

TAKING CHARGE OF YOUR HEALTH

LIFE AFTER TRANSPLANT



Revised July 2021

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INTRODUCTION

Congratulations! You have just received a liver transplant! Receiving a liver transplant is the first step in taking charge of your health. Once the doctors and nurses stabilize your general condition, you will be on the road to learning how to care for yourself at home. Before you leave the hospital, you will learn how to care for your incision, understand your medications, recognize the signs of rejection, and comprehend the lifestyle changes that will take place after your transplant.

You may feel a bit overwhelmed with all that you need to learn before your discharge, but this is a normal feeling. Don't worry—the transplant team will help make this transition as easy as possible for you and your family.

Remember, however, that YOU are ultimately responsible for your health. Taking charge of your health is a lifelong commitment to you and your new organ. We will include your family in the learning process, so please encourage them to be present for discussions and to ask questions. Transplantation is a lifestyle change that impacts the whole family, so it is important that their concerns be addressed as well.

Please read the information provided in this book and discuss it with your transplant team. All your questions should be answered before you leave the hospital, so please ask us about the things you do not understand.

HOW TO CONTACT US

Daytime Number

Call us at the Transplant Office. Hours are Monday to Friday, 8am to 4:30 pm

877-42-LIVER (425-4837) or 214-947-4400

Evenings, Nights, Holidays, Weekends After Hours Emergency Line

You will be dispatched to our answering service. Ask to be connected to the transplant coordinator on call. A transplant coordinator is available 24 hours a day, 7 days a week to take your call.

Rejection

It is natural for your immune system to see your new organ as foreign and try to attack it. Your body will react to the new organ the same way it reacts to germs: it will attack and destroy in an attempt to prevent you from getting sick. To help your body accept your new organ, we give you anti-rejection (or immunosuppressive) medications. These medications weaken your immune system so that it will not fight off your new organ and cause rejection. Rejection does not always mean you will lose your new organ. To protect your new organ from rejection, however, you must always take your anti-rejection medication as directed and report any changes in your health as soon as possible. Early detection and prevention are essential to reversing the process of rejection. Rejection usually occurs in the first three months after transplant, but it can occur at any time. Most patients experience at least one episode of rejection.

Sometimes you may experience rejection without having any symptoms at all. That is why it is very important to keep your follow-up appointments. The blood tests taken during your follow-up appointments may reveal the first signs of rejection. To find out if your organ is being rejected, we may ask that you repeat your lab tests and have an ultrasound or a biopsy. If the tests detect rejection, you will probably be admitted to the hospital for treatment and receive medication in your veins for a specific amount of time. Most rejection is reversed if it is found early, so **it is very important that you report any signs of rejection to your transplant team as soon as possible.**

Signs of Rejection

- Fever over 101.1° F
- Flu-like symptoms: chills, aches, pains, headache, fatigue, nausea, vomiting and loss of appetite
- Pain or fullness over your incision
- Elevated liver enzymes (verified with a blood test)

Infection

The anti-rejection medications you take to protect your new organ will also make your immune system weak. Since your immune system is weak, you are at greater risk for developing infections such as colds and the flu in the first three months after your transplant. You must be very careful to avoid infections, because even simple infections can be very serious to a transplant patient. During this time, you are also at the greatest risk for rejection. As a result, you will take higher doses of anti-rejection medication for the first few months after your transplant. As you get further past your transplant date, we will decrease your anti-rejection medications, and you will be better able to fight off infections. You will be taking anti-rejection medication for the rest of your life, so you will need to be very careful to avoid potential infections. If you stop or decrease your anti-rejection medication, your new organ will be rejected quickly.

Signs of Infection

- Fever over 101.1° F
- Redness, pain, or drainage at your incision
- Sore or scratchy throat
- Cough or shortness of breath
- Flu-like symptoms: chills, aches, pains, headache, fatigue, nausea and vomiting
- Diarrhea
- Poor appetite
- Burning, painful, frequent urination

You can decrease your risk of infection in a number of ways. We have listed some guidelines for you.

To Reduce the Risk of Infection

- Wash your hands often
- Maintain clean environment and good personal hygiene
- Avoid crowds
- Avoid people who may be sick
- Do not walk barefoot
- Avoid raw or undercooked meats
- Avoid raw or undercooked seafood, including sushi and raw oysters
- Avoid fresh fruits, vegetables, and flowers in the first few weeks after transplant

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- **PETS** Have all your pets checked by your veterinarian to be sure they are current with all vaccines and free of disease. Do not clean up after your pets, especially bird droppings and cat feces.
 - **VACCINES AND VIRUSES** You cannot receive any vaccines containing live viruses. These include smallpox, MMR, Shingles and oral polio. Avoid children who have received the live poliovirus vaccine. If you are exposed to chickenpox, call the Transplant Office. We do recommend a yearly flu shot, please consult your transplant team on the timing. A pneumovax vaccine for pneumococcal pneumonia should be received once every five years.
 - **GARDENING** You must wear gloves and a mask while gardening (for life- no matter how far out from transplant) to protect against molds and fungus. Wash your hands thoroughly after gardening or working outside.
 - **DENTAL WORK** You should brush and floss every day to protect from gum disease that can lead to infection. Do not have any dental work done for the first few months after your transplant. After this time, it is important to maintain regular dental appointments, because some of the immunosuppressive medications can affect your gums. A routine cleaning does not require antibiotics but do let your dentist know that you have had a transplant. Major dental work (extraction) requires oral antibiotics to prevent infection. Notify the transplant team if you are to have major dental work so that you can receive the proper antibiotics.

If you notice any symptoms of infection, report them immediately.

The Most Common Infections:

- Infection near the incision
- Infection in the mouth
- Chest or lung infection
- Urinary tract infection
- Fever blisters or herpes
- **CMV** Cytomegalovirus (CMV) is a common infection in transplant patients. Most people have had exposure to CMV at some time in their lives. If you have not been exposed to the virus and you receive an organ that has been exposed, you will need to take medication for three months after transplant. CMV has flu-like symptoms, including low-grade fever, aches, chills, and pains.

Medications

To prevent rejection, you will need to take medications for the rest of your life. Your medications must be taken exactly as they are prescribed. Failure to take prescribed medications is the number one cause of rejection.

Your transplant coordinator will give you a medication schedule that fits your lifestyle. Always use a pencil to make changes and keep it up to date. Be sure to bring your medication list with you to all your doctor appointments.

Here are some helpful guidelines to follow while taking your medication:

- Never let anyone other than your transplant team change your immunosuppressive medication.
- Never skip a dose of medication or change a dose.
- If you accidentally skip a dose of medication, call your transplant team.
- You may take your medications with or without food; we ask that you just take your medications the same way every day.
- If you are having side effects from your medication, discuss them with your transplant team. Never stop taking the medication.
- Store medications in a dry place away from heat and light.
- Do not take any over-the-counter medications, health supplements, or herbal remedies without checking with your transplant team. These medications may cause a negative reaction if taken with your immunosuppressives.
- Do not take any antibiotics without checking with your transplant team.
- Learn the names of your medications, the doses, the schedule, and the reason you are taking them.
- Always keep a list of your medications with you in case of an accident.
- You must notify your pharmacy when you need a refill. Always have a one week supply on hand. Do not wait until you are out of medicine to call.
- If you are unsure of the medicine you are taking, check with your pharmacist or transplant coordinator.
- Do not take any antibiotics without checking with your transplant team.
- Learn the names of your medications, the doses, the schedule, and the reason you are taking them.
- Always keep a list of your medications with you in case of an accident.

Medications

Helpful guidelines to follow while taking your medication (continued):

- You must notify your pharmacy when you need a refill. Always have a one week supply on hand. Do not wait until you are out of medicine to call.
- If you are unsure of the medicine you are taking, check with your pharmacist or transplant coordinator.

The following pages describe some of the medications you will be taking. The information includes the names of the drugs, the reason for taking them, and possible side effects. Generic medications may look different so check with your pharmacist if you are unsure. All of your medications may not be listed here.

Specialty Pharmacies

As you get ready to be discharged from the hospital, your transplant coordinator will help set you up with a specialty pharmacy for all of your new medications. We strongly encourage you to continue to use these pharmacies for your refills – especially for your immunosuppressant prescriptions.

While local pharmacies may not stock your medications on a regular basis, causing a delay while you wait for them to be ordered and shipped, specialty pharmacies keep a constant supply of your specific medications in stock. The specialty pharmacists and staff also understand the unique challenges you're facing after your transplant, and they offer their customers numerous additional benefits:

- The pharmacists and staff are highly educated in transplant immunosuppressant medications, and they are available to answer any questions you may have about your prescriptions and insurance benefits.
- The staff is trained in billing transplant immunosuppressants, and they know how to maximize your insurance benefits.
- You will usually receive your prescriptions within one to two business days— and there is no additional charge for shipping.
- Specialty pharmacies understand the financial challenges that you face, and they can send you a bill for your medications and set up a payment plan if needed.
- As a welcome gift, your specialty pharmacy will give you a complimentary blood- pressure monitor, thermometer, and pillbox.

Anti-Rejection Medications:

Typically you will be started on 3 antirejection medications: Prograf (Tacrolimus), Cellcept (Mycophenolate) and Prednisone after your transplant. **Please focus your reading on these 3 medications.** Over time you may be able to stop one or more of these medications. Every patient is unique and your doctor will help adjust these medications based on your specific needs.

Prograf (Tacrolimus, fk506, Envarsus or Astagraf)

PURPOSE: Prevents rejection

DOSES: 1mg, 5mg

INSTRUCTIONS:

- Always take the exact dose at the same time every day. If you miss a dose, call your coordinator.
- On the days when you have lab work, take this medication after your morning lab work.
- If you are a diabetic, check your blood sugar levels as directed and record them in your patient diary.
- Do not eat or drink grapefruit or pomegranate while taking this medication.

SIDE EFFECTS:

- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

High blood pressure

WHAT TO DO

Take your blood pressure daily. Call if your blood pressure is elevated two readings in a row. Talk to your coordinator about what “elevated” means for you

Hand tremors, shaking

Call your coordinator. Your dose may be adjusted.

High blood sugar

Your lab work will detect this. Your coordinator will discuss this with you.

Alopecia (hair loss)

Use Nioxin shampoo.

Prednisone (Deltasone)

PURPOSE: Prevents rejection

DOSES: 1mg, 5mg, 10mg, 20mg tablets

INSTRUCTIONS:

- Your dose will be tapered – that is, it will be slowly decreased over a period of time. Your transplant coordinator will discuss your tapered regimen with you.
- Always take the exact dose at the same time every day. If you miss a dose, call your transplant coordinator.
- Take with food.

SIDE EFFECTS:

- Many side effects will go away after the dose is lowered.
- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

Upset stomach

Swollen feet and legs

Increased blood pressure

Increased appetite

Insomnia

Increased blood sugar

Joint pain

Mood changes

Acne

WHAT TO DO

Take medication with food

Weigh yourself daily and call if you gain 5 pounds or more. Stay on low-salt diet.

Take your blood pressure daily. Call if your blood pressure is elevated two readings in a row. Talk to your coordinator about what “elevated” means for you

Eat three balanced meals daily. Ask to speak with your transplant dietitian

Take medication in the morning.

If your lab work indicates elevated blood sugar, your transplant coordinator will discuss this with you.

Call us if this lasts longer than 24 hours.

Call us if symptoms persist.

Wash face with PhisoHex soap three times daily. Keep hands clean. Call us if the acne does not clear up.

Cellcept (Mycophenolate Mofetil)

PURPOSE: Prevents rejection

DOSES: 250mg, 500mg

INSTRUCTIONS:

- Always take the exact dose at the same time every day. If you miss a dose, call your coordinator.
- Never crush or cut these pills. Take whole pills.

SIDE EFFECTS:

We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

Upset stomach

WHAT TO DO

Take with food. Call us if symptoms persist.

Nausea/diarrhea

Take with food. Call us if symptoms persist.

Increased risk of infection

Your lab work will detect this. Your coordinator will discuss this with you

Other Anti-Rejection Medications

If you have side effects or other issues you may be changed to one or more of the following medications:

Cyclosporine (Neoral, Sandimmune, Gengraf, Eon)

PURPOSE: Prevents rejection

DOSES: 25mg, 100mg

INSTRUCTIONS:

- Always take the exact dose at the same time every day. If you miss a dose, call your coordinator.
- Do not crush or puncture pills. Take whole pills.
- **On the days when you have lab work, take this medication after your morning lab work.**
- Do not eat or drink grapefruit or pomegranate while taking this medication

SIDE EFFECTS:

- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

High blood pressure

WHAT TO DO

Take your blood pressure daily. Call if your blood pressure is elevated two readings in a row. Talk to your coordinator about what “elevated” means for you

Thickening gums

Brush and floss teeth daily. Have regular dental checkups.

Shaking or tingling in hands or feet

Call us. We may adjust your dose.

Increased body hair

Use hair-removal cream.

Rapamune/Sirolimus

PURPOSE: Prevents rejection

DOSES: 1mg in 1ml solution, 1mg tablet, 5mg tablet

INSTRUCTIONS:

- Always take the exact dose at the same time every day. If you miss a dose, call your coordinator.
- This medication should be taken 4 hours apart from Cyclosporine and Prograf.
- If taking solution formula, mix in a glass cup with 2 ounces of water or juice and drink immediately. Refill cup with additional 4 ounces of water or juice to make sure the complete dose is taken.

SIDE EFFECTS:

- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

Delayed wound healing

WHAT TO DO

Keep wounds dry and clean. Call us if there are signs of infection.

Increased cholesterol

Eat a low-fat diet. We will monitor these and triglycerides levels with your lab work.

Rash

Call us.

High blood pressure

Take your blood pressure daily. Call if your blood pressure is elevated two readings in a row. Talk to your coordinator about what “elevated” means for you

Blood Pressure Medications

Because high blood pressure is a common side effect of your anti-rejection medication, you may be placed on high blood pressure medication. You may be on one of these medications only for a short time or until your anti-rejection medications are decreased. You may have been on high blood pressure medications prior to your transplant. If so, your dose or medication may change.

Here is a list of the most common blood pressure medications:

- Procardia, Adalat (Nifedipine)
- Norvasc (Amlodipine)
- Coreg (Carvedilol)
- Lopressor or Toprol XL (Metoprolol)
- Hydral (Hydralazine)
- Catapres (Clonidine)

Please call your coordinator if you have any of these potential side effects:

- Headache
- Dizziness
- Nausea
- Flushing
- Unusual heartbeats
- Swelling in legs and feet
- Muscle cramps

It is very important to check your blood pressure every day, especially if you are on high blood pressure medication. You should keep a record of your blood pressure readings in your patient diary.

Prevacid/Protonix/Nexium/Pepcid

PURPOSE: Protects the stomach from acid, which can cause ulcers.

DOSES: Prevacid 30mg capsules; Protonix 20mg and 40mg capsules; Nexium 20mg and 40 mg capsules; and Pepcid 20mg tablets

INSTRUCTIONS:

- Do not break capsules.
- Take whole.
- Take with or without food.

SIDE EFFECTS:

- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

Itching

WHAT TO DO

Call us

Increased cholesterol

Take with food. If symptoms persist, call us.

Aspirin

PURPOSE: Prevents blood from clotting.

DOSES: 81mg tablet

INSTRUCTIONS:

- Take with a glass full of water.
- Do not take anything else that contains aspirin.

SIDE EFFECTS:

- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

WHAT TO DO

Bleeding

Call us immediately

Bleeding gums

Call us immediately

Bloody urine

Call us immediately

Bruising

Call us immediately

Stomach pains

Call us immediately

Nosebleeds

Call us immediately

Bactrim/Dapsone/Septra

PURPOSE: Prevents infection

DOSES: Single Strength

INSTRUCTIONS:

- Take with a glass full of water.
- Take Bactrim SS as prescribed.
- Drink plenty of water while taking this medication

SIDE EFFECTS:

- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

Itching/Rash

Sensitive to the sun

Nausea/vomiting

Bruising

WHAT TO DO

Call us.

Wear sunscreen SPF 15 or greater

Take with food. Call us if symptoms persist

ALLERGIC REACTION:

If you are allergic to sulfa medications you may be given an alternative medication.

Nystatin or Mycelex

PURPOSE: Prevents fungal infection in the mouth, called thrush. Thrush is a white plaque-like substance that can form in the mouth as a result of high-dose steroids (Prednisone). As your Prednisone dose decreases, we will stop the Mycelex.

DOSES: Mycelex 10mg tablets or Nystatin liquid

INSTRUCTIONS:

- Mycelex- Do not chew. Suck on the pill and let it dissolve in your mouth.
- Nystatin – shake well before each use
- Take this medication after meals and at bedtime.
- Do not eat or drink for 20 minutes after taking the tablet.
- Remove dentures or retainers before taking this medication.

SIDE EFFECTS:

- We have listed some of the common side effects along with things you can do at home to help with the symptoms. Remember that these are just guidelines. If any of the side effects persist, or if you are unsure what to do, call us.

SIDE EFFECT

Stomach ache

WHAT TO DO

Call us.

Diarrhea

Call us.

Nausea/vomiting

Call us.

Supplements

You will be given **magnesium supplements** for several months or longer after your transplant to replace the magnesium lost in your urine as a result of taking Prograf or Neoral. If your magnesium level falls too low, you are at an increased risk for experiencing seizures or worsening nervous system side effects such as tremors and headaches. You are also encouraged to eat foods high in magnesium, such as green leafy vegetables and legumes (lentils, peas). However, high doses of magnesium may cause diarrhea, in which case reducing your magnesium dose may be appropriate. It is important to separate your magnesium supplement from your Prograf by at least one hour. Talk with your coordinator before changing or adding any supplements.

Multivitamins are safe to take with the understanding that they are not substitutes for good nutrition through a well-balanced diet. If you are told that your potassium level is too high, you will need to find a multivitamin that is low in potassium.

You may require an **iron supplement** due to anemia. Anemia is common for the first one or two months after liver transplantation, because it takes time for your body to replenish the blood cells you may have lost during your transplant surgery. Poor kidney function and some of your medications also can contribute to anemia. Vitamin C may be prescribed with your iron supplement to improve absorption of the iron.

Folate also may be added as a supplement for anemia. Iron supplements can cause constipation and dark stools, as well as nausea and upset stomach.

Calcium supplements such as TUMS or Os-Cal (oyster calcium) may be prescribed for patients at high risk for osteoporosis, such as women who are no longer menstruating (postmenopausal) or patients who already have documented osteoporosis. Fosamax, vitamin D, and sodium fluoride also may be given with the calcium to help strengthen bones.

Pain Medications

You will be given up to 1 week of pain medication (usually Tramadol or Tylenol with codeine) upon discharge from the hospital to reduce pain caused by your transplant surgery (incisional and muscle pain). You will not be given refills by any member of the transplant team for this pain medication when you have used it up. If you are continuing to experience considerable discomfort for which there is a good cause that has been identified by examination, you may be given a refill. Your surgical pain should be markedly improved within four to six weeks after your transplant and should be controllable by then with Tylenol. If it is not, you should contact your coordinator so that the cause of your ongoing pain can be understood and treated appropriately.

You must not take nonsteroidal anti-inflammatory drugs (NSAID) at any time post-transplant, unless specifically ordered by your transplant physicians, due to the risk of kidney damage. Common NSAID to avoid are Motrin, Advil, Aleve, Naproxen, Ibuprofen, Orudis, Indomethacin, Meloxicam or Aspirin (doses over 81 mg).

Over-the-Counter Medications

The following over-the-counter (OTC) medications are safe to take, but any symptoms for which you are taking medications that persist longer than 24 hours should be brought to the attention of your transplant coordinator.

- Tylenol (for headache, pain; NOT FOR FEVER until coordinator is notified)
- Chlortrimeton (for colds, decongestion)
- Mylanta (antacid)
- Colace/Docusate (for constipation)
- Benadryl (for insomnia, itching)

Again, nonsteroidal anti-inflammatory drugs should be avoided. Any cold medications or decongestants containing pseudoephedrine should be avoided because they can cause or worsen high blood pressure



NOTES

DATE:



NOTES

DATE:

Caring for Yourself at Home

Incision Care

When you leave the hospital, you will be responsible for caring for your incision. You will be going home with your staples in place. The staples will be removed at the clinic in about four weeks. If your incision is healing well, you may shower. Do not take a tub bath, however, until the staples are removed. Sitting in a bathtub may increase the risk of infection to your fresh wound. Use an antibacterial soap for cleaning. After your staples are removed, steristrips will be placed across the incision. You may then shower or bathe. Do not remove the steristrips. They will fall off on their own in about five days.

Nutrition and Diet

Following a healthy eating plan after transplant is important to maintain your overall health. Your entire family can follow this eating plan to achieve and maintain good nutrition. Most foods you enjoy can fit into your eating plan. A registered dietitian is available to work with you after your transplant to individualize a plan for you. The nutrition goals include:

- Maintenance of your ideal body weight
- Weight loss if overweight (a BMI greater than 30)
- Low saturated fat and cholesterol intake
- Low sodium (salt) intake

A dietitian is available both during your hospitalization and in the outpatient clinic to help guide you with your nutrition goals.

Immediately following your transplant your body has increased nutrition needs, especially for protein. Protein helps with wound healing, replaces lost muscle mass, and counteracts the breakdown of muscle tissue that can result from prednisone, a medication you may receive. High quality protein is found in poultry, fish, lean beef, egg whites, and low-fat dairy products.

For the first several weeks after transplant (approximately two to four weeks), you should consume extra protein. Unless instructed by your dietitian, 15 to 20 extra grams of protein a day should be adequate. This amount would be 3 ounces of meat or two 8-ounce glasses of milk or yogurt daily.

In order to maintain your long-term after transplant, you should aim for a heart-healthy lifestyle. A heart-healthy diet consists of whole grains, fruits, vegetables, low-fat dairy products, fish (such as tuna, salmon, or mackerel), poultry, legumes, and lean meats.

Saturated fat, salt, and excessive sweets should be limited. In preparing meats, try baking, broiling, grilling, sautéing, boiling, or roasting instead of frying. Use vegetable oils, such as canola or olive oil, rather than butter, shortening, lard, or meat fat. Choosing healthy foods and limiting portion sizes are the keys to an ideal diet after transplant.

Foods to Avoid

Following a transplant avoid grapefruit and pomegranate juice, as it interacts with some of the medications you may be taking. Food safety is very important after transplant because your body is more susceptible to infections while on immunosuppressive medications. Always wash your hands before cooking and avoid cross contamination of foods in the kitchen. Consider having different cutting boards for meats and vegetables, or always cut your vegetables first. Cooking food to appropriate temperatures is vital. Buy a meat thermometer to ensure all meats are appropriately cooked. The “danger zone” for bacteria growth is 40°F to 140°F. Do not leave food sitting on the counter after meals and refrigerate leftovers quickly to minimize time food spends in the danger zone. When eating out, avoid raw seafood, such as raw oysters, sushi, or seared (undercooked) tuna, because bacteria and parasites can be found in uncooked seafood. We also suggest you avoid raw eggs and sprouts and forgo buffets and salad bars.

Medications and Their Influence on Diet

Some immunosuppressive medications impact your nutritional status in a variety of ways. Medications may affect your blood glucose (sugar), cholesterol, or triglyceride levels. To improve your blood sugar levels, avoid overeating and limit sweets. Eating several smaller meals a day instead of one or two large meals can help control blood sugar levels, and limiting drinks containing sugar may help control blood sugars and weight gain. Limit juice to no more than 8 ounces a day. Try to avoid regular soda, energy drinks, sweet teas, lemonades, and flavored waters. Instead try the diet or sugar-free varieties. A low-calorie drink should have no more than 10 calories per serving. Ask your dietitian if you have questions about your beverage intake. If you were diabetic pre-transplant, you may need adjustments in your diabetes medications. Sometimes modifications in your diet may not be enough to maintain normal blood glucose levels and you may require medications. A member of the transplant team and your dietitian will help determine if you need medications.

Following a heart-healthy eating plan can help maintain or lower cholesterol and triglyceride levels. See the following pages for detailed information about a heart-healthy diet. Medications can sometimes cause an increased appetite, which can be difficult and frustrating. Overeating as a result of increased appetite can lead to unwanted weight gain. If you are feeling hungry, try avoiding food by engaging in other activities such as a walk, hobbies, or talking with friends. Also try drinking a low-calorie beverage to help your stomach feel full. Sometimes you may have to remind yourself not to eat, or keep a food journal to determine which times of day you are particularly hungry. Your dietitian can help you figure out an eating pattern to avoid excessive appetite and limit weight gain.

Balancing Calories and Exercise

The key to prevent weight gain is to balance your calorie intake with daily activities and exercise. Exercise can help maintain a healthy weight, and you are encouraged to walk daily. Several 10- to 15-minute walks can be just as effective as one 30- to 40-minute walk. Once you are comfortable walking for 20 to 30 minutes, varying the speed and the incline (include hills) can help burn more calories. Swimming is also a great form of exercise, but make sure to only swim in clean water. Lakes, rivers, and some public pools may contain excessive bacteria. If you choose to work out at a health club, wipe down your machine with antibacterial wipes before you use it. Exercise bikes and elliptical machines are good low-impact exercise options.

During the first six to eight weeks following your transplant surgery, you need to be careful about straining your body too much.

- Do not lift objects heavier than ten pounds
- Do not push or pull objects heavier than 15 pounds, unless instructed by a physical therapist
- Do not attempt weight-lifting, sit-ups, push-ups, or pull-ups
- Discontinue any activity that causes pain or pulling across your abdomen or incision area


Weight gain can be a concern after a successful transplant. If you are concerned about gaining weight or need to lose weight, talk to your dietitian.







Some general tips include:




- Using a smaller plate to limit your portion sizes
- Buying foods in small quantities and avoiding purchasing unhealthy foods
- Limiting drinks with calories
- Taking some of your meal home when eating out.
- Following a heart healthy diet

In addition to walking and working out, try incorporating exercise into your daily routine. When doing errands, try parking farther away from the store, or take the stairs instead of the elevator. Take a walk at lunch time or meet a friend for a walk or bike ride instead of a meal. Purchase some dumbbells and exercise while watching television

After transplant, you will make many changes in your lifestyle. Eating healthy and exercising daily can be part of a healthy lifestyle that you and your family can enjoy together.







Eat most of your foods from the “Choose” list. Remember to also limit foods marked with a SALT SHAKER  that are high in sodium.





Heart Healthy Eating Plan		
Meats and Protein	Choose	Limit
<p>Eat 6 ounces per day, which is the size of two decks of playing cards</p> <p>1 serving = 3 ounces (cooked), 4 ounces (raw), 1 large egg</p>	<ul style="list-style-type: none"> • Prepare by broiling, baking, roasting, grilling, microwaving, poaching, pan frying with nonstick spray • Lean ground beef, chicken, or turkey (at least 90% lean) • Lean cuts of beef, lamb, pork, and veal with fat trimmed, such as loin or round • Chicken without skin • Fish (tuna, mackerel, or salmon) • Shellfish • 95% fat-free lunch meats  • Eggs (2 to 4 yolks a week); use more egg whites or egg substitute • 2 tablespoons peanut butter • 1 cup cooked dry beans, peas, or lentils 	<ul style="list-style-type: none"> • Deep-fat Frying • Smoked or cured meat, such as ham  • Sausage or bacon  • Regular ground beef such as ground chuck, corned beef , or prime rib • Pork spareribs • Goose or duck • Poultry (dark meat, drumsticks, or buffalo wings) • Organ meats such as liver, kidney, brain, and sweetbreads • Regular lunch meats  • Hot dogs (beef, pork, turkey, or chicken) 

Dairy Products	Choose	Limit
<p>Eat 2 to 4 servings per day.</p> <p>1 serving = 1 cup of yogurt or milk, 1 ounce of cheese, ½ cup cottage cheese</p>	<ul style="list-style-type: none"> • Nonfat (skim) or 1% (low-fat) milk including evaporated skim milk • Low-fat buttermilk  • Low-fat or fat-free yogurt • Greek yogurt • Fat-free or low-fat cheese  (2 to 6 grams of fat per ounce) • Fat-free or low-fat cream cheese • Fat-free creamers • Fat-free or low-fat sour cream • Soy milk with calcium 	<ul style="list-style-type: none"> • Whole, 2%, evaporated or condensed milk • Whole-milk yogurt • Whole-milk cheese  • Regular cream cheese • Cream, half-and-half, powdered creamers with palm kernel oil, palm kernel oil, or coconut oil • Regular sour cream, or cream cheese

Fruits/Vegetables	Choose	Limit
<p>Eat 2 to 4 fruits per day.</p> <p>1 serving = 1 small piece of fresh, ½ cup frozen or canned, or 4 ounces 100% fruit juice</p> <p>Eat 3 to 5 servings vegetables per day.</p> <p>1 serving = ½ cup cooked or 1 cup raw</p>	<ul style="list-style-type: none"> Choose colorful fruits and vegetables, fresh, frozen, or canned Choose a variety to meet vitamin/mineral needs Try low-fat cooking methods such as steaming, sautéing, broiling, grilling, or microwaving Canned vegetables (labeled No Added Salt, or rinse prior to use) Canned fruits packed in juice or light syrup Monitor your potassium level and watch potassium content of fruits and vegetables if needed 	<ul style="list-style-type: none"> Avoid frying Vegetables prepared with butter, cheese, whole milk, or cream sauces Vegetables prepared with bacon, bacon grease, fatback, lard, or salt pork ⚠ Vegetables soaked in brine or pickled such as pickles and olives ⚠ Coconut and coconut milk

Breads, Cereals, Pasta, Rice, Dried Beans and Peas	Choose	Limit
<p>Eat 6 to 11 servings per day, aim for 3 servings as whole grains</p> <p>Whole grains = brown rice, whole-wheat pasta and wheat bread</p> <p>1 serving = ½ cup of cooked cereal, pasta, rice; ¾ cup of puffed cereal; 1 slice bread; ½ an English muffin, small bagel, or bun</p>	<ul style="list-style-type: none"> Whole-grain breads such as whole wheat, multigrain, pumpernickel, or rye Plain small bagels, English muffins, dinner rolls, rice cakes Pancakes, waffles, muffins, biscuits (made with low-fat ingredients) Hot cereals (instant) ⚠ Most cold cereals (choose unsweetened cereals with at least 5 grams of fiber per serving) Pasta/Noodles (try whole-wheat versions) Brown rice Dried beans and peas Low-fat and low-salt crackers (such as saltines) 	<ul style="list-style-type: none"> Croissants, butter rolls, biscuits, sweet rolls, doughnuts, Danish, pastry, and muffins Crackers or cereal with no greater than 3 grams of fat per serving Granola cereals Foods made with cream, butter, and cheese sauces ⚠ Ramen noodles ⚠

Fats and Oils	Choose	Limit
<p>3 to 4 servings per day</p> <p>1 serving = 1 teaspoon oil, regular margarine, butter, or mayonnaise 1 tablespoon low-fat margarine or mayonnaise</p> <p>2 teaspoons of regular salad dressing or 2 tablespoons low-fat salad dressing</p>	<ul style="list-style-type: none"> Vegetable oils such as canola and olive oil are best Nonstick cooking spray Margarines labeled “no trans-fat per serving”  Liquid or lower-fat tub margarine or substitutes  Low-fat or fat-free mayonnaise and salad dressings  Avocados Unsalted nuts such as almonds, or walnuts Unsalted seeds such as sunflower 	<ul style="list-style-type: none"> Butter, lard, coconut oil, palm kernel oil, palm oil, meat fat and drippings, vegetable shortening, bacon fat,  and fatback  Margarine with hydrogenated oil as the first ingredient Other trans fats such as shortening or deep-fat-fried food Dressings made with egg yolks Regular gravy 

Sweets and Snacks	Choose	Limit
<p>Limit</p> <p>Avoid if your blood sugars are elevated or you take insulin</p>	<ul style="list-style-type: none"> Low-fat frozen desserts such as sherbet, sorbet, ices, low-fat ice cream or yogurt, or popsicles Homemade baked goods with low-fat ingredients Angel food cake, fat-free baked goods, fig bars, gingersnaps, or animal crackers Pudding with nonfat milk Plain popcorn, bread sticks, or pretzels  	<ul style="list-style-type: none"> Ice cream and frozen yogurt made with whole milk Cakes, pies, store-bought cookies and pastries, doughnuts Chocolate, coconut Buttered popcorn , potato chips , corn chips Most snack crackers  High-sugar sweets and beverages

Dining Out	Choose	Limit
<p>Limit</p>	<ul style="list-style-type: none"> Grilled, baked, broiled, roasted, steamed, or poached foods Ask for salad dressing, sour cream, butter, and cheeses on the side so you can control your portions Request no butter, oil, or other fat added to your vegetables and entrées Divide your portion and take food home 	<ul style="list-style-type: none"> Battered, deep-fried, or crispy food items Watch the portion sizes of your meal Appetizers with high-fat dips or sauces Regular salad dressings, sauces, and additives Cream sauces (avoid)

Safe Food Handling

As a transplant recipient, you are on multiple immunosuppressive medications. These medications keep your body from rejecting or attacking your new organ, so it is vital to always take them. However, the immunosuppressives can put you at great risk for foodborne illness. For this reason, it is very important that you practice good food safety. According to the USDA, the four basic steps to food safety are:

Clean: WASH HANDS AND SURFACES OFTEN

Separate: DON'T CROSS CONTAMINATE

Chill: REFRIGERATE FOOD PROMPTLY

Cook: COOK FOODS TO PROPER TEMPERATURES

You cannot eat certain foods due to risk of foodborne illness. **Do not eat:**

- Raw or undercooked seafood such as sushi, sashimi, and seared tuna.
- Raw, undercooked, or rare meat.
- Raw eggs or products that contain raw eggs.
- Undercooked, runny, soft-boiled, or over-easy eggs.
- Unpasteurized juice or milk (such as fresh cider).
- Sprouts
- Avoid unpasteurized soft cheeses such as feta, Brie, Camembert, and blue- veined cheeses.

Always avoid having food in the “Danger Zone” of 40-140°F

- Keep foods at the correct temperature to help slow bacteria growth.
- Store cold foods below 40° F.
- Keep hot foods above 140° F.
- If food has been in the “Danger Zone” during shopping, transportation, cooking, or eating for two hours or more, THROW IT OUT.
- If the outside temperature is over 90° F and food has been in the “Danger Zone” for one hour or more, THROW IT OUT.

Tips:

- Buy a cooler bag and use it when transporting food from the grocery store.
- Shop close to home to limit transportation time.
- When shopping, add perishable items to your cart last.

Clean

- Wash hands in warm, soapy water for at least 20 seconds. Wash before and after handling food and after using the bathroom, changing diapers, or handling pets.
- Wash cutting boards, dishes, utensils, and countertops with cleaner or hot and soapy water often.
- Use paper towels or antibacterial wipes to clean counter tops. Do not use sponges or cloth towels.
- Wash ALL produce well. Firmly rub skinned fruits and vegetables under running water.
- Wipe off lids of canned goods before opening.

Tips:

- Get in the habit of washing your hands or using a gel sanitizer every time you return to the house.
- Keep antibacterial wipes available on the counter for quick clean-up of counters, faucets, and door handles prior to and while cooking food.
- Consider using a vegetable wash or a little dish soap on firm-skinned fruits and vegetables.

Separate








- Separate raw meat, poultry, and seafood from other food while shopping and in the refrigerator.
- Store eggs in the original container.
- Never reuse marinades.
- Never place cooked food on a plate or in a container that held raw food without washing it with hot, soapy water first.

Tips:

- When shopping, place raw meat, seafood, and poultry in plastic bags.
- Do not use reusable shopping bags for transporting meat, seafood, and poultry.
- Store raw meat, seafood, and poultry in plastic bags, on a plate, or in a container in the refrigerator on the bottom shelf.
- Use a different cutting board for produce and raw meat – try color-coded boards.
- Wash cutting boards after each use in warm, soapy water or in the dishwasher.
- Avoid wooden cutting boards for meat, seafood, and poultry.

Cook

- Food must be cooked to the recommended internal temperature regardless of cooking method (baking, grilling, or microwaving).
- Use a food thermometer to check foods for doneness at the appropriate temperature.
- Color is not an appropriate indicator of when a food is cooked through.
- Wash the food thermometer in warm, soapy water after EACH use.
- When microwaving, avoid cold spots in the food by removing it and stirring partway through cooking.
- Generally, the food thermometer goes into the thickest part of the meat or the middle of a dish. Avoid areas with bones or fat. With ground beef patties, insert the thermometer at an angle.

USDA Recommended Safe Minimum Internal Temperatures						
Steaks and Roast	Fish	Ground Beef	Pork	Egg Dishes and Casseroles	Chicken Breast	Whole Poultry
						
145° F	145° F	160° F	160° F	160° F	165° F	165° F

- Soups, sauces, gravy, and leftovers must be heated to 165° F.
- Turkey or chicken stuffing must be cooked to 165° F and cooked separate from the bird.
- Reheat hot dogs, and deli meats to 165° F.
- Fish should be firm, and flake easily with a fork.

Chill

- Chill foods to 40° F or below to prevent bacteria growth. Check the temperature in the refrigerator with an
- Appliance thermometer. Refrigerate foods within two hours of cooking or purchasing.
- Chill large quantities of food in shallow dishes (no deeper than two inches) to cool quicker.

More Tips

Thawing

- Thaw food in the refrigerator or under cold running water.
- Do not thaw food on countertops.
- If you thaw food in the microwave, cook it immediately.
- Thawed food should not be refrozen.

Eating Out

- Make sure all meats are thoroughly cooked.
- Avoid salad bars and buffets.
- At barbeques and potlucks, monitor temperatures of foods and don't eat anything that has been sitting out for over an hour.
- Refrigerate leftovers within two hours of the food being served.

Tips for the Grocery Store

- The “Sell-By” date is the date the product needs to be sold before it expires. DO NOT buy food past the sell-by date and use or freeze all food before the sell-by date.
- The “Best if Used By” date is the date recommended for quality. It is not a safety date.

At Home

- Resealable zipper storage bags are for single use only.
- Replace sponges often.
- Use clean scissors or blades to open bags.
- Discard all cans with dents, rust, or bulges.
- Eat leftover meat within two days and eat leftover pastas and vegetables within four days.



NOTES

DATE:

Activities

You should not drive a car for at least one month after transplant. This is to protect your new organ from injury in case you are in an automobile accident and the steering wheel were to hit you near your wound. Your vision and depth perception may also be impaired during this time due to the higher doses of anti-rejection medication. If you ride in a vehicle, wear a seatbelt. The seatbelt will not hurt your new organ. If you have a partially healed wound, then you may place a small towel or pillow under the seatbelt for protection.

You may return to work or school when you feel that you are ready. Remember that you will have regular appointments and lab tests included in your schedule. The goal is to get you back to a normal, productive life after transplant.

You may resume sexual activity when you and your partner are ready. Condoms are vital to prevent the spread of diseases, especially if you have hepatitis. Birth control is recommended for all patients. You should wait at least one year after transplant before considering pregnancy or fathering a child. Many men become impotent as a result of their liver disease. After transplant, sexual function normally returns. However, some post-transplant medications can prolong periods of impotency. Feel free to discuss your concerns with your doctor or coordinator. Many females who have not had menstrual cycles during their disease will see them return within a few months after transplant. Ovulation can resume even before the cycles begin. This is why it is important to use birth control and discuss concerns about childbearing with your transplant team. We recommend that all women use a condom, diaphragm, and spermicides. IUDs are not recommended due to the increased risk of infection. **Check with your transplant team before considering birth control pills or the Norplant system.**

We advise patients not to do any extensive traveling during the first six months after their transplant. Traveling to third-world countries is prohibited due to the risk of exposure to serious infections. When you are considering traveling, please check with your transplant team before making any arrangements. We can often provide you with the name and number of a physician in the area of travel in case of emergency. Remember to keep your medications with you while you are traveling, and never place them in a bag that needs to be checked at a terminal. This will prevent you from ever being out of medicine in case your luggage does not meet your destination. Consider wearing a medical alert bracelet when traveling or at home. This will help other physicians know your general health status in case of an emergency.

Healthy Lifestyle

It is important to maintain a healthy lifestyle after transplant. Compliance with prescribed diet and weight will help you do this. You must also avoid tobacco products, alcohol, and illegal drugs. Healthy lifestyle choices will maximize the function of your new liver and improve your quality of life.

Risk of Cancer

Because you are taking immunosuppressive medications, you are at increased risk for developing certain cancers. The most common type is skin cancer.

Here are some suggestions for decreasing sun exposure:

- You must wear SPF 15 sunblock or greater.
- Wear protective clothing, including hats and long sleeves.
- Limit time in the sun. Avoid the sun between 10 am and 2 pm.
- Never use artificial tanning beds, tanning lotions, or tanning lamps.
- Examine your skin regularly and look for changes. Report any new or different- looking moles or lesions to your transplant team.

Healthcare Provider Appointments

Once you have been discharged from the hospital, your transplant coordinator will discuss your follow-up visits. We will schedule you for an appointment with the transplant clinic before you go home. We will also schedule lab tests for you. Your coordinator will advise you as to when and where your tests are to be done. Your lab tests may be as frequent as twice a week. For these tests, you will receive standing orders. Always keep a copy of your standing orders with you when you go for lab work. The results of these tests will be sent to the transplant office for review. You are responsible for keeping your appointments. If you cannot make an appointment, please call the transplant office so we can make other arrangements. Remember that lab tests can be the first sign of organ rejection. Obtaining lab tests is vital to managing your care.

We prefer that you have your lab tests done in the morning. This gives us time to review them and call you back the same day with results. Also, having your lab work done in the morning gives you time to repeat the lab work that same day if necessary. We use your lab work to monitor your anti-rejection medication levels. **For that reason, we ask that you do not take your morning dose of immunosuppressive (Cyclosporine, Prograf, Rapamune). Wait until after your labs are drawn to take this medication.** You must never miss a dose of medication; therefore, your blood tests need to be done 12 hours after the dose the night before. If this is not done correctly, you may need to have your lab work repeated.

After your transplant, it is very important to have regular checkups with your primary care physician for routine cancer screening and healthcare maintenance. You might also return to your gastroenterologist or hepatologist between visits to the transplant center. You should see your dentist at least once a year and have a yearly eye exam with an ophthalmologist. We recommend that you wait at least three months after your transplant before scheduling an eye exam or changing your eyeglass prescription because of the effect Prednisone may have on your eyesight shortly after the transplant. Women should have a yearly gynecological exam and mammogram. Men should have a yearly prostate screening. You are responsible for maintaining these visits along with your visits to the transplant center.

Communicating with the Donor Family

Transplantation is made possible only through the generosity of organ donors and their families. Each year thousands of people are given a second chance at a time when the donors' loved ones are experiencing profound grief. Many families report that their reason for donating was to help someone, and they frequently say that this act of selflessness created a positive moment during an otherwise devastating event. Often they want to learn the outcome of the donation and the difference it has made in someone's life. This personal account from the recipient can bring the family comfort and help them to heal.

When you're ready, we encourage you to write a letter of thanks to your donor's family. These letters are anonymous. Neither the donor family nor the recipient is identified by name. In the letter you may include your first name, marital status, occupation, hobbies, condolences to the family, and how the transplant has and will affect your life. All letters remain confidential and are mediated by the local organ procurement organization. You may not include your last name, date of transplant, or place of transplant in your letter. If you need help writing it, your transplant social worker or coordinator can assist you.

After you have written your letter:

- Place it in an unsealed envelope.
- On a separate sheet of paper write your full name, date of transplant, and the organ you received.
- Then place all the material, the envelope holding your letter to the family and the separate piece of paper with your personal information, in an envelope and give it to your transplant social worker or coordinator.

To Remember Me

By Robert N. Test

Give my sight to the man who has never seen a sunrise, a baby's face or love in the eyes of a woman.

Give my heart to a person whose own heart has caused nothing but endless days of pain.

Give my blood to the teenager who was pulled from the wreckage of his car, so that he might live to see his grandchild play.

Give my kidneys to the one who depends on a machine to exist from week to week.

Take my bones, every muscle, every fiber and nerve in my body and find a way to make a crippled child walk.

If you must bury something, let it be my faults, my weakness and all prejudice against my fellow man.

Give my sins to the devil.

Give my soul to God.

If, by chance, you wish to remember me, do it with a kind deed or word to someone who needs you.

If you do all I have asked, I will live forever.

Understanding Your Lab Tests

After your blood is drawn, your coordinator will discuss your results with you and make medication changes if necessary. Most lab results are available the same day; however, there are times when the blood must be sent to an outlying facility, and it may take a few days to get the results. A copy of your lab results will be sent to your primary physician or gastroenterologist.

We have included a description of some common lab tests:

ALBUMIN

(normal range 3.2–5.5 g/dL)

A blood protein produced by the liver. Decreases may indicate malnutrition and liver damage.

ALKALINE PHOSPHATASE:

(normal range 30–115 U/L)

An enzyme present in the liver, bones, and intestinal tract. Elevations may occur with bone disease or if there is a blockage of the bile ducts, as in primary biliary cirrhosis and primary sclerosing cholangitis.

AST/ALT: (normal range 5–50 U/L)

Enzymes found in the liver. An increase may reflect damage to the liver, such as hepatitis, infection, or rejection.

BILIRUBIN:

(normal range 0.4–1.5 mg/dL)

A bile pigment in the blood. An increase may reflect breakdown of red blood cells or liver damage.

GGT: (normal range 8–78 IU/L)

An enzyme present in the liver and gall bladder. May be elevated with bile duct disease or liver damage. GGT is a very sensitive test, so it may be elevated in normal, healthy adults.

CREATININE:

(normal range 0.7–1.5 mg/dL)

A waste product that is found in muscle and blood and is removed by the kidneys. An elevation may indicate dehydration or immunosuppression toxicity.

Understanding Your Lab Tests

GLUCOSE:

(normal range 70–125 mg/dL) The amount of sugar in your blood. Increases are often seen with diabetes and with patients on steroids.

POTASSIUM:

(normal range 3.5–5.0 mEq/L) A salt present inside cells. An increase may be seen with immunosuppression toxicity. Diuretics or “water pills” can increase or lower the value.

TOTAL CHOLESTEROL:

(normal range 0–200 mg/dL)

TRIGLYCERIDES:

(normal range 0–250 mg/dL)

Fats found in the blood. If these are elevated, you may need to decrease the fat and cholesterol in your diet, or you may need to take medication to lower these values. Elevations can also be seen with certain immunosuppressive medications.

PROTHROMBIN TIME (PT):

(normal range 11–13 seconds)

A protein that helps your blood clot. Increases can indicate significant liver damage.

CYLCOSPORINE/PROGRAF/ RAPAMUNE:

Drug levels are obtained and your medications are increased or decreased to maintain therapeutic levels of the drug. This is important to keep your body from rejecting your new organ.

When to Call Your Coordinator

Because it's natural to feel overwhelmed by all of the information you have received while in the hospital, we have compiled this book to help guide you when you're home. After you leave the hospital, it is your responsibility to inform us of any changes or problems with your health. A member of the transplant team is available 24 hours a day, 7 days a week, and we urge you to call us if you have any questions or difficulties. The following guide will help you determine the urgency of your concern:

Call us immediately if you have:

- Any signs of infection or rejection (please refer to the first two sections of this book for information about infection and rejection)
- Temperature above 101 degrees
- Nausea and/or vomiting
- Redness, swelling, or drainage around your incision
- Any aches or pains that are rated 7 or greater on the pain scale of 1 to 10, or pain that is unrelieved by pain medication
- A visit to the ER or a hospitalization outside your transplant center
- Missed any doses of medication
- Finger-stick blood sugar measurement greater than 400 or less than 65
- Changes in blood pressure, especially if you are also dizzy or have a headache

Call during normal business hours or make a note of the problem to discuss at your next clinic visit if you have:

- Gained or lost more than 5 pounds in 2 days
- Swelling
- Constipation or diarrhea
- Received care from another physician
- Received new medication prescribed by another physician
- Bruised easily
- A persistent cough
- A sore throat

When to Call Your Coordinator

Because the on-call coordinator may not have the access to your medical file, please reserve calls regarding the following for normal business hours when we are best able to be of assistance:

- Lab results
- Medication changes
- Appointment time or rescheduling
- Medication refills – unless you are completely out and are in need of an immediate refill

If you are calling because you are ill, you should have the following information readily available to discuss with your transplant team:

- Temperature
- Weight
- Blood sugar, if applicable
- Blood pressure and pulse
- List of current medications
- Name and phone number of pharmacy

Transplant Test

You must be able to pass this test before you are discharged from the hospital:

1. It is 5 pm on Friday. You realize that you forgot to take your Neoral/Prograf that morning. What do you do?
2. You wake up at 3 am with chills, nausea, and vomiting. What would you do?
3. How long must you wait before driving a car?
4. You have a dental appointment to have your teeth cleaned next week. What should you do first?
5. You open a new bottle of medication and it looks different. What should you do?
6. You have been discharged from the hospital, and a week later your friend wants you to go to the movies. What would you do?
7. Your stomach has been upset. You vomit after taking your medication. What do you do?
8. You have a clinic appointment at 8 am. What things must you bring to the clinic?
9. Rejection always leads to loss of your transplanted organ. True or false?
10. What are some signs of infection?
11. What are some signs of rejection?
12. Rejection is common and should be expected at some time after a transplant. True or false?
13. When is it appropriate to call for refills on your medications and whom do you call?

Sources of Support

METHODIST DALLAS MEDICAL CENTER

Transplant Support Group

Hosted by the transplant social workers at Methodist Dallas Medical Center

SOUTHWEST TRANSPLANT ALLIANCE (STA)

8190 Manderville Lane

Dallas, TX 75231

214-522-0255

Organ Transplant Support

Provide education, support, and resources for transplant families and also to promote organ and tissue donor awareness

630-527-8640

www.organtransplantsupport.org

AMERICAN LIVER FOUNDATION

39 Broadway, Suite 2700

New York, NY 10006

800-465-4837

www.liverfoundation.org

Transplant Living

www.transplantliving.org

TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION, INC.

TRIO is a nonprofit organization committed to improving the quality of life for transplant recipients.

www.trioweb.org

AMERICAN DIABETES ASSOCIATION (ADA)

800-342-2383

www.diabetes.org

Patient Diary

You will need to keep a patient diary so that we can track your progress at home. Your coordinator will let you know what needs to be recorded and for how long. You will need to bring this diary with you to all clinic appointments for review.

Temperature

Take your temperature if you feel chilled, have flu-like symptoms, or have any sign of infection. If your temperature is higher than 101.1° F, call us!

Blood pressure

Check your blood pressure every morning and evening, especially if you take blood pressure medications. Call us if you have two readings in a row that are elevated. If you have an elevated or significantly decreased number, take your blood pressure in both arms and call us. We may need to adjust your medication. Your coordinator will tell you what “elevated” means in your case.

Weight

Weigh yourself every morning before breakfast. If you have a weight gain of 5 pounds or more in two days, call us.

Blood sugar

If you have diabetes or a problem with increased blood sugar, then you may need to check your blood sugar before each meal and at bedtime. If you need to check your blood sugar at home, the diabetes educator will give you instructions on how to do this before you go home.

PATIENT DIARY

Date	WT	Temp- AM	Temp- PM	BP- AM	BP- PM	Blood Sugar- AM	Blood Sugar- PM	Symptoms & Comments

WT: Weight Temp: Temperature BP- AM: Blood Pressure Morning BP- PM: Blood Pressure Evening

PATIENT DIARY

Date	WT	Temp- AM	Temp- PM	BP- AM	BP- PM	Blood Sugar- AM	Blood Sugar- PM	Symptoms & Comments

WT: Weight **Temp:** Temperature **BP- AM:** Blood Pressure Morning **BP- PM:** Blood Pressure Evening

PATIENT DIARY

Date	WT	Temp- AM	Temp- PM	BP- AM	BP- PM	Blood Sugar- AM	Blood Sugar- PM	Symptoms & Comments

WT: Weight
 Temp: Temperature
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PATIENT DIARY

Date	WT	Temp- AM	Temp- PM	BP- AM	BP- PM	Blood Sugar- AM	Blood Sugar- PM	Symptoms & Comments

WT: Weight **Temp:** Temperature **BP- AM:** Blood Pressure Morning **BP- PM:** Blood Pressure Evening