylactically with antiviral medications to help prevent CMV infection. Symptoms of CMV infection can be: fever, extreme fatigue, diarrhea, abdominal pain, cough, and low white blood cell count. CMV is diagnosed by a lab test called a CMV PCR. Once a diagnosis is made your Transplant Team will determine what treatment is to be prescribed.



WRITING YOUR DONOR'S FAMILY

Making the choice to write to your donor family is a personal one that each transplant recipient has the option to make. In this page we will share a few guidelines for the letter/card, the process of writing to your donor family and correspondence from the donor family.

Please know that there are no requirements or expectations for you to write to your donor family or, if you choose to write, when correspondence occurs. Again this is a very personal decision that each recipient must decide for themselves.

What to Write

While we cannot give you the words, which can be difficult to find, we hope to give you some ideas for what to include in a letter/card to your donor family.

- “Thank you” While this may not convey the depth of your appreciation for the gift of transplant it is a sentiment that is always welcome.
- Share a bit about yourself (occupation, hobbies, etc.), your family and the impact that transplant has had on your life (what can you do now or have been able to experience because of transplant).
- Photos of yourself or family.
- As you do not know the donor family please avoid overtly religious tones. Generalized statements of “feeling blessed” or something similar is perfectly acceptable.
- Do not pressure the donor family to meet in person or to write back to you.

On a separate piece of paper please write your full name, transplant center and date of transplant. This will help Pacific Northwest Transplant Bank (PNTB) get your letter to your donor family.

What to Keep Private

In an effort to provide you with privacy we ask that you not include the following items in your correspondence:

- Last name
- City of residence, address or phone number
- Hospital where transplant occurred
- Names of your medical team



The Process

After you write your donor family please complete the following steps so PNTB can get the correspondence to your donor family:

- Place your letter or card in an unsealed envelope
- Place both the unsealed letter and paper with your personal information together and mail to:
Transplant Social Work
Mail Code: SJH 569
3181 S.W. Sam Jackson Park Rd.
Portland OR 97239

What Happens Next

You will receive a call to confirm receipt of the letter, which will then be sent to PNTB. PNTB will then forward the letter to your donor family with the donor family's permission. It could take several weeks for your letter to get to the donor family. Although it's rare, should the donor family decide not to receive the letter, or if PNTB is unable to connect with the donor family, you will be notified.

Will I Hear from the Donor Family?

Just like you had the opportunity to decide if writing to the donor family was right for you, each donor family will make the same decision. Please keep this in mind when writing your letter to the donor family, you are encouraged to write a letter without the expectation of hearing back from the donor family.

If you do receive a letter from your donor family you will be notified by your social worker and given the opportunity to accept or decline receiving the letter.

What Support is Available?

If you are unsure if writing to your donor family is right for you or what to write to your donor family you can always talk with your social worker. Your social worker will not make these decisions for you but can help you process your feelings and concerns around writing to your donor family, which can help you make a decision that you are most comfortable with.



REFERENCES

Diagnostic Tests

What is a biopsy?

A biopsy is a procedure used for diagnosing rejection. The doctor will numb your skin with a local anesthetic and take a very small piece of your liver using a needle.

If you are on any blood thinning agents such as, Aspirin, Plavix, Persantine, or Coumadin, you need to call your Coordinator to discuss a plan prior to being scheduled for a biopsy.

What is a MRCP (Magnetic Resonance Cholangiopancreatography)?

An MRCP is a special type of Magnetic resonance imaging (MRI) that specifically images the biliary and pancreatic ducts in a non-invasive manner. This test is an excellent tool for visualizing blockages in the ducts and pancreatic cysts. It can also diagnose bile duct stones or tumors.

What is a PTC (Percutaneous Transhepatic Cholangiography)?

A procedure that x-rays the hepatic and common bile ducts. This procedure is done under local anesthesia by a radiologist. During the exam, a thin needle is inserted through the skin (percutaneous) and through the liver (transhepatic) into a bile duct. Then contrast media is injected, and the bile duct system is outlined. If necessary, a thin, flexible tube (catheter) may be inserted to allow the bile to drain into a collection bag outside the body, or into the small intestine. This procedure is called biliary drainage. Drainage catheters may be placed to divert bile. Stones can be removed or balloon inserted to dilate strictures (narrowing of a duct or passage)

What is an ERCP (Endoscopic Retrograde Cholangiopancreatography)?

Endoscopic refers to the use of an instrument called an endoscope – a thin, flexible tube with a tiny video camera and light on the end. The endoscope is used by a highly trained gastroenterologist, to diagnose and treat various problems of the GI tract. The GI tract includes the stomach, intestine, and other parts of the body that are connected to the intestine, such as the liver, pancreas, and gallbladder. Retrograde refers to the direction in which the endoscope is used to inject a liquid enabling X-rays to be taken of the parts of the GI tract called the bile duct system and pancreas. The process of taking these X-rays is known as cholangiopancreatography. Cholangio refers to the bile duct system.

What is an Ultrasound with Doppler's?

The doppler allows the doctor to evaluate the blood flow through the arteries and veins of your abdomen. The scan can help diagnose obstructions in the blood flow to your liver as well as some problems in the organs.

What is a CT (CAT) scan (Computed Tomography Scan)?

CT scans use X-Ray technology and advanced computer analysis to create detailed pictures of your body. A CT can help diagnose problems in the liver, spleen, colon, pancreas, kidneys and other internal organs. Sometimes the exam includes a contrast dye. The dye improves the image quality by highlighting certain structures, such as arteries or the colon, making them more visible on the scan. The contrast is usually given by IV and in some cases may be given orally.

Over the Counter Medications

Symptoms	Recommendation
Headaches, fever & body aches	Acetaminophen (Tylenol®)
Sneezing, itching or runny nose	Loratadine (Claritin®), Cetirizine (Zyrtec®)
Nasal & sinus congestion	Nasal sprays: Oxymetazoline (Afrin®), Phenylephrine (Neosynephrine®), Sodium chloride (Ocean®), (SinuCleanse®), Pseudoephedrine (Sudafed®) <u>do not use Sudafed if you have high blood pressure</u>
Chest congestion	Guaifenesin (Robitussin®), Coricidin® HBP Chest Congestion & Cough
Productive cough	Guaifenesin (Robitussin®)
Dry cough	Dextromethorphan (Delsym®), Guaifenesin/Dextromethorphan (Robitussin DM®), Coricidin® HBP Chest Congestion & Cough
Sore throat	Lozenges
Constipation	Psyllium (Metamucil®), Docusate (Colace®), Docusate with senna (Senokot-S®), Bisacodyl (Dulcolax®), Polyethylene glycol (MiraLAX®), Senna
Diarrhea	Loperamide (Imodium AD®)
Insomnia	Diphenhydramine (Benadryl®), Doxylamine (Unisom®)
Stomach upset	Calcium carbonate (TUMS®)
Heartburn	Ranitidine (Zantac®), Famotidine (Pepcid AC®), Nizatidine (Axid®), Omeprazole (Prilosec OTC®)
Gas	Simethicone (Gas-X®)
Dry eyes and eye irritation	Artificial Tears, Ketotifen (Zaditor®)
Nausea & vomiting	Meclizine (Antivert®)
Joint pain	Capsaicin cream (Capzasin-P®)
Skin irritation, insect bites, poison ivy	Hydrocortisone (Cortisone-10®)

Medications You May Be Taking

ACYCLOVIR (ZOVIRAX®)

What is it for?

Acyclovir is used to prevent or treat Herpes Simplex Virus (HSV or 'cold sores') or Cytomegalovirus (CMV).

When do I take it?

Acyclovir is started around the time of transplant and continued for three months after the transplant. It is given 2-3 times daily depending on where you are in the course of your treatment.

How is it given?

This medication is given orally or intravenously.

What side effects might I experience?

Possible side effects may include headache, nausea, and vomiting.

What else do I need to know?

While taking this medication drink plenty of fluids. This medication can be taken with or without food.

AZATHIOPRINE (IMURAN®)

What is it for?

Azathioprine is an immunosuppressive drug that may be used post-transplant to prevent rejection.

When do I take it?

Azathioprine is given once daily and most patients will continue for life.

How is it given?

This medication is given orally or intravenously, depending on the condition being treated.

What side effects might I experience?

Possible side effects may include low white blood cell count and hair thinning.

What else do I need to know?

It is important that you tell your doctor if you are taking Allopurinol (a medicine sometimes used to treat gout).

SULFAMETHOXAZOLE / TRIMETHOPRIM (BACTRIM®, SEPTA®)

What is it for?

Bactrim® is an antibiotic that is used to prevent or treat Pneumocystis Jiroveci Pneumonitis (PJP) and bladder infections.

When do I take it?

Bactrim® is given once a day after transplant for 3 months.

How is it given?

This medication is given orally or intravenously.

What side effects might I experience?

Possible side effects may include a photosensitivity reaction (a sunburn-like reaction when exposed to sunlight), rash, and diarrhea.

What else do I need to know?

Bactrim® should be taken with a full glass of water. Drink plenty of fluids while taking Bactrim®.

CYCLOSPORINE (SANDIMMUNE®, NEORAL®, GENGRAF®, EON®, APOTEX®)

What is it for?

Cyclosporine is an immunosuppressive agent used to prevent rejection post-transplant.

When do I take it?

Cyclosporine is typically started 2-5 days after transplant. In most cases it is continued for a lifetime. It is given once or twice a day.

How is it given?

This medication is usually initially given intravenously. After several days, patients are usually switched to an oral formulary.

What side effects might I experience?

Possible side effects may include kidney problems, high blood pressure, leg cramps, gum tenderness/inflammation, and tremors.

What else do I need to know?

Avoid grapefruit, mandarins, pomegranates, and their juices; they will make the level of medication in your blood rise too high. Cyclosporine levels are measured using blood tests. Do not take your cyclosporine in the morning until after the blood test has been drawn on days they are due. There are two formulations of cyclosporine: Sandimmune and Apotex are one formulation. They are not to be substituted for Neoral, Sidmak, Gengraf, Eon or Plevia.

FLUCONZOLE (DIFLUCAN®)

What is it for?

Fluconazole is an antifungal medication that is used to treat or prevent fungal infections namely thrush. Thrush is a fungal infection in the mouth. It can also be in the esophagus.

How is it given?

This medication is given intravenously or orally.

When do I take it?

Fluconazole is taken by mouth once a week, on Mondays for the first two months after your transplant surgery.

What side effects might I expect?

Side effects include but are not limited to rash, headache, dizziness, nausea, vomiting, abdominal pain, diarrhea, elevated liver enzymes and/or change in ability to taste food.

MAGNESIUM

What is it for?

Magnesium is used as a supplement to replace natural magnesium stores which have been lost.

When do I take it?

The Transplant Team will monitor your magnesium levels and will determine if you need supplementation. The amount of supplementation you require will determine how often you receive it.

How is it given?

This medication, given as a supplement, is given orally or intravenously.

What side effects might I experience?

Possible side effects when given orally may include diarrhea; possible side effects when given intravenously may include flushing.

What else do I need to know?

It is important that you tell your doctor if you are taking any over the counter vitamin supplements. Report excessive diarrhea to your doctor.

MYCOPHENOLATE, MYCOPHENOLIC (CELLCEPT®, MYFORTIC®)

What is it for?

Mycophenolate is an immunosuppressive drug that may be used post-transplant. Mycophenolate may also be used to prevent further rejection after a first rejection occurs.

When do I take it?

Mycophenolate is given twice daily and most patients will continue throughout the lifetime.

How is it given?

This medication is given orally or intravenously, depending on the condition being treated.

What side effects might I experience?

Possible side effects may include nausea, vomiting, loss of appetite, diarrhea, and stomach cramps.

What else do I need to know?

It is important that you tell your doctor if you are taking any over-the-counter iron tablet supplements. Report excessive diarrhea to your doctor. This medication should be taken with food.

OXYCODONE (ROXICODONE®)

What is it for?

Oxycodone is an opioid analgesic used to treat or prevent moderate to severe pain.

When do I take it?

Oxycodone is given every 3 to 6 hours as needed and as directed by your doctor.

How is it given?

This medication is given orally.

What side effects might I experience?

Possible side effects may include drowsiness, dizziness, light-headedness, nausea, vomiting, headache, and constipation.

What else do I need to know?

Avoid alcohol, antihistamines, or other drugs that may intensify the drowsiness caused by oxycodone. It can be taken with or without food. Avoid driving or operating heavy machinery while taking oxycodone.

PENTAMIDINE

What is it for?

Pentamidine is used to prevent Pneumocystis Jiroveci Pneumonia (also called PJP).

When do I take it?

Pentamidine is given once a month for three months.

How is it given?

This medication is intravenously or inhaled into the lungs using a machine called a nebulizer.

What side effects might I experience?

Possible side effects may include nausea, vomiting, dizziness, headache, cough, rash, abdominal pain, diarrhea, and shortness of breath.

PREDNISONE (DELTASONE®)

What is it for?

Prednisone is used to prevent and treat acute rejection post-transplant.

When do I take it?

Prednisone is given once daily for lifetime or as determined by your doctor.

How is it given?

This medication is given orally, in the morning.

What side effects might I experience?

Possible side effects may include difficulty sleeping, mood changes, nervousness, increased appetite, and indigestion.

What else do I need to know?

Take this medication with food to prevent nausea. Do not abruptly stop taking prednisone unless you are told to do so by your doctor. Do not take calcium containing antacids (Tums) at the same time as prednisone.

OMEPRAZOLE (PRILOSEC®)

What is it for?

Omeprazole is used to treat or prevent heartburn and/or ulcers, which can be the result of the use of high dose or a prolonged duration of steroids.

How is it given?

This medication is given orally. It is usually dosed once or twice a day.

What side effects might I expect?

Side effects are rare but can cause headache, nausea, and diarrhea.

What else do I need to know?

Capsules should be swallowed whole, not chewed. Capsules may be opened and contents can be sprinkled over applesauce and consumed immediately.

SIROLIMUS (RAPAMUNE®)

What is it for?

Sirolimus is used to prevent or treat acute rejection post-transplant.

When do I take it?

Sirolimus is given once daily for lifetime or as determined by your doctor. Take Sirolimus at the same time each day and consistently with or without food.

How is it given?

This medication is only given orally.

What side effects might I experience?

Possible side effects may include low white blood cell and platelet counts, and high cholesterol.

What else do I need to know?

If you take the oral solution, mix it with milk, chocolate milk or orange juice to make it taste better. Stir it well and drink it all at once. Mix it in a glass container only (no plastic), and rinse the container to make sure you get the full dose. Do not stop taking sirolimus unless you are told to do so by your doctor. Sirolimus levels are measured using blood tests. Do not take your sirolimus in the morning until after the blood tests have been drawn on days they are due. Your cholesterol should be monitored while on this medication.

TACROLIMUS (PROGRAF®, FK506)

What is it for?

Tacrolimus is used to prevent or treat acute rejection post-transplant.

When do I take it?

Tacrolimus is given twice daily, 12 hours apart, in the morning and at night. Take tacrolimus at the same times each day and consistently with or without food.

How is it given?

This medication is given orally or intravenously, depending on the condition being treated.

What side effects might I experience?

Possible side effects may include headache, tremors, muscle cramps, diarrhea, nausea, high blood pressure, and kidney problems.

What else do I need to know?

Take with food to prevent nausea. Do not stop taking tacrolimus unless you are told to do so by your doctor. Tacrolimus levels are measured using blood tests. Do not take your tacrolimus in the morning until after the blood tests have been drawn on days they are due. Avoid grapefruit, mandarins, pomegranates, and their juices; they will make the level of medication in your blood rise too high.

VALGANCICLOVIR (VALCYTE®)

What is it for?

Valganciclovir is used to prevent and treat cytomegalovirus (CMV).

When do I take it?

Valganciclovir is given 1-2 times daily.

How is it given?

This medication is given orally.

What side effects might I experience?

Possible side effects may include headache, nausea, low white blood cell and platelet counts.

What else do I need to know?

Always take Valganciclovir with food; drink plenty of fluids

AMLODIPINE (NORVASC®)

What is it for?

Amlodipine is used to lower blood pressure that may be elevated by some anti-rejection medications.

How is it given?

Amlodipine is given orally.

When do I take it?

Take amlodipine once a day.

What side effects might I expect?

Side effects may include dizziness, fatigue, headaches, increased swelling in the legs or arms, or flushing. Amlodipine may increase your risk of developing chest pain or a heart attack; therefore you should contact your physician immediately if you are having chest pain while taking amlodipine.

CARVEDILOL (COREG®)

What is it for?

Carvedilol is used to lower blood pressure that may be elevated by some anti-rejection medications. Carvedilol may also slows heart rate and may be used for other indications such as irregular heartbeats. It may be used alone or in addition to other blood pressure reducing medications.

How is it given?

This medication is given orally.

When do I take it?

Carvedilol is typically taken twice a day and should be taken with food. An extended release formulation is available and is taken only once daily.

What side effects might I expect?

Side effects may include dizziness, fatigue, shortness of breath, headache, or depression.

INSULIN

What is it for?

Post-transplant diabetes is a “condition in which the body does not produce or properly use insulin”. The cause of post-transplant diabetes may be tied to environmental factors and/or genetics. In some types of diabetes it is related to Hepatitis C or being overweight, sometimes the cause is related to temporary effects from steroids [prednisone].

Insulin is a hormone which is made naturally in your body, in the pancreas. It helps to control the levels of sugar (glucose) in your blood. If your body does not make enough insulin, or if it does not use the insulin it makes effectively, this results in the condition called post-diabetes mellitus.

How is it given?

Insulin is given under your skin between 1 to 3 times a day.

When do I take it?

Before starting insulin, talk to your pharmacist and coordinator as well as the information you have been given by your diabetes clinic and educator.

Use your insulin exactly as your doctor tells you to. Your doctor or diabetes nurse will show you how to inject yourself with insulin. It is usually injected into your upper arms, thigh, buttocks or tummy (abdomen).

Your treatment will be tailored to your needs. It may consist of one or more types of insulin and the amounts you use will be carefully chosen to suit you. **Insulin doses are referred to in terms of units.** Make sure you know how many units to use - ask your doctor or nurse if you are unsure.

You will be told when to inject your doses, as different types of insulins are given at different times in relation to food. It is important that you inject your doses as you have been advised.

What side effects might I expect?

Make sure you know what it feels like if your blood sugar is low. This is known as **hypoglycemia**, or a 'hypo'. The first signs of hypoglycemia are: feeling shaky or anxious, sweating, looking pale, feeling hungry, having a feeling that your heart is pounding (palpitations), and feeling dizzy. If these happen you should eat or drink something containing sugar or have a snack, straightaway.

Foods with Magnesium and Phosphorus

Selected food sources of magnesium

FOOD	Milligrams (mg)	% Daily Value
Halibut, cooked, 3 ounces	90	20
Almonds, dry roasted, 1 ounce	80	20
Cashews, dry roasted, 1 ounce	75	20
Soybeans, mature, cooked, ½ cup	75	20
Spinach, frozen, cooked, ½ cup	75	20
Nuts, mixed, dry roasted, 1 ounce	65	15
Cereal, shredded wheat, 2 rectangular biscuits	55	15
Oatmeal, instant, fortified, prepared w/ water, 1 cup	55	15
Potato, baked w/ skin, 1 medium	50	15
Peanuts, dry roasted, 1 ounce	50	15
Peanut butter, smooth, 2 Tablespoons	50	15
Wheat Bran, crude, 2 Tablespoons	45	10
Black-eyed Peas, cooked, ½ cup	45	10
Yogurt, plain, skim milk, 8 fluid ounces	45	10
Bran Flakes, ½ cup	40	10
Vegetarian Baked Beans, ½ cup	40	10
Rice, brown, long-grained, cooked, ½ cup	40	10
Lentils, mature seeds, cooked, ½ cup	35	8
Avocado, California, ½ cup pureed	35	8
Kidney Beans, canned, ½ cup	35	8
Pinto Beans, cooked, ½ cup	35	8
Wheat Germ, crude, 2 Tablespoons	35	8

Selected food sources of phosphorus

FOOD	Serving	Phosphorus (mg)
Mac and Cheese	1 cup (from mix/from scratch)	400 / 322
Liver and organ meats	3.5 ounces	400
Yogurt, plain nonfat	8 ounces	385
Pancakes, made from mix	3 4-inch pancakes	368
Yogurt (no added probiotics)	1 cup	326
Pudding, made with low-fat milk	½ cup	313
Dried beans and peas	1 cup, after boiling	266
Fish, salmon	3 ounces, cooked	252
Fish, halibut	3 ounces, cooked*	242
Milk, skim	8 ounces	247
Pizza (cheese and pepperoni)	1 slice	234
Ice cream, low fat	1 cup	200
Peanut butter	3 Tablespoons	180
# Lentils	½ cup, cooked	178
Beef and Turkey	3 ounces, cooked*	173
Cheese, low fat	1 ounce	171
Cream soup, made with low-fat milk	1 cup	160
Chicken	3 ounces, cooked*	155
Biscuit, made from mix	1	140
# Almonds	1 ounce (23 nuts)	134
Cheese, mozzarella; part skim	1 ounce	131
# Peanuts	1 ounce	107
Egg	1 large, cooked	104
Bread, whole wheat	1 slice	57
Bread, enriched white	1 slice	25

*A 3-ounce serving is about the size of a deck of cards.

#Phosphorus from nuts, seeds, and grains is about 50% less bioavailable than from other sources



Laboratory Tests that Monitor Liver Function

Test	Normal Range*	Function	Indicates
Total Bilirubin (T Bili)	0.1 – 1.2	A substance made from the breakdown of hemoglobin; red blood cells are trapped and destroyed in the spleen as they wear out. When these cells are destroyed, bilirubin is released into the blood. The liver then processes this bilirubin, combines it with another substance, and excretes the bilirubin through bile. Bile flows from the individual liver cells, through the bile ducts, and into the intestine where it leaves the body in the feces. The characteristic brown color of feces is due to bile.	<p>↑ Bile duct obstruction.</p> <p>↑ May be a sign of rejection or infection.</p>
Alkaline Phosphatase (Alk Phos)	45 – 129	An enzyme produced by the liver (and other) cells; elevated blood levels of this substance may indicate abnormal function of the liver or other organs.	<p>↑ Bile duct obstruction.</p> <p>↓ Malnutrition.</p>
Alanine Transaminase (SGPT or ALT)	9 – 57	Enzyme which occurs in high concentration in the liver.	↑ Liver injury, rejection, biliary obstruction, mononucleosis, pancreatitis, myocardial infarction, severe burns, trauma.
Aspartate Transaminase (SGOT or AST)	14 – 44	Enzyme present in tissues with high metabolic activity, including the heart, liver, muscles, kidney, brain, pancreas, lungs.	↑ Liver injury, rejection, myocardial infarction, pancreatitis, trauma.
Gamma Glutamyl Transferase (GGT)	9 – 59	Enzyme present mainly in the liver, kidney, prostate and spleen.	↑ Liver injury, rejection, bile duct obstruction.
Albumin (Alb)	3.5 – 5.0	A protein made by the liver that helps maintain fluid balance in the body.	↓ Malnutrition.
Total Protein (TP)	6 – 8.4	Total of multiple types of proteins found in the blood. They are a source of nutrition and a buffer system.	↓ Malnutrition, chronic liver dysfunction.

Tests that Monitor Kidney Function & Electrolytes

Test	Normal Range*	Function	Indicates
Blood Urea Nitrogen (BUN)	7 – 23	BUN is a product of protein breakdown, or a waste product, normally excreted by the kidney.	<p>↑ Kidney dysfunction, dehydration, high protein diet, side effect of some anti-rejection medications.</p> <p>↓ Liver disease, over-hydration.</p>
Creatinine (Cr)	0.6 – 1.1	Creatinine is a waste product produced by the muscles and released into the blood stream.	<p>↑ Kidney dysfunction, side effect of some medications, dehydration.</p> <p>↓ Muscle wasting.</p>
Sodium (Na)	131 – 142	A mineral needed by the body to keep body fluids in balance.	↓ Side effect of diuretics; kidney dysfunction.
Potassium (K+)	3.5 – 5.0	A mineral required for normal body functioning; important in helping the heart, nerves, and muscles function properly; helps change carbohydrates into energy and in forming proteins.	<p>↑ Kidney dysfunction, side effect of some medications.</p> <p>↓ Side effect of diuretics; decreased intake, vomiting.</p>
Magnesium (Mg++)	2 – 2.6	Mineral required for normal bodily function; involved in nerve, skeletal muscle, heart, and cell function; also involved in blood clotting and the metabolism of carbohydrates and proteins.	<p>↑ Kidney dysfunction.</p> <p>↓ Diarrhea; side effect of medications.</p>
Glucose (Glu)	71 – 109	A type of sugar in the blood that supplies energy to the cell; glucose levels vary with diet, medications, stress, and organ dysfunction.	<p>↑ Diabetes, pancreas problem, side effect of some medications.</p> <p>↓ Occurs in liver disease or with thyroid problems.</p>
Calcium (Ca++)	8.4 – 10.4	A mineral measured in the blood that is required for bone growth and for blood clotting; also needed for the heart and nerves to function.	<p>↑ High intake of calcium; bone disorders, thyroid problem.</p> <p>↓ Kidney dysfunction, over hydration, problems with the pancreas, severe malnutrition.</p>

Complete Blood Count (CBC)

Test	Normal Range*	Function	Indicates
White Blood Count (WBC)	4.4 – 10.8	Cells that fight infection; also involved in the rejection process.	<p>↑ May indicate infection.</p> <p>↑ Side effect of some medications, stress</p>
Hematocrit (hct)	<p>Males 40-54%</p> <p>Females 37-47%</p>	Measures the percentage of oxygen-containing red blood cell (RBC).	<p>↑ May cause blood clotting.</p> <p>↓ May be a sign of anemia.</p>
Hemoglobin (Hgb)	<p>Males 12-18</p> <p>Females 12-16</p>	The oxygen-containing part of the red blood cell (RBC)	<p>↑ May indicate dehydration or a blood disorder.</p> <p>↓ Can be a sign of anemia.</p>
Platelets (Plt)	150,000 – 350,000	Component of blood that helps stop bleeding	<p>↑ Can make your blood “thick” and lead to clotting.</p> <p>↓ May be a sign of liver disease, bleeding, anemia.</p>



Weekly Diabetes Record

Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood Sugar									
Insulin Dose									
Extra dose									
Phys. Activity									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood Sugar									
Insulin Dose									
Extra dose									
Phys. Activity									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood Sugar									
Insulin Dose									
Extra dose									
Phys. Activity									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood Sugar									
Insulin Dose									
Extra dose									
Phys. Activity									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood Sugar									
Insulin Dose									
Extra dose									
Phys. Activity									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood Sugar									
Insulin Dose									
Extra dose									
Phys. Activity									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood Sugar									
Insulin Dose									
Extra dose									
Phys. Activity									



Definitions

Acute Short, relatively severe.	Bacteria Germs that can cause disease or infection.
Albumin A protein made by the liver that helps maintain fluid balance in the body.	Bile A fluid produced by the liver, stored in the gallbladder, and released into the small intestine to help absorb dietary fats.
Alkaline Phosphatase (Alk Phos) An enzyme produced by the liver (and other) cells; elevated blood levels of this substance may indicate abnormal function of the liver or other organs.	Bile Duct The tubes through which bile flows.
Analgesic Pain medicine.	Bile Leak A hole in the bile-duct system that causes bile to spill into the abdominal cavity.
Anemia A low number of red blood cells.	Biliary Stenosis Narrowing or constriction of a bile duct.
Anesthetic Medication that dulls sensation in order to reduce pain.	Biliary Tree All passageways inside and outside the liver that carries bile to the intestines.
Antacid A drug that aids in protecting the digestive system and relieves heartburn and digestive discomfort.	Bilirubin A chemical that is excreted by the liver in the bile.
Antibody A part of the immune system that fights infection or foreign organisms or tissue.	Bladder The organ that receives and stores urine from the kidneys until it is urinated out of the body.
Antigen The “marker” that starts antibody production.	Blood Urea Nitrogen A waste product excreted by the kidney.
Arteriosclerosis A hardening of the arteries that blocks blood flow to the kidneys.	Cadaveric Donor A recently deceased organ donor.
B Cells A type of lymphocyte, or white blood cell that develops in the spleen that is responsible for the body’s immunity; B cells produce antibodies.	Calcium A mineral measured in the blood that is required for bone growth and for blood clotting; also needed for the heart and nerves to function.



Catheter

A soft rubber tube that is inserted into the bladder to drain urine.

Cellcept

An immunosuppressive drug used to limit or reverse rejection.

Cholangiogram

A test that examines the bile ducts in the liver for any leaks or blockages.

Cholangitis

A bacterial infection in the bile ducts.

Cholestasis

An accumulation of bile in the liver caused by medications, an injury to the liver, liver disease, total parenteral nutrition (TPN), or gallstones.

Cholesterol

A kind of fat that is necessary for bodily function, but that in excess can cause heart disease.

Chronic

Persisting over a long period of time.

Chronic Renal Insufficiency

Permanent damage to both kidneys, treated by dialysis or transplantation.

Cirrhosis

A disease causing irreversible scarring of the liver.

CMV (Cytomegalovirus)

A virus infection that is common in transplant recipients; it can affect the lungs and other organs as well; a member of the family of herpes viruses.

Coagulation

The process of blood clotting. The ability to clot is measured by the prothrombin time (PT), partial thromboplastin time (PTT) and platelet count.

Coagulopathy

Abnormal blood clotting.

Complete Blood Count (CBC)

A blood test that measures components of the blood including hemoglobin (Hgb), hematocrit (Hct), platelets (Plt), and the types of white blood cells (WBC).

Corticosteroids

A category of immunosuppressive medications that includes prednisone and prednisolone.

Creatinine

An indicator of kidney function, produced by muscle metabolism; the higher the creatinine level, the lower the kidney function.

Crossmatch

A test that determines the compatibility of the donor's blood with that of a potential recipient.

CT Scan

A 3-dimensional x-ray of internal organs.

Cyclosporine

A powerful immunosuppressive drug.

Cyst

A sac-like structure that contains fluid and matter.

Cytomegalovirus (CMV)

A common viral infection that can be harmful to transplant recipients if contracted after transplant.

Diabetes

A disease characterized by high levels of blood sugar.

Diabetic Nephropathy

Kidney failure as a result of diabetes.

Dialysis

A process by which blood is cleaned to restore a chemical balance.



Diastolic Blood Pressure

The bottom number when the blood pressure is measured; this is the pressure on the arteries between heart beats.

Echocardiogram

A test that uses beams of ultrasonic waves to measure the motion and position of the heart and nearby tissue.

Edema

Swelling of a specific area of the body, such as the hands or legs, due to retention of excess fluids.

EGD (esophagogastroduodenoscopy)

A diagnostic endoscopic procedure that visualizes the upper part of the GI tract to the duodenum.

Electrocardiogram

A test that uses electrodes placed on the chest to measure the heart rhythm and look for injury to heart tissue.

Electrolyte

A dissolved mineral, such as magnesium or potassium.

Endoscope

A small telescope-like instrument that is used to examine the esophagus, stomach and small intestine.

Endotracheal Tube

A tube inserted through the mouth and into the windpipe to aid a person in breathing during surgery.

Enzyme

A bodily protein that can break down other substances.

ERCP

Endoscopic retrograde cholangiopancreatogram; test that examines the drainage system or ducts of the gallbladder, pancreas, and liver (the biliary tree).

Fibrosis

The presence of fibrous tissue in the liver that causes scarring and liver dysfunction; fibrosis develops into cirrhosis.

Gallbladder

A muscular sac attached to the liver; stores bile. This is removed during transplant.

Gastroenterologist

A doctor who specializes in the diagnosis, treatment, and management of diseases of the digestive system, including the liver.

Gastrointestinal (GI)

The tract between the mouth and the rectum, including the intestines and stomach.

Glomerular Filtration Rate (GFR)

A test that determines the level of kidney function.

Glucose

Sugar found in the blood or urine.

Graft

A transplanted tissue or organ, such as a liver.

Helper T-cell

The white blood cell that tells the immune system to fight infection or foreign substances, such as a transplanted tissue.

Hematocrit

The measure of the number of red-blood cells in the blood.

Hematoma

A bruise or swelling caused by the accumulation of blood in tissue.

Hemoglobin

A substance in red blood cells containing iron and protein that gives blood its characteristic red color; carries oxygen from the lungs to the tissues and carbon dioxide from the tissues to the lungs.



Hepatic

Relating to the liver.

Hepatitis

Liver inflammation, usually caused by a virus.

Hepatologist

A physician who studies the liver and treats liver disease.

Hepatomegaly

An enlarged liver.

Herpes

A family of viruses that can cause lip, genital sores, or other symptoms.

Hirsutism

Excessive hair growth; a common side effect of cyclosporine seen in both male and female transplant recipients who receive cyclosporine.

Human Leukocyte Antigens (HLA)

Genetic markers, inherited from one's parents.

Human Leukocyte Antigen (HLA) Compatibility

A test done on the donor and the potential recipient to determine how actively the recipient's cells would attack the graft.

Hypertension

High blood pressure.

Hypotension

Low blood pressure.

Immune System

Complex fighting mechanism of the body that responds to foreign organisms or tissues that enter or are placed in the body.

Immunosuppression

Decrease of the body's immune response, accomplished through the use of certain drugs, in order to help prevent or control a rejection following a transplant.

Immunosuppressive Agents

Medications taken to prevent rejection of a transplanted organ.

Insulin

A hormone produced by the pancreas that regulates blood sugar levels.

Intravenous (IV)

Refers to fluids or medications administered to patients directly into a vein via a needle or catheter.

Jaundice

Yellowish discoloration of the skin and eyes indicating an excess of bilirubin in the blood.

Kidney

Organs located on both sides of the spine at waist level that rid the body of waste materials via the production of urine.

Leukocyte

A white blood cell that helps fight infection.

Liver Enzymes

Substances produced by the liver and released into the blood; these are measured to assess liver function.

Liver Function Tests (LFTs)

Blood tests used to determine how well the liver is functioning; includes the ALT, AST, GGT, bilirubin, and alkaline phosphatase.

Lymphocyte

Cells produced by the lymph glands that are responsible for immunity and defending the body against infection and foreign substances by producing antibodies and other substances.



MRCP (Magnetic Resonance Cholangio-pancreatography)

An alternative for Endoscopic retrograde cholangio-pancreatogram; test that examines the drainage system or ducts of the gallbladder, pancreas, and liver (the biliary tree) using an MRI.

Nephrologist

A physician who specializes in diagnosing and treating kidney disease.

Neutrophil

A type of white blood cell.

Noncompliance

Failure to follow health care instructions regarding taking medications and treatments, getting tests on time, and taking vital signs; noncompliance often shortens the lifetime of the transplanted organ(s).

Orally

By mouth.

Phlebotomy

Removal of approximately one pint of blood through a vein.

Platelet

A small blood cell necessary for clotting.

PTLD

Post-transplant lymphoproliferative disease; a wide spectrum of viral disorders associated with the Epstein Barr Virus (EBV) that may range from a self-limiting mononucleosis (“mono”) to a type of lymphoma, or cancer of the lymph nodes; a complication of a suppressed immune system; Treatment includes lowering immunosuppression and administering antiviral medications.

Pneumocystis Jiroveci Pneumonia (PJP)

A type of pneumonia that is mostly contracted by individuals with suppressed immune systems.

Potassium

A mineral; high potassium levels can irritate the heart and is a problem often associated with poor kidney function.

Prophylactic Medication

Medication taken to help prevent disease.

Red Blood Cells

The part of the blood that transports oxygen to body tissues.

Rejection

When the immune system attacks what it thinks is a foreign substance (such as a transplanted liver).

Renal

Anything regarding the kidneys.

Sepsis

A severe infection that has spread to the blood stream.

Shingles

A herpes virus infection that usually affects a nerve, causing localized pain.

Signs

Things you or someone else can see that are determined by measurement, such as in increase in temperature or blood pressure.

Sodium

The main salt that is found in blood.

Stenosis

Narrowing of a passage in the body (also known as “stricture”).

Systolic Blood Pressure

The top number when the blood pressure is measured. This is the pressure when the heart muscle contracts.



Symptoms

Things you feel, such as pain, dizziness or fatigue.

T Cells

White blood cells that play a major part in rejection.

T-Tube

A tube placed in the bile duct that allows bile to drain into a bag outside the body.

Thrombosis

The development of a blood clot.

Thrush

A fungal infection found in the mouth.

Tissue Typing

Identifying a person's major antigens used to evaluate the match between a donated organ and a potential recipient via a blood test.

Toxins

Waste products in the blood that are poisonous to the body in high concentrations.

Turcotte Tube

A tube placed in the bile duct that allows bile to drain into a bag outside the body.

Ultrasound

A method of picturing internal organs using sound waves. It is often used to detect masses, abscesses, organ size, or blood flow to a transplanted organ.

Ureter

One of a pair of tubes that carries urine elimination.

Urethra

The tube from the bladder which carries urine out of the body.

Urinary Catheter

A soft rubber tube that is inserted into the bladder to drain urine.

Urinary Tract

The body system that produces, transports, stores and eliminates urine; the urinary tract includes the kidneys, ureters, bladder and urethra.

United Network for Organ Sharing (UNOS)

The national body that sets policies for organ allocation in order to ensure fairness; UNOS also maintains statistics on different transplant programs and collects scientific data on transplant recipients and donors.

Virus

A small germ that causes infection.

Wean

To slowly withdraw or reduce; immunosuppression, particularly steroids, may be weaned slowly over time in patients who have stable function of the transplanted liver.

White Blood Cells

The part of the blood that fights infection.



Web Resources

American Cancer Society “Stay Healthy”

<https://www.cancer.org/healthy/find-cancer-early.html>

American Liver Foundation

<http://www.liverfoundation.org/>

1425 Pompton Avenue, Cedar Grove, NJ 07009
(800) 223-0179

American Organ Transplant Association (AOTA)

<http://www.aotaonline.org/>

PO Box 441766, Houston, Texas 77244
(281) 493-2047

American Society of Transplantation

<https://www.myast.org/>

Mainly geared toward medical professionals. Contains some patient educational brochures.

Insulin Free World Foundation

<http://www.insulinfree.org>

Information on technologies and research geared toward finding a cure for diabetes. Includes extensive information on pancreas transplant.

National Association of Boards of Pharmacy

<https://nabp.pharmacy/>

Information on legitimate online pharmacies

National Foundation for Transplants

(Formerly Organ Transplant Fund)

www.transplants.org

1102 Brookfield, Suite 200, Memphis, TN 38119
(800) 489-3863

National Transplant Assistance Fund

<https://helpholive.org/>

The financial side of organ transplantation, including advice to patients about raising funds for their transplants.

Needy Meds

<http://www.needymeds.com>

Links to drug assistance programs.

OHSU Transplant Medicine Web Site

<http://www.ohsu.edu/transplant/>

Information about the OHSU transplantation program, news clips, and videos on transplantation.

Organ Donor Program

<https://www.donatelifenw.org/>

Provides information on organ and tissue donation.

Transplant Recipients International Organization

<https://www.trioweb.org/>

7055 Heritage Hunt DR, #307
Gainesville, VA 20155
(800)-874-6386

TransWeb

<http://www.transweb.org>

Links to transplant-related sites and information for living donors.

United Network for Organ Sharing (UNOS)

<http://www.unos.org>

Information designed for the transplant recipient and living donor.

