

# You and your liver transplant:

# A handbook for patients and their families

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# General information

# **Important contacts**

Contact	Phone
My post-transplant coordinator:	503-494
	800-452-1369 ext
My social worker is:	
OHSU transplant office	503-494-8500
Weekdays 8 a.m 4 p.m.	800-452-1369 ext. 8500
	Fax: 503-494-5292
Urgent issues DURING open hours	503-494-8500
Weekdays 8 a.m 5 p.m.	Ask for a post-transplant coordinator
Urgent issues AFTER hours	503-494-8311
Nights, weekends, holidays, etc.	888-222-6478
EMERGENCIES ONLY	Say you are a liver transplant patient
	who needs to talk to a health care
	provider.
OHSU Pharmacy	503-346-3370
OHSU Laboratory	503-494-7383
OHSU MyChart	503-494-5252

# **Mailing address**

 $OHSU\ Clinical\ Transplant\ Services$ 

Liver Transplant Program

Mail code: L590

3181 S.W. Sam Jackson Park Road

Portland, Oregon 97239-3098

# What to do once you get home

You may be worried about all the new things you need to know about your health. It is a normal feeling, and we don't expect you to know it all right away. That's why we created this guide. You can read through it, write down any questions and discuss them with your transplant team. Please **ALWAYS ask us questions if you do not understand something**. We are here to help you return to an active life in family, work and play.

Start following these 5 steps as soon as you get home from the hospital.

- 1. Every day, write down your blood pressure and blood glucose (if we ask you to) in the forms in the Reference section.
- 2. **Take your medications**. The #1 reason why transplants fail is because patients do not follow their medication routine. Take all your medications as prescribed.
- 3. Go to the lab on schedule and learn what your lab results mean.

Routine lab schedule	
First 3 months — all labs will be done the first 3 months at OHSU	Monday, Thursday at OHSU
After 3 months	Monday
After 6 months	Every other Monday
After 1 year	Every 3 months

- 4. **Go to your clinic on schedule**. For the first 4 weeks, you will go to the OHSU liver transplant clinic 1 time a week. You will go less often once you are stable. Bring this guide and any questions to your clinic visits. We will look over your surgical wound, remove your staples when ready and talk to you about any medication changes.
- 5. Please call if you have any questions.

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# Labs and blood tests

Blood tests are extremely important! They tell us if your liver is being rejected or if you are having side effects from the drugs.

#### 5 things to know:

- 1. Have your blood drawn in the **morning** so you can get your results that day.
- 2. You must get your labs done at OHSU for the first 3 months after transplant.
- 3. After the first 3 months, you can start going to the lab of your choice. Our office will send lab orders to your new lab.
- 4. These orders will give the lab permission to release the results to you. They will also fax the results to our office.
- 5. Learn what the numbers mean and what is normal for you. We will NOT call you if your liver transplant numbers are normal for you.

# Drug level blood tests

# If you take Tacrolimus or Cyclosporine\*

On the day of your drug level blood test:

- Take your medication about **12 hours before** your blood draw. Your blood draw must be between 11 ½ and 12 ½ hours AFTER you take that dose.
- Do NOT take your next dose until after your blood draw.

# If you take Rapamune\*

On the day of your drug level blood test:

- Take your medication 20 24 hours before your blood draw.
- Do NOT take your next dose until after your blood is draw.

# \* If you cannot get your blood drawn within the right time frames:

- Do **NOT** get a drug level blood test, and
- > Tell your transplant coordinator.

#### Labs

#### The OHSU lab

The lab is on the 3rd floor of OHSU Physicians Pavilion. There are also labs at Center for Health and Healing Buildings 1 and 2. To get your test results:

 Sign up for OHSU MyChart to see your results online. Go to www.ohsu.edu/mychart.

Hours change on holidays and weekends, so be sure to check with the lab staff.

# If you use a non-OHSU lab

You and your transplant team must watch your lab work closely.

Routine lab schedule	
First 3 months — all labs will be	Monday, Thursday at OHSU
done the first 3 months at OHSU	
After 3 months	Monday
After 6 months	Every other Monday
After 1 year	Every 3 months

#### Normal blood test values

Every lab has slightly different normal ranges for blood tests. On this page, we've listed the normal values OHSU uses for patients who have not had a transplant. Please use them only as guidelines. Every transplant patient has their own normal.

We will help you understand your results and define what your baseline (starting point) is. Many times, labs will run other tests along with the ones we've listed.

Lab test	Normal range
Total Bilirubin (T Bili) The level of bilirubin (yellowish substance that travels through your liver) in your blood. Too high could be a sign of an obstruction, rejection or infection.	0.1 - 1.2
Alkaline Phosphatase (Alk Phos) The level of an enzyme your liver makes. Could be a sign of the liver or other organs not working right.	45 - 129
Alanine Transaminase (SGPT or ALT)  The level of an enzyme in your liver. Too high could be a sign of liver injury, rejection or obstruction.	9 - 57
Aspartate Transaminase (SGOT or AST)  The level of an enzyme in many of your organs. Too high could be a sign of liver injury or rejection.	14 - 44
Gamma Glutamyl Transferase (GGT) The level of an enzyme found in your liver and other organs. Too high could be a sign of an obstruction, rejection or infection.	5 - 59
Albumin (Alb) The level of a protein made by your liver. Too low could be a sign of malnutrition.	3.5 - 5.0
<b>Total Protein (TP)</b> The level many proteins found in your blood. Too low could be a sign of your liver not working right or malnutrition	6 - 8.4

Glucose (Blood Sugar) The level of sugar (glucose) in your blood.	71 - 109
Blood Urea Nitrogen (BUN) The level of nitrogen (a waste product of protein use) in your blood.	7 - 23
Creatinine (Cr) The level of creatinine (a waste product of muscle metabolism) in your blood.	0.6 - 1.1
Sodium (Na) A mineral needed to keep body fluids in balance.	131 - 142
Potassium (K) A mineral needed for muscles to work properly. This includes the heart.	3.5 - 5.0
Magnesium (Mg) A mineral needed for normal bodily function.	2.0 - 2.6
Calcium (Ca++) A mineral needed for properly working muscles, nerves, heart, blood clotting, strong bones and teeth.	8.4 - 10.4
White Blood Count (WBC) Special blood cells that help the body fight infection.	4.4 - 10.8
Hematocrit (Hct) The % of red blood cells in your blood. The red cells carry oxygen and carbon dioxide throughout the body.	Men: 40 - 54% Women: 37 - 47%
Platelet (Plt) Special blood cells that help your blood clot.	150,000 - 350,000
Hemoglobin (Hgb) Oxygen part of the red blood cell	Men: 12 - 18 Women: 12 - 16

# **Daily medications**

You need to take medications each day for the life of your new liver. This will help prevent your body from rejecting your liver.

- NEVER stop taking or miss these medications. It could risk rejecting your new liver.
- You may need to take other medications, too.
- Before you leave the hospital, a pharmacist will give you a list of medications and a schedule for when you should take them.
- We will teach you what the medications look like, what amounts to take, what they are for, and what side effects they may cause.

# Changes will happen often

- We will call you at home or send you MyChart messages to tell you about any medication changes.
- Write down any changes we ask you to make on your medication list.
- ALWAYS take your medication the way it says to on your medication list.
- When we give you a new medication list, be sure to destroy any old lists.

# You MUST take your medications at the correct time each day

- Set up a check system so you don't forget whether you took your pills or not.
- It may help to schedule around meals and bedtime.

#### Who manages your medications

OHSU will manage your immunosuppression medications for life. If your primary care physician wants to make any changes to these medications, please ask them to contact the OHSU transplant office. After 3 months, your primary care provider will manage all medications except for your immunosuppression.

#### Side effects

Medications can have side effects. We have a list of medications and their most common side effects for transplant patients, in the Reference section. If you have any problems with any of the medications you are taking, call us at 503-494-8500. NEVER change your dose of these medications without talking to your transplant team first.

# Prescription dos and don'ts

#### Do

- ✓ Call your regular pharmacy for medication refills.
- ✓ Keep the name and phone number of your local pharmacy handy.
- ✓ Call the OHSU transplant office if you have a problem with your immunosuppression prescriptions.
- ✓ Give the OHSU transplant office your list of allergies.
- ✓ Give your local pharmacist our phone number (503-494-8500) for refills.
- ✓ Ask for refills when you are seen in the transplant clinic.

#### Don't

- $\odot$  Go to the transplant floor for refills.
- Run out of medication before getting refills.
- $\bigcirc$  Wait until the weekend or after 3 p.m. to call for refills.

# Warnings

- Do **NOT** take any herbs or supplements without talking to your transplant doctor first. They can interact badly with your transplant medications. Transplant patients should **NEVER** take medications or herbs that claim to "boost" the immune system.
- Do **NOT** take ibuprofen, Motrin, Aleve, naproxen or any other NSAID (Non-steroidal Anti-inflammatory Drugs), unless your transplant team tells you to.
- Do NOT eat or drink grapefruit, grapefruit juice, mandarin oranges, orange marmalade, pomegranates and pomegranate juice. They will make the level of your immune suppression 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 your OHSU transplant team.

# Pain management and opioids

We will prescribe oxycodone to you after your transplant. It is an opioid that will help you with your pain. We will help you wean down off it within 8 weeks.

- If you were on long-term pain medicine (such as methadone, oxycodone or suboxone) before your transplant, you will need to tell the doctor who prescribed it that you will also be taking oxycodone.
- The OHSU transplant team does NOT prescribe methadone or suboxone.
- If you need more pain medicine after 8 weeks, you will need to work with your primary care provider or a pain clinic.

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# What you should eat right after your transplant

# Calories and protein

You need to eat extra calories and protein right after your transplant. Good nutrition helps your body:

- Heal your surgical wounds
- · Keep muscle strength
- Fight infection

If you take prednisone, you need to eat more protein. This medication can cause muscle loss. Protein helps you build muscle. It is in foods like eggs, meat, fish, poultry, milk, cheese, yogurt, beans, nuts and seeds.

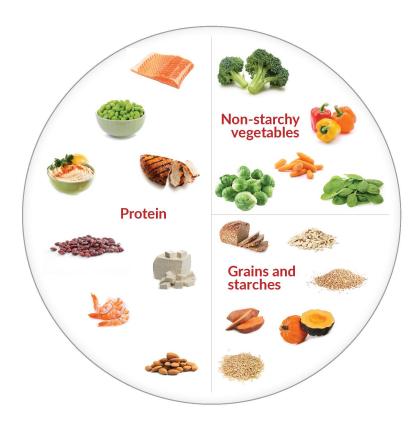
# Right after transplant surgery:

- You should eat \_\_\_\_\_ grams of protein each day.
- You should eat \_\_\_\_\_ calories each day.

# 8 weeks after surgery:

- You will no longer need a high protein diet. You should eat at least \_\_\_\_\_ grams of protein each day.
- Your dietitian may change the amount of calories you should eat based on how much activity you get.

# A healthy plate for the first 2 months after transplant



Use the plate method of eating, where ½ your plate is protein, ¼ is non-starchy vegetables and ¼ is starchy food like whole grain bread, pasta, rice, cereal or starchy vegetables.

# **High-protein foods**

Protein Food	Portion Size	Protein Grams
Meat, cooked:		
Chicken breast	3 oz	26
Hamburger, lean	3 oz, 1 patty	18
Pork chop	3 oz	24
Steak, lean	3 oz	26

Protein Food	Portion Size	Protein Grams	
Fish, cooked:			
• Fillet	3 oz	15	
Salmon patty	3 oz, 1 patty	15	
Fish, canned:			
Tuna or Salmon	1 oz	7	
Anchovies, sardines	1 oz	7	
Shellfish, cooked:	Shellfish, cooked:		
• Crab	1 oz	6	
Scallops, steamed	1 oz	7	
Shrimp	1 oz	6	
Beans, cooked:	Beans, cooked:		
<ul> <li>Kidney, black, garbanzo,</li> </ul>	½ cup	7	
pinto			
Lentils, split peas	½ cup	8	
Cheese:			
Cottage cheese	¼ cup	6	
<ul> <li>Soft (goat, mozzarella)</li> </ul>	1 oz	5	
<ul> <li>Hard (cheddar, Swiss)</li> </ul>	1 oz	7	
Ricotta	½ cup	7	
String cheese	1 oz (1 stick)	7	
Milk:			
• Whole, 2% 1%, skim or soy	1 cup	8	
Non-fat, powdered	½ cup	10	
Yogurt:			
Greek	5.3 oz	12-18	
Regular	5.3 oz	5-6	

Protein Food	Portion Size	Protein Grams
Nuts and seeds:		
<ul> <li>Peanuts, almonds, sunflower</li> </ul>	1 oz	6-7
<ul> <li>Cashews, flaxseed (ground), walnuts</li> </ul>	1 oz	4-5
Nut butters	2 Tablespoons	5-8
Protein drinks:		
Ensure Clear, Glucerna	8 oz	8-10
Isopure Plus	16 oz	20
<ul> <li>Boost High Protein, Boost Plus, Ensure Plus</li> </ul>	8 oz	13-16
Boost VHC, Nepro	8 oz	19-22
Premier Protein Shakes	11 oz	30
Carnation Instant     Breakfast with 1 cup milk	8 oz	13
Other:		
Whey protein powder     (protein depends on brand)	1 oz	12-20
• Egg	1 large	6
Quinoa, cooked	1 cup	8
Tempeh	1 oz	5
Tofu (soft, firm, extra firm)	3 oz	5-9

# How to eat more protein

- Eat 5-6 small meals and snacks during the day instead of 3 large meals. Try to have:
  - o 20+ grams of protein at each meal
  - $\circ$  8+ grams of protein at each snack
- Eat Greek yogurt instead of regular yogurt. Greek yogurt has 2 times the protein of regular yogurt.
- Add diced meat, beans, cheese, nuts or seeds to salads, casseroles or soups.
- Spread nut butters or hummus on low sodium crackers, toast, or raw fruits and vegetables.

- Keep ready-made protein-rich foods like hard-boiled eggs, cheese sticks, single- serving yogurts, unsalted nuts and trail mix on hand for easy snacks.
- Add a glass of milk or protein drink to your meals or as a snack.
- Add protein powder or powdered milk to casseroles, soups or oatmeal.
- Try cottage cheese or ricotta cheese with fruit, vegetables or mixed into casseroles.
- Make your own smoothie using milk, Greek yogurt, protein powders, nut butters or tofu.
- Eat whole grains such as quinoa and high protein cereals.

#### Foods NOT to eat

Some foods may interfere with your immunosuppressant medications, especially tacrolimus (Prograf) and cyclosporine. For this reason, **do NOT eat**:

- Grapefruit and grapefruit juice
- Mandarin oranges (also satsumas, clementines, tangerines and blood oranges)
- Pomegranate and drinks with pomegranate juice
- Starfruit
- Herbal dietary supplements

# Carbohydrates

Some of the medications you are taking may raise blood glucose (blood sugar) levels. Carbohydrates in foods can also raise your blood glucose levels. If you have too much sugar in your blood for a long time, it can cause serious health problems such as heart disease, stroke, kidney disease, eye problems and nerve problems.

You can keep your blood glucose levels in control by learning which foods to include in your meals and snacks. Also, limit simple sugars in your diet such as regular soda, juice, sugar, syrups and candy.

Foods with Carbohydrates	Foods with Little or No Carbohydrates
Fruit and fruit juice	Most vegetables
Starches – grains, dried beans and starchy vegetables like potatoes, corn and peas	Meat, poultry, fish, eggs, cheese and meat substitutes
Milk and yogurt	Fats (oil and butter)
Desserts, candy, and other sweets	

#### How much carbohydrates you should eat

Your needs may be different, but most men need 4 to 5 servings (60-75 grams) of carbohydrate foods per meal. Most women need 3 to 4 servings (45-60 grams) per meal. Each serving should have about 15 grams of carbohydrates.

# Food with 1 serving of carbohydrates

#### Fruits:

- 1 small piece of fresh fruit
- 4 oz of juice
- ½ banana
- 2 tablespoons of dried fruit

#### Starches:

- 1 slice of bread
- 1/3 cup cooked rice or pasta
- ½ cup corn, peas or beans
- ½ cup hot cereal or ¾ cup dry cereal
- 1 small tortilla

#### Dairy:

- 1 cup of milk
- ¾ cup yogurt

#### Tips for good blood glucose control

- Try to eat well-balanced meals that include carbohydrates, protein and fat at the same times every day.
- You can keep your blood sugars in balance by eating the same number of servings of carbohydrate foods at the same times each day.
- Try to eat something every 4 to 5 hours to keep you from getting too hungry between meals. If you will not be able to eat a meal for 5+ hours, eat a small snack in between.
- Fill half of your plate with non-starchy vegetables. These do not contain a lot of carbohydrates, but provide good nutrients.
- If you eat starchy foods, choose high fiber choices such as whole grain bread, brown rice and whole-wheat pasta.
- Limit or avoid foods high in added sugars. Read food labels to find out how many grams of added sugars are in the foods you commonly eat.

#### Minerals in food

We may ask you to change the amount of some minerals you eat. This will depend on how well your kidneys are working and how you are responding to your medications.

#### **Potassium**

Potassium is a mineral that keeps muscles and nerves working well. Too much or too little potassium can affect your heart.

Some medications, such as tacrolimus and cyclosporine, can make you have too much potassium in your blood. If this happens, you may need to eat less high-potassium foods.

Once your blood levels of potassium are stable, you should go back to eating potassium-rich foods. High-potassium foods have many health benefits.

#### Foods High in Potassium

- Artichokes
- Avocado
- Banana
- Beet greens
- Broccoli, cooked
- Dairy (milk, yogurt)
- Dried fruit
- Melons (cantaloupe, honeydew)
- Mango
- Kale
- Kiwi
- Nectarines
- Nutritional supplements (i.e. Ensure, Premier Protein shakes)
- Oranges and orange juice
- Parsnips
- Potatoes (baked, French fries, chips)
- Prunes and prune juice
- Some sports drinks
- Soy beans, cooked
- Spinach, cooked
- Tomatoes (including tomato sauce and juice)
- White beans, cooked
- Winter squash (acorn, butternut, pumpkin)

#### Magnesium

Magnesium helps your muscles work, reduces cramping, helps control blood pressure and blood glucose, and keeps your heartbeat steady.

Tacrolimus and cyclosporine may cause you to need more magnesium. You may need to take magnesium supplements to keep your levels in a healthy range. But, if you eat magnesium-rich foods each day, you may not need supplements. Foods high in magnesium often also have protein, fiber and phosphorus.

#### Tips for eating more magnesium

- Eat many kinds of high-magnesium foods every day.
- Crush magnesium tablets if they are hard to swallow. Crushing may help your body absorb it better.
- Some people may get diarrhea when they take high-dose magnesium supplements. Tell your provider if that happens to you. A different form of magnesium may work better for you.

# Foods high in magnesium

- Fish and other seafood
- Beans, peas and lentils
- Chocolate and chocolate milk
- Coffee
- Fruits such as bananas, avocado
- Nuts and seeds, nut butters
- Quinoa
- Soybeans and soymilk
- Vegetables such as potatoes, corn and spinach
- Whole grains such as brown rice and wild rice
- Whole grain cereals and bran

#### **Phosphorus**

Phosphorus helps our kidneys and muscles to work. It also sends signals to our nerves and helps our bodies use the nutrients we eat.

If your kidneys don't work as well after your transplant, you may need to lower the amount of phosphorus you eat. Your dietitian will tell you if you need to follow a low phosphorus diet after your transplant.

If your phosphorus levels become low after your transplant, you need to eat high-phosphorus foods each day. You may need to take phosphorus supplements if you do not get enough from your food.

#### Foods high in phosphorus

- Dairy products like milk, yogurt and cheese
- Bran cereals
- Dried beans and peas
- Lentils
- Fish
- Beef, pork, turkey, chicken
- Nuts and nut butters
- Pancakes made from a mix
- Some cola drinks (diet preferred if you have elevated blood sugar levels)

#### Calcium

You could get bone and joint weakness as a possible long-term side effect of taking prednisone. To help avoid osteopenia (low bone mass) and osteoporosis (brittle bones), you must eat enough calcium, phosphorus and vitamin D each day.

Eat a few servings of calcium-rich food in your diet each day. We may ask that you take calcium and vitamin D supplements when you leave the hospital.

#### Foods high in calcium

- Milk
- Yogurt
- Cheese
- Salmon
- Orange juice with added calcium
- Soy or almond milk with added calcium
- Tofu, firm (processed with calcium)
- Sesame seeds
- Bok choy, boiled or steamed
- Broccoli, boiled or steamed
- Collard greens, boiled or steamed
- Kale, boiled or steamed

# **Food safety**

You are more likely to get infections now that you are on medicine that suppresses your immune system. You'll need to practice food safety to help stop foodborne illnesses.

Food that looks fine can still contain pathogens (disease-causing bacteria, viruses or parasites) that can make you sick. You should never taste a food to determine if it is safe to eat.

# How to prepare food safely

Keep your hands and kitchen surfaces clean and free of bacteria by following these rules:

- Cleaning
  - Wash hands in warm soapy water for at least 20 seconds before and after handling food, or when you change tasks (like loading the dishwasher and then chopping vegetables).

- o If you can't always wash your hands, pack hand sanitizer or moist towelettes to use before eating.
- Clean the tops of canned goods before opening them.
   Clean the can opener after each use.

#### Fruits and vegetables

- Wash fresh fruits and vegetables under running tap water, even those with skins and rinds that you will not eat.
- Wash fresh foods that are hard to clean (like leafy greens, berries and mushrooms) by soaking them in water first, then rinsing with fresh water.

#### • Lunch meat

- Do NOT eat deli or lunch meat directly from the package. Instead, you can:
  - Heat lunch meat in the microwave until it is steaming hot before putting it in a cold sandwich.
  - . Make a hot grilled sandwich.

#### Raw meat and food

- Use different dishes, utensils and cutting boards for raw and cooked foods.
- Wash cutting boards, dishes, utensils and counter tops with hot soapy water after they have had raw meat, poultry or seafood on them.
- Keep raw meat, poultry, seafood and eggs away from other foods in your grocery cart and in your refrigerator.
- NEVER place cooked food on an unwashed dish that held raw meat, poultry, seafood or raw eggs.
- Do NOT reuse marinades that you used on raw foods, unless you boil them first.
- Marinate food in the refrigerator, not at room temperature.
- Defrost food in the refrigerator, not at room temperature. If you defrost in the microwave, cook the food right after defrosting it.

- Do NOT taste raw or partly-cooked meat, poultry, eggs, fish or shellfish. This includes cake batter and cookie dough that contains raw eggs.
- Do NOT eat undercooked eggs, meat, poultry or fish. Use a meat thermometer and cook to these internal temperatures:

Food	Internal Temperature or State
Beef, pork veal, lamb (chops, roasts or steaks)	145° (let meat rest for 3 minutes after you remove it from heat)
Ground meat	160°
Fully cooked ham	145°
Poultry (ground, whole, parts, stuffing)	165°
Eggs	Cook until yolk and egg white are firm
Egg dishes	160°
Fin fish	145° or meat is opaque (not clear) and flakes easily with a fork
Shrimp, crab or lobster	Cook until the meat is pearly and opaque (not clear)
Clams, oysters or mussels	Cook until the shells open during cooking
Scallops	the meat is milky-white or opaque (not clear) and firm
Leftovers, casseroles	165°

# If you do not have a meat thermometer:

- Cook steaks to medium-well done.
- Cook ground meat, fish and poultry to well done.

#### Refrigeration and storage tips

- Refrigerate or freeze meat, poultry, seafood, eggs and other dishes within 2 hours after cooking (within 1 hour if the room temperature is above 90°F).
- Break up large amounts of food into small containers for quicker cooling in the refrigerator.
- Keep your refrigerator temperature just below 40°F (4.5°C).
- Keep your freezer temperature at 0°F (-18°C).
- Do NOT eat food that has been left out at room temperature for 2+ hours. This includes meat, potato salad and other dishes at barbecues or picnics.
- Keep leftover seafood, stuffing and foods in broth or gravy in the refrigerator no longer than 1-2 days.
- Keep other leftovers in the refrigerator for no longer than 3-5 days (when in doubt, throw it out).

#### **Eating at restaurants**

- Do NOT eat from salad bars or at buffet-style restaurants.
- Do NOT eat sushi (raw or cooked), poke or ceviche.
- Choose hot sandwiches. All sliced meats must be heated.
- Ask the server how foods are prepared.
- Do NOT eat food made from raw eggs, such as mayonnaise, salad dressings or sauces. These foods should be identified on the restaurant menu.

#### Cleaning

- Wash kitchen surfaces and tools with hot soapy water or a bleach solution after each use.
- To make your own bleach solution, mix 1 teaspoon of bleach with 1 quart of water.
- Use paper towels to clean up kitchen surfaces. If you use cloth towels, change them often and wash them in hot water in the washing machine.
- Throw away any cracked dishes, utensils, pots, pans and cutting boards. They are hard to clean well.

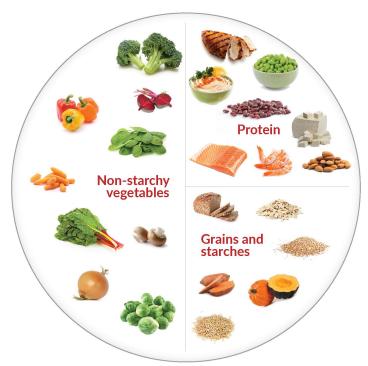
#### Raw and unpasteurized food

- Do NOT eat raw seed and vegetable sprouts.
- Eat only pasteurized dairy products.
- Wash all bagged "pre-washed" vegetables.
- Do NOT eat unroasted nuts and nuts in the shell.
- Drink only pasteurized juices and ciders.
- Do NOT drink kombucha.

# How to eat 2+ months after surgery

About 2 months after your transplant surgery, you will need fewer calories and less protein. This is a good time to work on long-term nutritional goals.

# A healthy long-term diet after transplant



Use the plate method of eating, where ½ your plate is non-starchy vegetables, ¼ is protein and ¼ is starchy food like whole grain bread, pasta, rice, cereal or starchy vegetables. You should also eat low-fat dairy products and fruit.

#### Heart health

Patients who have had liver disease are at increased risk of heart disease. Some of your new medications may raise your cholesterol and triglyceride levels. This can also increase your risk. Follow a heart healthy lifestyle to lower your risk.

#### **Exercise**

Start exercising as soon as your doctor says it is okay. Try to exercise for 30-60 minutes, 5+ days a week. Do heart-healthy exercise like:

- Walking
- Biking
- Aerobics
- Gardening
- Housework
- Strength training
- Swimming
- Running
- Yoga

# Heart healthy eating

- Choose lean sources of protein, such as fish, chicken, turkey, beans, nuts or tofu.
- Add more heart-healthy fats to your diet. Unsaturated fats and omega-3 fatty acids may lower cholesterol and triglycerides:
  - Heart-healthy fats are in olive oil, canola oil, avocado, ground flaxseed, chia seeds, hempseeds and walnuts.
  - Eat 2 or 3 servings of fish every week. Salmon, tuna and mackerel are good sources of healthy fats.
- Lower the amount of saturated fat you eat:
  - Do NOT eat red meat more than 2 times a week. When you do eat red meat, choose lean cuts such as loins or rounds.
  - $\bigcirc$  Try not to eat fried foods and butter.
  - o Choose low-fat or non-fat dairy products.

- Eat no more than 2000 mg of sodium (salt) a day by following these tips:
  - Do NOT add salt when cooking or at the table.
  - Season foods with spices, herbs, lemon juice and vinegars.
  - o Cook at home. Use fresh meats and produce.
  - Try not to eat fast food or processed food.
  - Choose products with labels that say "Without Added Salt", "No Salt Added" or "Unsalted".
  - Read the "Nutrition Facts" label to find the amount of sodium in packaged foods.
    - For meals, avoid food with more than 600 mg of sodium per serving.
    - For a side dish or condiment, avoid food with more than 140 mg sodium per serving.
  - Eat 25 to 35 grams of fiber a day. Fiber helps you absorb less cholesterol and fat. It may also help you feel full so you don't gain weight. Good sources of fiber include whole grains, beans, fruits and vegetables.

#### Heart health diets

If you want more information about heart healthy eating, we recommend two well-researched diets: The Mediterranean Diet and the DASH Diet (DASH = Dietary Approaches to Stop Hypertension).

# Mediterranean Diet: Suggested books and resources

- The New Mediterranean Diet Cookbook: A Delicious Alternative for Lifelong Health by Nancy Harmon Jenkins and Marian Nestle. New York: A Bantam Book, 2009
- The Mediterranean Diet Plan: Heart Healthy Recipes and Meal Plans for Every Eater by Susan Zogneib and Phillip Anderson III. Berkley, CA: Rockridge Press, 2016
- Good Food and Great Medicine: A Mediterranean Diet and Lifestyle Guide by Miles Hassell and Mea Hassell. Hillsboro, OR: Lithtex, 4th edition 2018

 Harvard School of Public Health Diet Review: Mediterranean Diet: www.hsph.harvard.edu/nutritionsource/healthyweight/diet-reviews/mediterranean-diet/

#### DASH Diet: Suggested books and resources

- The DASH Diet Action Plan: Based on the National Institutes of Health Research: Dietary Approaches to Stop Hypertension by Marla Heller. Deerfield, IL: Amadon Press, 2007
- Your Guide to Lowering Your Blood Pressure with DASH www.nhlbi.nih.gov/files/docs/public/heart/new\_dash.pdf

# Weight control

It is best to be at a healthy weight after your transplant and to stay that way. Being at a healthy weight will:

- Reduce your risk of diabetes, or improve your blood glucose control if you have diabetes.
- Reduce your risk of heart disease.
- Improve your blood pressure.
- Ease joint and back pain.
- Improve your energy level.

# Watch for weight gain

After your transplant, you will be feeling better and your appetite may increase. You may also have fewer limits on your diet than you did before transplant. Medicines such as prednisone may increase your appetite, which can cause you to overeat and gain weight.

# Tips for Keeping a Healthy Weight

- Eat from a smaller plate or bowl. This can make your mind feel like you are eating more than you are.
- Include regular exercise as part of your lifestyle after your transplant. Exercise helps build muscle and burn calories.
- Eat 3 smaller meals and 1 snack each day.

- Wait 20 minutes before taking a second helping. It takes that long for your body to feel full after eating.
- Chew on gum instead of eating between meals.
- Limit sweets and sugars.
- Limit sweetened beverages. They have calories but don't make you feel less hungry.
- Drink plenty of water.

If you find yourself gaining weight, try some of these internet resources:

- Aim for a Healthy Weight from the National Heart, Lung and Blood Institute
  - www.nhlbi.nih.gov/health/educational/lose wt/index.htm
- USDA Nutrition
   www.nutrition.gov/healthy-weight
- Academy of Nutrition and Dietetics www.eatright.org/health#weight-loss

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# Caring for your health

#### **Activity**

#### Limits

After your transplant, we want you to get back to an active life. There are only a few limits during the first 3 months:

#### Lifting

- o For the first 6 weeks, do NOT lift 10+ pounds.
- For the next 6-12 weeks after transplant, do NOT lift 20+ pounds.
- o 3+ months after transplant, there are no lifting limits.

#### Running

 For the first 3 months, do NOT jog or run on hard surfaces, such as cement or asphalt.

# Soaking

 Until your surgical cut is healed (6-7 weeks), NO tub baths or swimming.

# **Building muscle**

Your muscles may feel weak from not using them and as a side effect of prednisone. You can make your leg muscles stronger by walking and bike riding. After 3 months, you can do sit-ups and other abdominal exercises to tone of your stomach muscles.

# Returning to work

We encourage you to return to work as soon as you can. Most people can go back to work in 4 - 6 weeks, unless they do manual labor. You may be eligible for up to 12 weeks of job protected leave through OFLA or FMLA — check with your employer.

#### **Play**

Use common sense as your guide to any activity. As you get stronger, you will increase your amount of physical activity. If you are unsure if you should do an activity, please call the transplant office.

#### **Sexual Activity**

Wait 6 weeks before having sex to allow your surgical cut and muscles to heal. Your new liver is well protected. You will not harm it by having sex. Always practice safe sex since you are less able to fight sexually transmitted diseases (STDs).

#### Men's Fertility

Some men are able to father children, desire sex and function again — even if they couldn't during liver failure. Your sexual function may change depending on how your liver is doing and due to certain medications. If you notice a change in your sexual ability, ask your provider for advice. Talk to your hepatologist before you decide to have a child.

# Women's Fertility

Many women are fertile after transplant. Be sure to use a reliable form of birth control right away. You should start getting your periods again within several months of transplant. You may still be ovulating even if you do not have a regular period. Many women get pregnant and deliver healthy children after a liver transplant. If you are on Cellcept or Myfortic, talk to your transplant team if you are pregnant or want to be pregnant. Cellcept increases the risk of birth defects.

If you want to get pregnant, it is best to:

- Wait until at least 1 year after transplant.
- Not have other medical problems that might add to the risk of the pregnancy.
- Get lab tests more often.
- Adjust your immunosuppression drugs.
- Get proper prenatal care.

Make sure to get your yearly well-woman check-up, with a Pap smear and a breast exam.

# Long-term health

Transplant patients should follow these guidelines to care for the long-term health of your whole body.

#### Heart attack and stroke

Prevent heart attack and stroke by doing the following:

- Exercise daily
- Eat a low-fat, balanced diet with plenty of fruits and vegetables
- Limit weight gain
- Control blood pressure
- Watch blood sugars people with diabetes should get help to control blood sugar
- Check cholesterol
- Do NOT smoke or use tobacco
- See your doctor every year

#### **Diabetes**

Post-transplant diabetes is a known risk for transplant patients. Watch your blood sugar and start treating it with diet and exercise. Many patients need insulin after transplant.

#### **Travel**

Contact a travel clinic before you go to another country. They will tell you which vaccines you need to travel there and what your risks of infection are. Please check with your transplant team with any questions. Remember, after transplant you should **NEVER get LIVE virus vaccines.** 

#### Bone disease

Transplant patients are at risk to get bone disease. You should have a bone density study at least once every 2 years. Ask your primary care provider how to prevent bone disease with diet and exercise.

### Regular cancer screenings

Contact the transplant office if you are ever told you have cancer. Due to the immunosuppression drugs you are on, you should have the following tests:

#### Women

- All women pelvic exam and pap smear every year
- Age 40+ yearly mammogram
- Age 30+ who has a female relative diagnosed with breast cancer before menopause yearly mammogram

#### Men

- Age 45 if your father or brother has had prostate cancer your first prostate-specific antigen test (PSA)
- Age 45 if you are African American your first PSA test
- Age 50+ yearly PSA test

# Everyone ages 50+

- Colon cancer screening (with rectal exam), every 2 years
- Fecal occult blood test, every year
- Colonoscopy, every 5 years

#### Skin cancer

You have a **much higher risk of skin cancer** due to the medicine you take to help prevent rejection. The most common type of skin cancer we see after transplant is squamous cell carcinoma — can be up to **65 times more common** than in non-transplant patients! Patients usually get their first skin cancer 3-8 years after their transplant. You are at even higher risk if you are light-skinned, had much sun-exposure in your lifetime, are older, or have already had skin cancer.

### How to lower your risk

- Avoid the sun from 11 a.m. to 3 p.m. when the harmful rays are most intense.
- Wear sunscreen with both UVA/UVB protection of SPF 30+ every day.
- Use plenty of sunscreen on any exposed skin and reapply every 2 hours.
- Don't forget to protect your lips and ears.
- Wear a wide-brimmed hat and protective clothing, such as long sleeves, pants and sunglasses.
- See a dermatologist for skin exams after your transplant.



# Call your dermatologist or primary care doctor right away if you:

- See any change in your moles, or
- Have a new sore that does not heal

# Preventing infectious disease

- 1. **Wash your hands often**. It is the one best way to prevent infection!
- 2. Wear masks and gloves at these times:
  - First 3 months after transplant, when you are:
    - o In the hospital
    - o Around active construction
    - $\circ \quad \text{Near farming areas} \\$
    - o In crowds
  - From 3 months to 1 year after transplant, when you are gardening. Do NOT garden during the first 3 months after transplant.
  - After 1 year, always wear gloves when you garden.

## 3. Get the right vaccines.

- Get your flu shot every year.
- If you get hurt but haven't had a tetanus booster within the last 5 years, call your primary care provider.
- Transplant patients should NEVER get LIVE vaccines. Live vaccines have live organisms and you could get the actual disease since your immune system is less. Vaccines made from dead organisms are safe.

## **○** Do NOT get these vaccines:

- Oral polio
- Chicken pox

## ✓ You CAN get these vaccines:

- ✓ Injectable polio
- ✓ Flu shot (Influenza A and B) every year
- ✓ Pneumovax every 5 years
- ✓ TB skin test
- ✓ Diphtheria/Tetanus every 10 years
- ✓ Shingrix (a specific Shingles vaccine)
- ✓ COVID

### **Dental** care

Make sure to get a dental checkup every 6 months. Infections could be serious because of your lowered immunity. Be sure to:

- Wait until 3 months after transplant to get routine dental care.
- Let your dentist know you had a liver transplant and are on immunosuppressive medications.
- Ask your dentist to call our transplant office if they have any questions.
- If your dentist is unsure about antibiotics before dental procedures, we follow the American Heart Association recommendations.

# Drugs, tobacco and alcohol

#### **Tobacco**

Do NOT use tobacco.

- Chewing tobacco can lead to neck and mouth cancers.
- Smoking raises your risk of:
  - o Bad surgery results
  - Cancer
  - o Atherosclerosis (fatty deposits in blood vessels)
  - Heart attack
  - o Stroke
- Please contact your transplant nurse if you need help quitting tobacco.

# Marijuana

We do NOT recommend that you use marijuana. It can cause lung and brain fungal infections.

### Alcohol

Do NOT drink alcohol. Do NOT drink "nonalcoholic" drinks like "near beers" and wine coolers. Any type of alcohol can harm your liver and destroy its cells.

# Pets at home

For the most part, transplant patients can still live with pets in their home. Wash your hands after handling or cleaning up after your pets, and follow the guidelines below.

# Dogs and cats

- Keep vaccinations up to date.
- Treat regularly for flea and tick prevention.
- Transplant patients CANNOT clean out a cat's litter box.

#### **Birds**

• Transplant patients CANNOT clean out a bird cage or chicken coop.

# **Reptiles**

○ Transplant patients should NOT touch reptiles. They may carry salmonella and should NOT be pets.

# Complications

# Rejection

Your body may treat your new liver as a foreign object and start attacking it. This is called "rejection" and it can happen at any time. Rejection does not mean loss of your organ. Often, we can treat it with medication. Some patients need more intense treatment. We watch for rejection by looking at your labs and biopsies of the organ. Up to 30% of all liver transplant patients will have at least 1 rejection episode. The first one often happens within 3 months of surgery.

#### **Treatment**

If your body starts to reject your liver, we can control that by changing the amount of your immunosuppressive medications or by adding a new one. We will watch your liver function tests (LFTs) to see what is happening to your liver. If you have a severe rejection, we may need to admit you to the hospital for stronger IV medicine.

#### Risk

The risk of rejection goes down over time. But, it can still happen at any time. Lower your risk by taking good care of yourself, taking your medications as prescribed, and having your blood tests done.

# Recurring Hepatitis C

A liver transplant does not cure Hepatitis C since the virus is found in the blood. If you had Hepatitis C before your transplant and did not get treatment or clear the virus, you will have it again (recur) at some point after your transplant. Most people with recurring Hepatitis C will get cirrhosis within 5 years of their transplant, if the virus is not treated. There are many new medications to treat

Hepatitis C. Talk to your hepatologist about when you should start treatment.

### Infection and viruses

You are at more risk of getting infections due to the anti-rejection medications you take. These infections can be serious, so let us know right away if you have any of these symptoms:

- Fever
- Chills
- New diarrhea
- New or unexplained pain
- Cough
- Tiredness for no reason
- Not feeling well
- Urine problems such as going too much, pain when urinating or cloudy urine

Also, let us know if you have a viral infection like Cytomegalovirus (CMV).

#### **CMV**

Cytomegalovirus (CMV) is a very common viral infection that usually has no symptoms in non-transplant patients. Transplant patients need antiviral medications to help prevent CMV infection. Symptoms of infection can be fever, extreme tiredness (fatigue), diarrhea, stomach (abdominal) pain, cough and low white blood cell count. We can do a lab test called a CMV PCR to see if you have the infection. If you are infected, your transplant team will let you know what treatment you need.

### **Diabetes**

Your anti-rejection medications increase your risk of developing diabetes after transplant. If you had diabetes before transplant, you may need to take more diabetic medications. You may need to see a diabetic specialist.

### Cancer

Your anti-rejection medications increase your risks of 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).

All patients should see a dermatologist once a year. Learn about your cancer risks, and tell your doctor right away about any new symptoms or concerns.

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# Writing to your donor's family

Some transplant patients choose to write to their donor family. This is strictly your choice. It is not expected and there are no requirements. But, if you would like to write the family, here are some tips.

### What to write

We know the words can be hard to find, so here are some ideas to help you get started:

- Say "thank you." It may not completely get across how much the gift of transplant means to you, but it is always welcome.
- Share a bit about yourself (job, hobbies, etc.), your family and how the transplant has changed your life (what you can now do or enjoy because of the transplant).
- Include photos of yourself or family.
- Avoid religion since you do not know the donor family. Instead, you can use general statements of "feeling blessed."
- Do NOT pressure the donor family to meet in person or to write back to you.

# What to keep private

#### Do NOT include:

- City where you live, address or phone number
- $\bigcirc$  Hospital where you had the transplant
- Names of your medical team

## The process

After you write your donor family:

- 1. Place your letter or card in an unsealed envelope.
- 2. On a separate paper, write your full name, transplant center and date of transplant. This will help get the letter to your donor family.
- 3. Put the paper and unsealed letter together in another envelope and mail to:

OHSU Transplant Social Work

Mail Code: SJH 569

3181 S.W. Sam Jackson Park Rd.

Portland OR 97239

### What happens next

We will call you to let you know we got the letter. We will send it to Cascade Life Alliance (CLA). CLA will forward the letter to your donor family if the family allows it. It could take many weeks for your letter to get to the family. We will let you know if your donor family decides not to accept letters or if the CLA cannot reach them.

# How will I know if the donor family writes back?

If the donor family writes you back, your social worker will let you know and ask you if you would like to accept the letter.

# What if I need help deciding if I should write or what to write?

You can always talk with your social worker. They will not decide for you, but they can help you process your feelings. This can help you make the right choice for you.

# **Diagnostic tests**

## **Biopsy**

We use this procedure to see if your body is rejecting your liver. We numb your skin and take a very small piece of your liver using a needle.

If you are on any blood thinners such as aspirin, Plavix or Coumadin, your coordinator will discuss a plan with you before scheduling your biopsy.

### MRCP (Magnetic Resonance Cholangiopancreatography)

We use this special non-invasive MRI (magnetic resonance imaging) to look at the drainage system or ducts of the gallbladder, pancreas and liver. This test helps us find blockages, pancreatic cysts, bile duct stones, narrowing in the ducts or tumors.

# PTC (Percutaneous Transhepatic Cholangiography)

This procedure x-rays the bile ducts. We numb the area and insert a thin needle in your skin, through the liver and into a bile duct. Then, we inject a dye so we can see the bile duct system. We may need to insert a thin tube to drain bile into a bag outside the body or into the small intestine. We can also remove stones and insert balloons to open up narrowing ducts.

# ERCP (Endoscopic Retrograde Cholangiopancreatography)

For this test, we use an endoscope to look at and treat the GI tract. An endoscope is a thin, flexible tube with a tiny video camera and light on the end. The GI tract includes the stomach, intestine, liver, pancreas and gallbladder.

# **Doppler Ultrasound**

This test uses sound waves to see the blood flow in your abdomen. It can help us find blockages in the blood flow to your liver, as well as other problems in the organs.

# CT (Computed Tomography) Scan

We use a CT scan to get a 3-dimenional x-ray of your internal organs. It can help us find problems in the liver, spleen, colon, pancreas, kidneys and more. Sometimes we use a dye to see better. We usually give the dye by IV but sometimes by mouth.

# Over-the-counter medicines that are safe to take

Symptoms	Safe over-the-counter choices		
Fever	Acetaminophen (Tylenol). Call your nurse coordinator or on-call nurse if your fever is over 101° F.		
Head and body aches	Acetaminophen (Tylenol)		
Sneezing, itching or runny nose	Loratadine (Claritin), Cetirizine (Zyrtec)		
Stuffy nose (nasal and sinus congestion)	Nose sprays: Sodium chloride (Ocean), (SinuCleanse), Oxymetazoline (Afrin), Phenylephrine (Neo- SynephrineNeosynephrine), Pseudoephedrine (Sudafed). Do NOT use Sudafed if you have high blood pressure.		
Chest congestion	Guaifenesin (Robitussin), Coricidin HBP Chest Congestion & Cough		
Wet cough (lots of phlegm)	Guaifenesin (Robitussin)		
Dry cough (no phlegm)	Dextromethorphan (Delsym), Guaifenesin/ Dextromethorphan (Robitussin DM), Coricidin HBP Chest Congestion & Cough		
Sore throat	Lozenges		
Constipation	Polyethylene glycol (MiraLAX), Psyllium (Metamucil), Docusate (Colace), Docusate with senna (Senokot-S), Bisacodyl (Dulcolax), Senna		
Diarrhea	Loperamide (Imodium AD).		
Trouble sleeping (insomnia)	Diphenhydramine (Benadryl), Doxylamine (Unisom), Melatonin		
Stomach upset	Calcium carbonate (TUMS)		
Heartburn	Ranitidine (Zantac), Famotidine (Pepcid AC), Nizatidine (Axid), Omeprazole (Prilosec)		
Gas	Simethicone (Gas-X)		
Dry, irritated eyes	Artificial Tears, Ketotifen (Zadiator)		
Nausea and vomiting	Meclizine (Antivert)		
Joint pain	Capsaicin cream (Capzasin-P)		
Skin irritation, insect bites, poison ivy	Hydrocortisone (Cortisone-10)		

# Medications you may be taking

Drug	What it's for	When to take	How to take	Common side effects	What else to know
Acyclovir (Zorvirax)	To prevent recurrence of Cytomegalo virus (CMV) or Herpes Simplex Virus (HSV)	Start around the time of transplant. Take for 3 months.	By mouth (orally) or by IV (intra- venously).	Headache, nausea, vomiting.	Drink plenty of fluids. You can take this drug with or without food.
Amlodipine (Norvasc)	To lower blood pressure that may go up due to anti-rejection drugs.	1 time a day.	By mouth.	Dizziness, tiredness, swelling in arms or legs, flushing.	May raise your risk of chest pain or heart attack. Call your doctor right away if you get chest pain while on this drug.
Azathioprine (Imuran)	To prevent your body from rejecting your liver.	You may use it before and after your transplant. Take 1 time a day. Most patients will take it for life.	By mouth (orally) or by IV (intra- venously).	Low white blood cell count, hair thinning.	Tell your doctor if you are taking Allopurinol (a medicine used to treat gout).
Carvedilol (Coreg)	To lower blood pressure that may go up due to anti-rejection drugs.	2 times a day with food.	By mouth.	Dizziness, tiredness, shortness of breath, headache, depression.	Can be used with other blood pressure drugs. Also, can come in a form that only needs to be taken 1 time a day.

Drug	What it's for	When to take	How to take	Common side effects	What else to know
Cyclosporine (Sandimmune, Neoral, Gengraf, Eon, Apotex)	To prevent your body from rejecting your liver.	Start 2-5 days after transplant. Take 2 times a day. On lab days, do NOT take in the morning UNTIL AFTER your blood draw. Most patients will take it for life.	Will start out by IV (intra- venously). Will switch to by mouth (orally) after a few days.	Kidney problems, high blood pressure, leg cramps, tender or swollen gums, tremors.	Do NOT eat grapefruit, mandarins, pomegranates, or drink their juices. Do NOT substitute Sandimmune or Apotex for Neoral, Sidmak, Gengraf, Eon or Plevia.
Fluconzole Fluconazole (Diflucan)	To treat or prevent a fungal infection in the mouth called thrush.	By mouth 1 time per week on Mondays for the first 2 months after your transplant.	By mouth (orally) or by IV (intra- venously).	Rash, headache, dizziness, nausea, vomiting, stomach pain, diarrhea, high liver enzymes, change in how to taste food.	

Drug	What it's for	What it's for When to take take		Common side effects	What else to know
Insulin	If you get post-transplant diabetes, you will need to take insulin to control your blood sugar.	day, depending on the food you eat. Follow the instructions that your doctor, diabetes nurse and pharmacist give you.		When your blood sugar is low, you will feel shaky, anxious, sweaty, hungry, dizzy and like your heart is pounding.	Learn what it feels like if your blood sugar is low. Once this happens, you should eat or drink something with sugar, or have a snack right away.
Magnesium	To replace your natural magnesium stores that you have lost.	your natural your magnesium magnesium stores that levels to see if you have you need it.		By mouth: diarrhea. By IV: flushing.	Tell your doctor if you are taking any over-the-counter vitamins or have a lot of diarrhea.
Mycopheno- late, Mycho- phenolic (Cellcept, Myfortic)	To prevent or stop your body from rejecting your liver.	Take 2 times a day with food. Most patients will take it for life.	By mouth (orally) or by IV (intra- venously).	Nausea, vomiting, not wanting to eat (loss of appetite), diarrhea, stomach cramps.	Tell your doctor if you are taking any over-the-counter iron pills or have a lot of diarrhea.

			How to	Common	What else to
Drug	What it's for	When to take	take	side effects	know
Omeprazole (Prilosec)	To treat or prevent heartburn and ulcers — which can be result of using steroids	1 – 2 times a day.	By mouth	Headache, nausea, diarrhea	Swallow pills whole. Do NOT chew them. You may open the capsules, sprinkle them on applesauce and eat it right away.
Oxycodone (Roxicodone)	To treat or prevent moderate to severe pain.	Take every 3 to 6 hours as you need it, as directed by your doctor. You can take with or without food.	By mouth (orally).	Drowsiness, dizziness, light- headedness, nausea, vomiting, headache, constipation	This is an opioid. Do NOT take alcohol, antihistamines or other drugs that may add to your drowsiness. Do NOT drive or operate heavy machinery.
Pentamidine	To prevent Pneumocystis carinii Pneumonia (PCP).	Take 1 time a month for 4 months.	Inhale into the lungs by using a machine called a nebulizer.	Nausea, vomiting, dizziness, headache, cough, rash, stomach pain, diarrhea, shortness of breath.	We can give you a different medication if you have a hard time with this one.

Drug	What it's for	When to take	How to take	Common side effects	What else to know
Prednisone (Deltasone)	To prevent or stop your body from rejecting your liver.	Take 1 time a day in the morning with food. Most patients will take it for life.	By mouth (orally).  Do NOT stop taking unless your doctor says to.	Trouble sleeping, mood changes, nervousnes s, wanting to eat more (increased appetite), heartburn.	Do NOT take antacids (like Tums) at the same time.
Sirolimus (Rapamune)	To prevent or stop your body from rejecting your liver.	Take 1 time a day at the same time each day, with or without food. On lab days, do NOT take in the morning UNTIL AFTER your blood draw. Most patients will take it for life.	By mouth (orally) as a tablet or liquid.  Do NOT stop taking unless your doctor says to.	Low white blood cell and platelet counts, high cholesterol.	If you take as a liquid: Mix it with chocolate milk or orange juice for taste. Stir well and drink all at once. ONLY mix in a GLASS container (NO plastic) and rinse to make sure you get the full dose.  Keep an eye on your cholesterol while you take this drug.

Drug	What it's for	When to take	How to take	Common side effects	What else to know
Tacrolimus (Prograf, FK506)	To prevent or stop your body from rejecting your liver.	Take 2 times a day, 12 hours apart, at the same times each day, with food to prevent nausea. On lab days, do NOT take in the morning UNTIL AFTER your blood draw.	By mouth (orally) or by IV (intravenously).  Do NOT stop taking unless your doctor says to.	Headache, tremors, muscle cramps, diarrhea, nausea, high blood pressure, kidney problems.	Do NOT eat grapefruit, mandarins, pomegranates, or drink their juices.
Valganciclo- vir (Valcyte)	To prevent and treat cytomegalov irus (CMV).	Take 1-2 times a day, with food.	By mouth (orally) or by IV (intra- venously).	Headache, nausea, low white blood cell and platelet counts.	Drink plenty of fluids.

# Magnesium in certain foods

	Milligrams	% Daily
	(mg)	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
Shredded wheat cereal — 2 rectangular biscuits	55	15
Oatmeal (instant, fortified) — cooked with water, 1 cup	55	15
Potato (with skin) — baked, 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, nonfat) — 8 fluid ounces	45	10
Bran flakes — ½ cup	40	10
Vegetarian baked beans $-\frac{1}{2}$ cup	40	10
Brown rice (long-grained) — cooked, ½ cup	40	10
Lentils (mature seeds) — cooked, ½ cup	35	8
Avocado (California) — $\frac{1}{2}$ cup pureed	35	8
Kidney beans (canned) $-\frac{1}{2}$ cup	35	8
Pinto beans — cooked, ½ cup	35	8
Wheat germ (crude) — 2 tablespoons	35	8

# Phosphorus in certain foods

	Serving size	Phosphorus (mg)
Mac and cheese (from mix)	1 cup	400
Liver and organ meats	3.5 ounces	400
Yogurt (plain, nonfat)	8 ounces	385
Pancakes (from mix)	3 4-inch pancakes	368
Yogurt (regular, no added probiotics)	1 cup	326
Mac and cheese (from scratch)	1 cup	322
Pudding (made with low fat milk)	½ cup	313
Dried beans and peas	1 cup, after boiling	266
Salmon	3 ounces, cooked*	252
Halibut	3 ounces, cooked*	242
Milk (nonfat)	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 (from mix)	1	140
Almonds**	1 ounce (23 nuts)	134
Mozzarella cheese (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

<sup>\*</sup> A 3-ounce serving is about the size of a deck of cards.

<sup>\*\*</sup> Your body is only able to absorb 50% (half) of the phosphorus from nuts, seeds and grains.

# Glossary

#### **Acute**

Short and severe

### **Albumin**

A protein made by the liver that helps your body maintain its balance of fluids

# **Alkaline Phosphatase (Alk Phos)**

An enzyme made by the liver. High levels can mean your liver or other organs aren't working well.

# **Analgesic**

Pain medicine

#### Anemia

A low number of red blood cells

#### **Anesthetic**

Medication that reduces pain

#### **Antacid**

A drug that protects your digestive system and relieves heartburn

# **Antibody**

A part of the immune system that fights infection or foreign organisms or tissue

## **Antigen**

A harmful substance that enters your body and starts an immune response to make antibodies

#### Arteriosclerosis

A hardening of the arteries that blocks blood flow to the kidneys

#### **B** Cells

A type of white blood cell that makes antibodies

#### **Bacteria**

Germs that can cause disease or infection

#### Bile

A fluid made by the liver that is stored in the gallbladder and released into the small intestine to help absorb the fats you eat

#### **Bile Duct**

The tubes that bile flows through

#### **Bile Leak**

A hole in a bile duct that causes bile to spill into the abdominal cavity

# **Biliary Stenosis**

When a bile duct gets narrow

# **Biliary Tree**

All bile ducts in and out of the liver that carry bile to the intestines

#### **Bilirubin**

A fluid made by the breakdown of red blood cells in the liver. High levels can lead to jaundice.

# **Biopsy**

Procedure to see if your body is rejecting your liver, where we numb your skin and take a very small piece of your liver using a needle.

#### **Bladder**

The organ that receives and stores urine from the kidneys until it is urinated out of the body

### **Blood Urea Nitrogen**

A waste product that your kidneys remove from your blood

#### **Cadaveric Donor**

An organ donor who has just died

#### **Calcium**

A mineral needed for bone growth, blood clotting, and for the heart and nerves to work

#### Catheter

A small rubber tube (commonly inserted into the bladder to drain urine)

# CellCept

An immunosuppressive drug used to limit or reverse rejection

# Cholangiogram

A test that looks for leaks or blockages in the liver's bile ducts

# **Cholangitis**

A bacterial infection in the bile ducts

#### **Cholestasis**

A buildup of bile in the liver — caused by medicines, injury to the liver, liver disease, total parenternal parenteral nutrition (TPN)

#### Cholesterol

A kind of fat that your body needs, but too much can cause heart disease

#### **Chronic**

Something that lasts over a long period of time

## **Chronic Renal Insufficiency**

Permanent damage to both kidneys, treated by dialysis or transplant

#### **Cirrhosis**

A disease that causes permanent scarring of the liver

## **CMV (Cytomegalovirus)**

A common viral infection that can be harmful to transplant recipients if they get it after transplant

# Coagulation

The process of blood clotting

## Coagulopathy

Abnormal blood clotting

# **Complete Blood Count (CBC)**

Blood test that measures what makes up blood, including hemoglobin (Hgb), hematocrit (Hct), platelets (Plt), and the types of white blood cells (WBC)

#### **Corticosteroids**

A group of immunosuppressive medications that includes prednisone and prednisolone

#### Creatinine

A waste product made by your muscles as part of normal activity. Normal kidneys filter out creatinine. The higher the creatinine level in your blood, the lower your kidney function.

#### Crossmatch

A test to see how compatible a donor's blood is with that of someone who could receive it

#### 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 they get it after transplant

#### **Diabetes**

A disease that makes your blood sugar higher than it should be, causing health problems

# **Diabetic Nephropathy**

Kidney failure as a result of diabetes

# **Dialysis**

A procedure where toxins are cleaned out of your blood

#### **Diastolic Blood Pressure**

The bottom number of a blood pressure measurement. It is the pressure on the arteries between heartbeats.

# **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 certain area of the body (such as the hands or legs) due to too much fluid

# EGD (esophagogastroduodenoscopy)

A test where we use an endoscope to look at the lining of the esophagus, stomach and first part of the small intestine

# Electrocardiogram

A test where we place electrodes on your chest to measure the heart rhythm and look for injury to heart tissue

## **Electrolyte**

A dissolved mineral (such as magnesium or potassium) that helps the body function

## **Endoscope**

A small telescope-like instrument that we use to look into your body to see the esophagus, stomach and small intestine

#### **Endotracheal Tube**

A tube we insert through the mouth and into the windpipe to help you breathe during surgery

# Enzyme

A bodily protein that can break down other substances

# ERCP (endoscopic retrograde cholangiopancreatogram)

A test where we use an endoscope to look at the drainage system or ducts of the gallbladder, pancreas, and liver (the biliary tree).

#### **Fibrosis**

When healthy tissue in your liver becomes scarred and can't work as well, leading to cirrhosis

#### Gallbladder

An organ that stores bile, which helps break down fat from food. It is attached to the liver and we remove it during transplant.

# Gastroenterologist

A doctor who treats 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 to measure the level of kidney function

#### Glucose

Sugar found in the blood or urine

#### Graft

A transplanted tissue or organ, such as a kidney or pancreas

# **Helper T-cell**

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

#### Hematocrit

A blood test that counts the number of red-blood cells in your blood

#### Hematoma

A bruise or swelling caused by a build-up of blood in tissue

## Hemoglobin

Protein in red blood cells that carry oxygen from the lungs to the rest of your body.

# Hepatic

Relating to the liver

# Hepatitis

Liver inflammation, usually caused by a virus

## Hepatologist

Doctor who treats liver disease

# Hepatomegaly

**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 in both men and women.

# **Human Leukocyte Antigens (HLA)**

Genetic markers you get from your parents

# Human Leukocyte Antigen (HLA) Compatibility

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

# Hypertension

High blood pressure

## Hypotension

Low blood pressure

### **Immune System**

Your cells, tissues and organs that work together to fight foreign organisms or tissues in your body

## **Immunosuppression**

Making it hard for your body to fight a foreign object like a transplant or disease. You can do this by taking certain drugs to help prevent or control a transplant rejection.

## **Immunosuppressive Agents**

Medications you take to prevent your body from rejecting an organ transplant

#### **Insulin**

A hormone made by your pancreas that controls blood sugar levels

### Intravenous (IV)

Putting fluids or drugs directly into your vein with a needle or catheter

### **Jaundice**

When your skin and eyes look yellow because your liver doesn't work as well as normal

# **Kidney**

Organ that filters the waste and extra fluid from your blood that becomes urine.

# Leukocyte

A white blood cell that helps fight infection

### Liver Enzymes

Proteins that speed up chemical reactions in the body

### **Liver Function Tests (LFTs)**

Blood tests to see how well the liver is working — measures ALT, AST, GGT, bilirubin and alkaline phosphatase.

### Lymphocyte

White blood cells made by the lymph glands and defend your body against infection and foreign substances.

### MRCP (Magnetic Resonance Cholangio-Pancreatography)

A special kind of MRI to look at the drainage system or ducts of the gallbladder, pancreas, and liver (the biliary tree). It is used to find blockages, pancreatic cysts, bile duct stones and tumors.

## Nephrologist

A doctor who treats kidney disease

# Neutrophil

A type of white blood cell

# Noncompliance

When you fail to follow a treatment plan — like taking medications, getting tests on time, taking vital signs, etc. This often shortens the lifetime of the transplanted organ(s).

# **Orally**

By mouth

# Phlebotomy

Removal of around 1 pint of blood through a vein

#### **Platelet**

A small blood cell you need for clotting

## PJP (Pneumocystis Jiroveci Pneumonia)

An infection of the lungs found in people with weakened immune systems

### PTC (Percutaneous Transhepatic Cholangiography)

A procedure that x-rays the bile ducts

### PTLD (Post-Transplant Lymphoproliferative Disease)

A group of life-threatening disorders that can happen after transplant. It is treated by lowering immunosuppression and giving antiviral medications.

#### **Potassium**

A mineral your body needs but too much can harm your heart. High levels often happen when your kidneys don't work well.

## **Prophylactic Medication**

Drugs that help prevent disease

#### **Red Blood Cells**

The part of the blood that carries oxygen to body tissues

# Rejection

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

#### Renal

Related to the kidneys

### **Sepsis**

A severe infection that has spread to the blood stream

# **Shingles**

A herpes virus infection that causes a red, painful skin rash

### **Signs**

Things you can measure to see how well your body is working — such as heart rate, blood pressure, breathing rate and temperature

#### **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 of a blood pressure measurement. It is the pressure on the arteries when the heart beats.

# **Symptoms**

Things you feel, such as pain, dizziness or fatigue

#### T Cells

White blood cells that play a major part in rejection

### **T-Tube (Turcotte Tube)**

A tube we place in the bile duct so that bile can drain into a bag outside the body

#### **Thrombosis**

A blood clot

#### **Thrush**

A fungal infection in the mouth

## **Tissue Typing**

A blood test to compare a person's major antigens with a donor's to see if they are a good match

#### **Toxins**

Waste products in the blood that are bad for the body when there is too much

#### **Ultrasound**

Procedure that uses sound waves to see the size of an organ and if there is fluid around it or urinary blockage

#### **Ureter**

One of 2 tubes in your body that carries urine from the kidney to the bladder

#### Urethra

The tube in your body that carries urine out of the bladder

## **Urinary Catheter**

Tube that we insert into the bladder to drain urine

### **Urinary Tract**

The body system that makes, carries, stores and gets rid of urine. It is made up of the kidneys, ureters, bladder and urethra.

# United Network for Organ Sharing (UNOS)

Organization that manages the national transplant waiting list to make sure it is fair, and collects data on transplant recipients and organ donors

#### Virus

A small germ that causes infection

### Wean

To slowly withdraw or reduce. We may wean immunosuppression slowly over time if your transplanted liver is working well.

#### White Blood Cells

The part of the blood that fights infection

#### Web resources

# American Cancer Society "stay healthy"

www.cancer.org/Healthy/FindCancerEarly

#### **American Liver Foundation**

www.liverfoundation.org

# American Organ Transplant Association

www.aotaonline.org

### **American Society of Transplantation**

www.myast.org

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

### **National Association of Boards of Pharmacy**

www.safe.pharmacy

Find legitimate online pharmacies.

## **National Foundation for Transplants**

www.transplants.org

#### **National Transplant Assistance Fund**

www.helphopelive.org

The money side of organ transplants — including advice to patients about how to raise funds for their transplant.

#### **Needy Meds**

www.needymeds.com Links to drug assistance programs.

### **OHSU Transplant Medicine**

www.ohsu.edu/transplant Information about the OHSU transplant program, news clips and videos.

### **Organ Donor Program**

www.donatelifenw.org Information on organ and tissue donation.

# Transplant Recipients International Organization

www.transweb.org

#### **TransWeb**

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

### United Network for Organ Sharing (UNOS)

www.unos.org

Information for the transplant recipient and living donor.

# Forms

# Blood pressure record

Date				
Blood pressure (morning)				
Blood pressure (evening)				
Date				
Blood pressure (morning)				
Blood pressure (evening)				
Date				
Blood pressure (morning)				
Blood pressure (evening)				

# Weekly diabetes record

Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood sugar									
Insulin dose									
Extra dose									
Exercise									
							<b>5</b> 111		
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood sugar									
Insulin dose									
Extra dose									
Exercise									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood sugar								J	
Insulin dose									
Extra dose									
Exercise									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood sugar									
Insulin dose									
Extra dose									
Exercise									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood sugar									
Insulin dose									
Extra dose									
Exercise									
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood sugar								_	
Insulin dose									
Extra dose									
Exercise									
						-			
Date:	Breakfast	Snack	Lunch	Snack	Dinner	Snack	Bedtime	Night	Notes
Blood sugar									
Insulin dose									
Extra dose									
Exercise									