

# Liver Transplant Handbook

## *Your Liver Transplant*

A Guide For Your Healthcare After Liver Transplantation



**ITNS**

[www.itns.org](http://www.itns.org)



# Liver

## Transplant Handbook

A guide for your health care after liver transplantation

**Beverly Park MSN, CRNP**  
Clinical Nurse Specialist  
Starzl Transplantation Institute  
Children's Hospital of Pittsburgh

### CONTRIBUTORS AND REVIEWERS

**Tracey Dudley RN, BSC**  
Post-transplant Hepatitis Nurse Specialist  
The Liver Transplant and  
Hepato-biliary Surgery Unit  
Queen Elizabeth Hospital  
Birmingham, UK

**William McGhee Pharm.D.**  
Adjunct Assistant Professor of  
Pharmacy and Therapeutics  
Clinical Pharmacy Specialist  
University of Pittsburgh School of Medicine

**Jorge Reyes MD, FACS, FAAP**  
Professor of Surgery  
Thomas E. Starzl Transplantation Institute  
University of Pittsburgh

**Mimi Funovitz RN, BSN, CCTC**  
Transplant Coordinator  
Thomas E. Starzl Transplantation Institute  
University of Pittsburgh

**Beth Kassalan MBA**  
Executive Director  
International Transplant Nurses Society

**Jane Hartman RN**  
Patient Care Coordinator  
Multi-Organ Transplant Program,  
London Health Sciences Center  
London, Ontario  
Canada

ITNS would also like to acknowledge the following Past-Presidents  
who developed the first ITNS Liver Transplant Handbook (1995):

**Nancy Stitt RN**  
ITNS Past-President 1993

**Kandy Yarris Newell RN, BSN, CCTC**  
ITNS Past-President 1994

**Les Wheeler RN, MS**  
ITNS Past-President 1995



## Congratulations on your recovery following liver transplant!

**This manual will provide you with important information about your care as you and your family prepare for discharge from the hospital.**

This may have been a challenging time for you and your family as you endured the symptoms and complications of your liver disease, waited for a suitable organ, and finally received your transplant. As you are learning by now, liver transplantation is far more than the operation you recently experienced. Now that you are recovering, it is important for you to learn about your care so that you will have the best possible outcome with your healthy liver. You are the most important member of the transplant team and active participation in your care will lead to your successful recovery.

Having a liver transplant has given you a second chance at a healthier, more active life, but also brings new and important responsibilities for your care.



### *Purpose*

This handbook is intended to provide information about life after liver transplantation. It includes information about common healthcare routines, medications, clinic visits, monitoring guidelines, activities of daily living, signs and symptoms of possible complications, and how to contact your healthcare team.

This handbook is designed as a general reference for care after liver transplantation. Transplant centers often have different care routines, monitoring guidelines, and immunosuppressive routines following liver transplant, so it is always very important to check with your transplant coordinator when you have questions or concerns about any aspect of your care. It is important to review this handbook with your nurse, transplant coordinator, or clinical nurse specialist to understand your center's specific guidelines. **Your center's specific guidelines should always be followed.**

### *Your Responsibilities*

As the most important caretaker of the transplanted liver, you will need to:

- ✓ Know all your medications:
  - Why am I taking this medication?
  - What is my dose?
  - When should I take this medicine?
  - What are the side effects of my medicines?
  - Are there any special instructions for my medicines?
  
- ✓ Follow your medication schedule daily and make changes only as ordered by your physician.



✓ Maintain routine contact with your transplant team through your transplant coordinator.

- My transplant coordinator is:

\_\_\_\_\_

- Phone number:

\_\_\_\_\_

- Fax number:

\_\_\_\_\_

- Email address:

\_\_\_\_\_

✓ Attend follow-up appointments and/or transplant clinic as instructed.

- My first clinic appointment is:

\_\_\_\_\_

- Clinic is located at:

\_\_\_\_\_

- My appointment time is:

\_\_\_\_\_

✓ Have blood tests drawn as required.

- I need to have my blood tests drawn every:

\_\_\_\_\_

- I will get my blood tests drawn at:

\_\_\_\_\_

- Any special instructions:

\_\_\_\_\_

\_\_\_\_\_

✓ Monitor your weight, blood pressure, and temperature as required.

- My discharge weight is:

\_\_\_\_\_

- My normal blood pressure is:

\_\_\_\_\_

- I should call my coordinator if my temperature is > \_\_\_\_\_ or if my blood pressure is > \_\_\_\_\_.

✓ Maintain a healthy lifestyle that includes a balanced diet, regular exercise, and routine check-ups.

## Your Transplant Team

As you have progressed through the transplant process, you have become acquainted with many members of the transplant team. After transplant, it is important that you maintain regular contact with the team. They will continue to provide advice and support for you and your family. Team members usually include:



### Transplant Surgeon

Transplant surgeons are medical doctors who specialize in liver surgery and transplantation. The surgeons perform the operation and will be involved in your care and medical management as you recover from surgery.

My transplant surgeon(s):

\_\_\_\_\_



**Hepatologist**

A hepatologist is a medical doctor who specializes in medical problems of the liver. You may have seen a hepatologist before your transplant.

My hepatologist:

\_\_\_\_\_

Management varies by transplant center, so you may have follow-up care with your transplant physician, transplant surgeon, or hepatologist. They will be responsible for the management of anti-rejection medications and any medical issues directly related to the transplant. For health problems not related to your liver transplant, you should continue to contact your local physician or general practitioner. Your transplant coordinator will help you plan your follow-up care after you leave the transplant center.

**Transplant Coordinator (RN, CCTC)**

Transplant coordinators, usually licensed registered nurses (RN), have extensive experience in the care and management of transplant recipients, both before and after transplant. Your coordinator will be involved in preparing you for discharge as well as your long-term outpatient care. Your coordinator may refer you to other team members for services that you need and will be available to discuss any questions or concerns you may have as you begin to adapt to life following your transplant. If you notice the initials CCTC after your coordinator's name it means that he or she is a Certified Clinical Transplant Coordinator.

My coordinator:

\_\_\_\_\_

Phone: \_\_\_\_\_

**Social Worker (MSW)**

A transplant social worker specializes in helping patients and families cope with the stresses and challenges of the transplant process. Your social worker may help you by identifying community supports, assisting you with housing while staying in the hospital community, helping with financial difficulties, providing emotional support, and providing information and referrals for support groups or counseling.

My social worker:

\_\_\_\_\_

Phone: \_\_\_\_\_

**Clinical Nurse Specialist (CNS)**

A clinical nurse specialist is a registered nurse with an advanced practice degree in a nursing specialty. The transplant clinical nurse specialist is usually involved in the transplant evaluation as well as post-transplant care and will provide information on all facets of the transplant process, assess any potential problems, provide supportive care, and will help prepare you for discharge. This nurse may be involved with your care while you are in the hospital and after discharge.

My CNS:

\_\_\_\_\_

Phone: \_\_\_\_\_





## Pharmacist

A pharmacist is a licensed medical professional who dispenses prescription medications. As part of the transplant team, the transplant pharmacist may help monitor your medications while you are in the hospital and at clinic visits. The pharmacist may also be involved in your discharge teaching and will provide information about your medications and instructions on how to take them.

My pharmacy:

\_\_\_\_\_

Phone:

\_\_\_\_\_



## Dietician

A dietician specializes in aspects of diet and nutrition. As part of the transplant team, your dietician will help manage your nutrition before and after transplant. The dietician may also work with you on any special dietary instructions or diets for medical complications such as diabetes, high blood pressure, high potassium levels, or high cholesterol.

My dietician:

\_\_\_\_\_

Phone:

\_\_\_\_\_

# Medications

One of the most important responsibilities you will have after transplant is taking your medications as they are prescribed. You will learn about your medications before you leave the hospital, but you should contact your transplant coordinator if you have any further questions or concerns. As you learn about your medications, be sure that you know and understand the following for each medication:

✓ **The brand name and generic name**  
Medications are known by two different names. The brand name is the name given to the medication by the pharmaceutical company that produces it. The generic name is the common, non-branded name of that medication. There can be several brand names for a generic medication.

✓ **The purpose or reason for taking each medication**

A medication often has more than one use and may be prescribed for different reasons. You should always know why you are taking each medication.

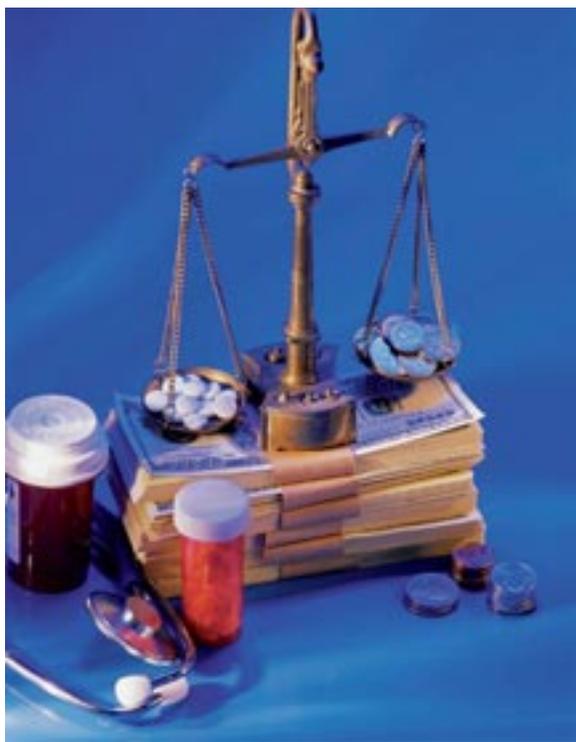
✓ **What each medication looks like**

It is important that you are able to recognize each medication by color, shape, and size. Many medications have a similar appearance with only slight differences and must be looked at closely to be sure the correct medication is being taken.



### ✓ **When to take each medication**

Some medications, such as the anti-rejection medications Prograf® (tacrolimus) or Neoral® (cyclosporine) must be taken on time daily so that the level of medication in your blood stays stable to help prevent rejection. It is important to know what time you take each medication. Work with your coordinator or nurse to arrange a medication schedule that is easy to follow with your daily routine.



### ✓ **How to take each medication**

You probably take most of your medications by swallowing a pill or capsule. Occasionally, particularly for children, a pill may be divided or crushed and mixed with food or liquids. Discuss how to take each of your medications with your nurse or coordinator.

### ✓ **How long each medication is prescribed**

Some medications may be prescribed only for 7-14 days, such as antibiotics. Others, like your anti-rejection medications, are usually prescribed for your lifetime. Some medications can be discontinued after a complication or side effect has resolved.

### ✓ **The most common side effects**

Every medication has side effects, but these are not experienced by everyone. You should know the most common side effects that each medication may cause and what will be done to relieve that side effect.

### ✓ **Any special instructions**

Some medications must be taken with food or on an empty stomach, or separated from certain meds. Discuss any special instructions for your medications with your nurse, pharmacist, or coordinator.

### ✓ **What to do if you are late, miss a dose, or forget to take a dose**

If you are very late taking a medication or have skipped a dose, either because you forgot or you have been vomiting, call your transplant coordinator. After asking you a few questions and considering your current health status, your coordinator will advise you on what to do.

### ✓ **How to order your medications**

Your transplant coordinator, nurse, or social worker will help you find the most convenient way to order your medications. Be sure that you have all your prescriptions before you leave the hospital.



### ✓ **When to order your refills/repeat prescriptions**

The number of refills you have for each medication depends on how long you will be taking the medication, as well as what your insurance coverage will allow. Once the prescription has been submitted to your pharmacy, you may call for refills/repeat prescriptions. However, all new prescriptions and any changes in the meds you are already taking must be called in or sent to your pharmacy by your physician. It is very important to monitor the number of pills you have so you can order your refills in time or call your coordinator to do this so that you avoid missing any doses. You should always have a 1-2 week supply.

### ✓ **What is my cost for my medications?**

It is also important that you know your financial responsibility for your medications so you can plan ahead. In the US, some medications may be completely covered by insurance, while others have co-pays. Often, insurance companies have a deductible you must meet until their coverage begins. It may be helpful for you or a family member to call your case manager or approved pharmacy provider before your medications are ordered. A toll-free number for “prescriptive authorization” is usually on the back of insurance cards. This contact person should be able to tell you what your cost is for each prescribed medication.

Internationally, medication costs vary from country to country. You should discuss the possible cost of your prescriptions with your transplant coordinator.

## Medication Guidelines

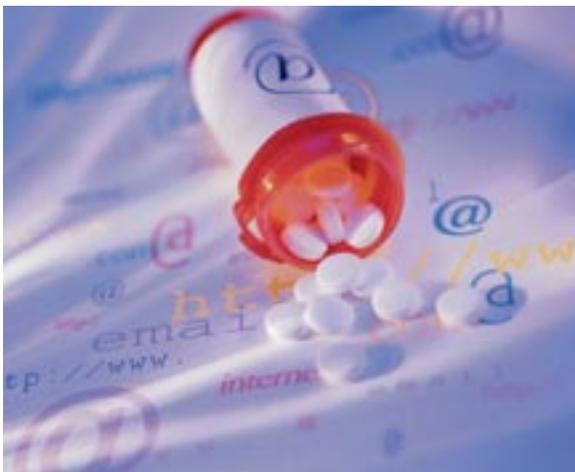
Medications should be taken daily, always as prescribed. Taking your medications correctly and following your medication schedule daily will help you achieve a healthy, active life as a transplant recipient. Liver rejection can occur at any time as a result of missed doses of anti-rejection medications.

### **Call your coordinator if you:**

- are unable to take your medications because you are nauseated, feeling sick, or vomiting
- have diarrhea and are worried that you are not absorbing your medications
- have forgotten to take your medication or missed any doses due to illness
- think that the directions on the medication label from the pharmacy are different than what you were told
- feel you are having an unusual reaction or side effects to a medication
- want to take Tylenol® (acetaminophen) or Advil® (ibuprofen) for fever (see Fever, page 24 )
- want to take an over-the-counter cold remedy, cough suppressant, diet aid, herbal medicine, or medication that you have not previously discussed with your doctor
- are ordered any new medications by your local physician or if any changes are made to your current medications by another physician.

**Organize a medication schedule that fits well with your daily routine.**

- Work with your transplant coordinator, nurse, or pharmacist to arrange a schedule that fits into your daily routine so that taking medications is most convenient for you. A comfortable schedule will improve your success for taking all your meds at the right time every day.
- Some people find it helpful to follow a written schedule or a check-off list. Pill reminder containers and medication alarms may also be helpful. Pill containers can be stocked with a week's supply of medications. Medication alarms are also available and can be set to remind you to take your medications on time.
- Always keep a copy of your medication schedule with you. If you are seen in clinic, your doctor's office, or in an emergency room, it will help to have a current list of your medications available.
- It is difficult for some people to take medicines that are prescribed three or four times a day. If this is a problem for you, talk to your doctor about the possibility of changing the dosage so that it may be taken less frequently. Unfortunately, dosages can not always be changed.

**Storing your medications**

- Keep medications in the original containers with the caps closed. If you use a pill reminder container, keep the container sealed. It is important that you can recognize different medications when they are together in a pill container in case a dose has changed.
- Store your meds in a cool, dry place away from sunlight. Do not store meds in the bathroom since moisture may interfere with the medication's effectiveness.
- Do not store meds in a refrigerator unless instructed to do so by your pharmacist.
- Keep all medications in a safe place, out of reach of children.
- It may be helpful to keep a few doses of your medications in another place, aside from your household. Sometimes transplant recipients will store extra doses of anti-rejection medications at a family member's house or in their office in case of an emergency.
- It may be helpful to bring your medications, filled med container and/or medication list with you for clinic visits or if you are admitted to the hospital. This will insure that you won't miss any doses.



# Commonly Prescribed Medications Following Liver Transplantation

The information about these medications is presented as an overview that includes the purpose of each medication, the usual dosage and dosage forms, the most common side effects, and other significant information. This information is meant to be a general guide for the liver transplant recipient and is not all-inclusive. Always contact your transplant coordinator or your transplant team to be aware of your center's recommendations and specific medication protocols.

Some medications may be harmful if you are pregnant. If you are pregnant or planning to become pregnant, your transplant physician and obstetrician/gynecologist should be consulted to discuss your medication history, stop any meds that may be harmful, and/or to readjust your immunosuppression, if necessary. If you are pregnant or breastfeeding, contact your physician before any new medications are started or to discuss your currently prescribed medications.

## Anti-Rejection Medications



### Tacrolimus (Prograf®)

**Purpose:** Tacrolimus is used to prevent or treat rejection after liver transplant. It prevents rejection by inhibiting certain cells in the immune system. Tacrolimus may be the only immunosuppressant medication prescribed for you, but some transplant patients take tacrolimus as well as one or two other anti-rejection medications such as steroids (prednisone/prednisolone), azathioprine (Imuran®), mycophenolate mofetil (Cellcept®), or sirolimus (Rapamune®).

**Dosage:** Tacrolimus is available in 0.5 mg (yellow), 1 mg (white), and 5 mg (pink) capsules. It is usually dosed twice daily and doses should be taken 12 hours apart. Tacrolimus should be taken on time every day to insure a stable level of immunosuppression.

**Side effects:** The side effects of tacrolimus vary and are usually related to the blood level of the drug. The most common side effects are:

**Nervous system side effects (neurotoxicities):** These side effects are more commonly seen with a high tacrolimus level (>15 ng/ml) and usually resolve as the level is decreased. High tacrolimus levels may cause headache, insomnia (trouble sleeping), numbness and tingling of the hands and feet, hand tremors, or an increased sensitivity to bright or blinking lights. Aphasia (difficulty speaking) and seizures are very rare side effects, but have occurred with very high levels.

**Kidney dysfunction (nephrotoxicities):** Tacrolimus can affect the kidneys by causing tiny arteries, called arterioles, to get smaller or constrict. When this happens, high blood pressure, high potassium levels, low magnesium levels, and/or abnormal kidney function tests may occur.



**Infection:** Your immune system is suppressed so that your transplanted liver is not easily rejected by your body. Because your body's natural ability to fight infections has decreased, you may be more likely to get infections. You are at greatest risk for developing infections when your tacrolimus level is high, usually during the first three months after transplant or if you are being treated for rejection with higher doses of tacrolimus.

Other side effects that may be experienced with tacrolimus are nausea, diarrhea, high blood sugar, and hair loss.

***Additional information:***

- Do not change the dose of tacrolimus or take it more or less often than prescribed for you by your transplant physician.
- Tacrolimus levels are monitored through blood tests. Levels are monitored daily in the early postoperative period, then less frequently over time. Most patients have a tacrolimus level checked monthly by the time they are several months post-transplant. Levels may range from 15 -18 ng/ml in the early post-operative period or during treatment for rejection, but may decrease to 5-10 ng/ml after 1-2 years.
- Your tacrolimus level should be drawn 1-2 hours before taking a dose, or about 10-12 hours after the previous dose. This is called a trough (lowest point) level. When you have your blood work done, do not take your tacrolimus, but bring a dose with you to take after your labs have been drawn.
- Your tacrolimus dose may be increased during an episode of rejection or to prevent rejection. The dose may be decreased if you have an infection or if you have problems with side effects of the drug.

- Food can affect the tacrolimus level and may lower it by as much as 30%. Some transplant centers prefer that patients not eat for an hour before or after taking tacrolimus. Please check with your coordinator or transplant pharmacist for your center's guidelines. A light breakfast or meal appears to have no effect on tacrolimus absorption. It is important to be consistent in the way and time you take tacrolimus daily to maintain a stable level.
- You should not eat grapefruit or drink grapefruit juice when prescribed tacrolimus. An ingredient in grapefruit can decrease the metabolism (breakdown) of tacrolimus, causing a higher level.
- Do not take tacrolimus within 2 hours of taking any antacids such as Carafate®, Mylanta®, or Tums®. Tacrolimus should be taken 3-4 hours from sodium bicarbonate.
- Tacrolimus interacts with some other medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medication to be sure that it does not interfere with tacrolimus.
- If you miss a dose of tacrolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose as your levels may need to be monitored more frequently.
- Store tacrolimus capsules at room temperature.
- If you are planning to become pregnant, discuss the use of tacrolimus with your transplant physician and obstetrician/gynecologist.



## Cyclosporine (Sandimmune®, Neoral®)

**Purpose:** Cyclosporine is used to prevent or treat rejection after transplant. It prevents rejection by inhibiting certain cells in the immune system. Cyclosporine may be the only immunosuppressant that is prescribed for you, but it is often prescribed to be taken with steroids (prednisone/prednisolone), azathioprine (Imuran®), sirolimus (Rapamune®), or mycophenolate mofetil (Cellcept®).

**Dosage:** Cyclosporine is available as Neoral (grey capsules) and Sandimmune (pink capsules) in 25 mg, 50 mg, and 100 mg capsules. Neoral and Sandimmune are different forms of cyclosporine and your body absorbs them differently. Be sure that your pharmacy always gives you the brand of cyclosporine that has been prescribed for you.

Cyclosporine is also available as a liquid (100 mg cyclosporine/ 1 ml). You may find that the liquid form of cyclosporine tastes better if diluted with milk, chocolate milk, or orange juice. Mix cyclosporine and a room-temperature liquid in a glass or cup and stir it with a metal spoon. Styrofoam cups and plastic are porous and should not be used since some cyclosporine could cling to the foam container or plastic.

Cyclosporine is usually dosed once or twice daily and should be taken at the same time each day to insure a stable level of immunosuppression.

**Side effects:** The side effects of cyclosporine vary and are usually related to the level of the drug. The most common side effects are:

**Nervous system side effects (neurotoxicities):** These side effects are more commonly seen with a high level and usually resolve as the level is lowered. High levels of cyclosporine may cause headache, hand tremors, trouble sleeping (insomnia), numbness and tingling of the hands and feet, or an increased sensitivity to bright or blinking lights.

**Kidney dysfunction (nephrotoxicities):** Cyclosporine can affect the kidneys by causing tiny arteries, called arterioles, to get smaller or constrict. When this happens, patients sometimes have high blood pressure, high potassium levels, low magnesium levels, and/or abnormal kidney function tests.

**Infection:** Your immune system is suppressed so that your transplanted liver is not easily rejected by your body. Because your body's natural ability to fight infections has decreased, you may be more likely to get infections. You are most at risk for developing infections when your cyclosporine level is high, during the first three months after transplant, and if you are treated for rejection with higher doses.

Other side effects of cyclosporine include: a high cholesterol level in the blood, excessive hair growth, and swelling or overgrowth of the gums.

### **Additional information:**

- Do not change the dose of cyclosporine or take it more or less often than prescribed for you by your transplant physician.



- Cyclosporine levels are monitored with your routine labs. Levels are monitored daily early after transplant, then less frequently over time. Most patients have a cyclosporine level checked monthly or every other month by the time they are several months post-transplant. Levels are usually lowered slowly over time if liver function tests are normal.
- Your cyclosporine level should be drawn 1-2 hours before taking a dose, or about 10-12 hours after the previous dose. This is called a trough (lowest point) level. When you have your blood work done, do not take your cyclosporine, but bring a dose with you to take after your labs have been drawn.
- Your cyclosporine dose may be increased during an episode of rejection or to prevent rejection. The dose may be decreased if you have an infection or if you have problems with side effects of the drug.
- It is important to be consistent in the way and time you take your cyclosporine each day to maintain a stable level.
- Do not eat grapefruit or drink grapefruit juice when taking cyclosporine. An ingredient in grapefruit can decrease the breakdown of cyclosporine, causing higher levels.
- Cyclosporine interacts with some other medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medication.
- If you miss a dose of cyclosporine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose. Levels may need to be monitored more frequently until the cyclosporine level is stabilized.

- Cyclosporine capsules and liquid should be stored at room temperature away from direct sunlight. An opened bottle of cyclosporine may be used for up to 2 months.
- If you are planning to become pregnant, discuss the use of cyclosporine with your transplant physician and obstetrician/gynecologist.



### **Prednisone/Prednisolone (Deltasone®)**

**Purpose:** Prednisone is a steroid used to help prevent or treat rejection in liver transplantation. It prevents rejection by inhibiting certain cells in the immune system and is often given with tacrolimus (Prograf®) or cyclosporine (Neoral®). Although some patients require prednisone for life, many transplant recipients are being weaned from steroids within weeks to a few months after transplant.

**Dosage:** Prednisone/Prednisolone is available in several strengths including 2.5 mg, 5 mg, 10 mg, and 20 mg tablets. It is also available in a liquid form. Prednisone is usually prescribed once daily, but if prescribed twice daily, doses should be taken about 10-12 hours apart.

**Side effects:** Prednisone can have many side effects, but these vary depending on the dose, frequency and duration of your treatment. The most common side effects include: an increased appetite leading to weight gain, stomach irritation and/or



stomach ulcers, mood changes, irritability, anxiety, and acne. You may also retain fluids which may make your face, hands, and ankles “puffy”. Side effects that can additionally occur with higher dosages over a longer period of time include: bruising, high blood pressure, high cholesterol levels in the blood, high blood sugar, muscle weakness, night sweats, osteoporosis (bone weakening), delayed wound healing, growth retardation (in children), vision problems due to cataracts, and glaucoma.

**Additional information:**

- Do not change the dose of prednisone/prednisolone or take it more or less often than prescribed.
- If prescribed once a day, prednisone/prednisolone should be taken in the morning to avoid insomnia (trouble sleeping).
- If prednisone/prednisolone is to be stopped, the dose must be decreased slowly over several weeks. Stopping prednisone completely may cause serious complications.
- Since prednisone/prednisolone may cause stomach upset, it is best to take it with meals.
- If you miss a dose of prednisone/prednisolone, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose. Since your own body’s production of a natural steroid (cortisol) is disturbed when you take prednisone/prednisolone, missing doses of prednisone could make you sick.
- If you are taking prednisone/prednisolone, examine your skin routinely for bruising. If you have any wounds that don’t seem

to be healing well, notify your transplant coordinator. Maintain good care of your skin.

- Your physician may advise you to avoid concentrated sweets, like candy bars and soda, while taking prednisone/prednisolone. High blood sugar can develop with higher doses of steroids. Patients who already have diabetes may find it more difficult to control their blood sugar.
- If you develop a stomach ulcer from prednisone/prednisolone, you may have an upset stomach or abdominal pain. Sometimes ulcers can cause bleeding which will make your stools look black and tarry. Call your transplant coordinator with any of these symptoms so medications and treatment can be prescribed promptly.

**Sirolimus (Rapamune®)**



**Purpose:** Sirolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting certain cells of the immune system. Sirolimus may be the only immunosuppressant that is prescribed for you, but in many cases, sirolimus is prescribed to be taken with tacrolimus (Prograf®) or cyclosporine (Neoral®).

**Dosage:** Sirolimus is available in 1 mg tablets and in a 1 mg/ml liquid. It is usually taken once or twice daily and should be taken on time to insure a stable level of immunosuppression. The liquid form of sirolimus should be mixed with 1-2 oz. of water or orange juice in a glass or cup. Do not use a styrofoam container since it may absorb some of the medication. The tablet should be swallowed whole and never crushed or broken.



**Side effects:** The side effects of sirolimus vary and are usually related to the level of the drug. The most common side effects are: an increased risk of infection, nausea, diarrhea, anemia (low blood count), high cholesterol and/or triglyceride levels in the blood, a low white blood cell count, headache, acne, arthritis, and muscle cramping. Side effects usually resolve as the dose is reduced.

**Additional information:**

- Do not change the dose of sirolimus or take it more or less often than prescribed for you by your transplant physician.
- Check with your transplant coordinator or pharmacist about the correct time to take your dose of sirolimus. Since sirolimus works with tacrolimus and cyclosporine, some centers prefer that sirolimus be taken about 4 hours from these medications while others recommend taking the medications at the same time.
- Sirolimus is usually not started immediately after transplant like other anti-rejections medications. It may be prescribed for you at 6-8 weeks after transplant.
- Your dose of sirolimus may be increased during an episode of rejection. The dose may be decreased if you have an infection or if you have problems with side effects of the drug.
- If you miss a dose of sirolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- Sirolimus tablets should be swallowed whole without crushing or breaking. The medication is coated on the outside of the pill, so breaking or crushing can result in losing some of the drug.
- If you take the liquid form of sirolimus, mix your dose in 1-2 oz. of orange juice or water in a glass or cup, avoiding styrofoam. Rinse the container with another ounce of water or orange juice and swallow that amount as well. You may want to additionally rinse your mouth with more water or orange juice. Some patients have developed mouth ulcers from the liquid form. These ulcers have resolved over time with decreased dosing.
- Store sirolimus tablets at room temperature. The liquid must be refrigerated.
- If you are planning to become pregnant, please discuss the use of sirolimus with your transplant physician and obstetrician/gynecologist.

**Azathioprine (Imuran®)**



**Purpose:** Azathioprine is used to help prevent or treat rejection in organ transplant recipients. Azathioprine is usually given with tacrolimus (Prograf®), cyclosporine (Neoral®), and/or prednisone.

**Dose:** Azathioprine is available as a 50 mg tablet. It is usually prescribed once daily and should be given at about the same time each day.

**Side effects:** Azathioprine may lower the number of white blood cells in your body, the cells that fight infection. It may also lower your platelets, which are cells that help your blood clot. Other side effects may include nausea, vomiting, and rash. Azathioprine may also cause an increase in the liver functions tests (LFTs).

**Additional information:**

- Do not change the dose of azathioprine or give it more or less often than prescribed.
- Your dose of azathioprine may be increased during an episode of rejection. The dose may be decreased if you have an infection or if you have problems with side effects of the drug.
- If you miss a dose of azathioprine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- Azathioprine may be discontinued after several months if you have not had any rejection and your liver is working well. You may only need one medication to control rejection by this time.
- Azathioprine interacts with a medication called Allopurinol, a drug used to treat gout. Call your transplant coordinator if you are diagnosed with gout or if a physician, other than your transplant doctor, has prescribed this medication for you.
- If you are planning to become pregnant, discuss the use of azathioprine with your transplant physician and obstetrician-gynecologist.

### Mycophenolate mofetil (Cellcept®)



**Purpose:** Mycophenolate is used to help prevent or treat rejection in organ transplant recipients. It is usually given with tacrolimus (Prograf®), cyclosporine (Neoral®), and/or prednisone.

**Dose:** Mycophenolate is available in 250 mg and 500 mg capsules. It is usually prescribed once or twice daily (3-4 times daily in some centers) and should be given at about the same time each day.

**Side effects:** Mycophenolate may lower the number of white blood cells in your body, the cells that fight infection. It may also lower your platelets which help your blood clot. Other side effects may include nausea, stomach irritation, vomiting, and diarrhea. Side effects may decrease or resolve with a lower dose.

**Additional information:**

- Do not change the dose of mycophenolate or take it more or less often than prescribed.
- Your dose of mycophenolate may be increased during an episode of rejection. The dose may be decreased if you have an infection or if you have problems with side effects.
- Mycophenolate capsules should be swallowed whole and should not be opened. The powder inside the capsule may be harmful if inhaled.
- If you miss a dose of mycophenolate, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- If you are planning to become pregnant, discuss the use of mycophenolate with your transplant physician and obstetrician/gynecologist. Women of childbearing age should use contraception while on this medication and for 6 weeks after discontinuing mycophenolate.



### **Antithymocyte globulin (ATG, Thymoglobulin<sup>®</sup>, Atgam<sup>®</sup>)**

**Purpose:** Antithymocyte globulin (ATG) is an immunosuppressant given in some transplant centers as “pre-treatment” (induction therapy) prior to transplantation. One dose of ATG is given about 4 hours before transplant surgery to reduce your body’s immune response and possibly reduce the risk of rejection. Some transplant centers also use ATG to treat rejection.

**Dose:** ATG is available only as an intravenous (IV) solution and is administered in the hospital.

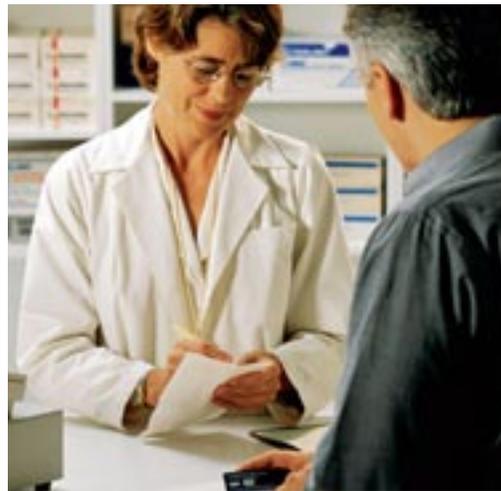
**Side effects:** Patients may have fever, chills, or difficulty breathing during the ATG infusion. To minimize this “infusion reaction,” patients are usually treated with methylprednisolone (a type of steroid), acetaminophen (Tylenol<sup>®</sup>)/paracetamol, and diphenhydramine (Benadryl<sup>®</sup>) before and during the infusion. The infusion may also be slowed down to decrease side effects. You will be closely monitored during the infusion to watch for any of these side effects.

ATG can increase the risk of viral infections, so you may also receive preventative doses of some antiviral medications. Other side effects include a low white count, low platelets, pain, headache, abdominal pain, diarrhea, high blood pressure, nausea, swelling of the hands and feet, an increased heart rate, low blood pressure and an increased level of potassium in the blood.

### **OKT3 (Orthoclone<sup>®</sup>, muromonab-CD3)**

**Purpose:** OKT3 is an immunosuppressant that is sometimes used to treat moderate to severe rejection

**Dose:** OKT3 is given through an IV once a day for 5 to 14 days.



**Side effects:** Some patients have a reaction to the first or second dose of OKT3. Methylprednisolone (an IV steroid) is given before the first and second doses of OKT3 to decrease these reactions. After the first dose, patients may react with low blood pressure, a high heart rate, fever, and flu-like symptoms. Patients may also have a reaction with wheezing, difficulty breathing, and fluid in the lungs (pulmonary edema). Patients are monitored closely during this period. In some transplant centers, patients are monitored in the Intensive Care Unit (ICU) for 24 hours after the first dose.

Other side effects may include high blood pressure, tremor, seizures, rash, itching, diarrhea, nausea, vomiting, joint pain, sensitivity to light (photophobia), and kidney dysfunction.



## Anti-Infective Medications



### Trimethoprim/sulfamethoxazole (TMP-SMX, Bactrim®, Septra®)

**Purpose:** This medication is used in transplant patients to prevent or treat a type of pneumonia called Pneumocystis carinii pneumonia (PCP).

**Dose:** To prevent PCP, patients are prescribed Bactrim/Septra three times a week, usually on Monday, Wednesday, and Friday. The adult dose is usually 80 mg, or one single-strength tablet. Bactrim/Septra is available as a tablet or liquid.

**Side effects:** Patients who are allergic to sulfa drugs may have an allergic reaction to Bactrim/Septra and may develop a rash, itching, and hives. If you are allergic, your transplant doctor will prescribe another medication to prevent PCP.

Other side effects may include nausea, vomiting, diarrhea, mouth ulcers, anemia, a low white blood cell count, or a low platelet count. Bactrim may also cause an increase in the liver and kidney function tests.



### Ganciclovir (Cytovene®) Valganciclovir (Valcyte®)

**Purpose:** Ganciclovir and valganciclovir are antiviral medications used to prevent or treat cytomegalovirus (CMV) and herpes simplex infections (HSV). Ganciclovir is also used to treat Epstein Barr Virus (EBV) infections.

**Dose:** Ganciclovir is usually given twice daily for 14 days through an IV to treat an active CMV infection. In some cases, it may be given longer until the virus resolves. Some transplant centers give a preventative course of therapy for 14 days following transplantation, particularly if the patient is at risk for developing CMV. An oral tablet form (valganciclovir, Valcyte) is also available and may be prescribed daily for 3-6 months after transplant to prevent CMV in patients who are at risk for the virus. Valcyte is available as a 450 mg tablet.

**Side effects:** Side effects may include: nausea, vomiting, headaches, pancreatitis, irritation from the IV infusion, confusion, and seizures. Ganciclovir can affect the white blood cell and platelet counts in the blood, but this usually resolves by decreasing the dose or by stopping the medication. Ganciclovir is eliminated by the kidneys, so patients with kidney dysfunction receive a lower dose. Animal studies have shown that ganciclovir affects fertility and sperm



production. It is recommended that male and female transplant patients receiving ganciclovir use contraceptive precautions during ganciclovir therapy and for at least 90 days after discontinuing the medication. Breastfeeding should be avoided during this period as well.

**Additional information:**

- The first few doses of IV ganciclovir are usually given in the hospital, but most patients are able to finish treatment at home.
- Since ganciclovir is eliminated by the kidneys, drink plenty of fluids while you are receiving this medication.
- If you are taking valganciclovir (Valcyte®), swallow the tablet whole and take with food. It is recommended that patients take 2-3 liters of fluid daily (unless fluid restricted) while receiving valganciclovir.
- Avoid handling crushed or broken tablets. Wash the affected area thoroughly if there is contact with the powder.
- There is an increased risk of infection while on ganciclovir and valganciclovir therapy. Call your coordinator for any fever, chills, unhealed sores, or white plaques in your mouth.

**Acyclovir  
(Zovirax®)**



**Purpose:** Acyclovir is an antiviral medication used in the treatment of herpes simplex infections (HSV-1, HSV-2) and varicella-zoster infections (chickenpox, shingles). Acyclovir will help decrease pain from the herpes lesions and also help them heal.

**Dose:** The dose varies according to the type of infection and if used to prevent or treat herpes simplex. The IV form may be used at first, and then changed to oral tablets (400 mg or 800 mg) or capsules (200 mg).

**Side effects:** The most common side effects are headache, tiredness, dizziness, seizures, pain, insomnia, fever, rash, nausea, vomiting, diarrhea, elevated liver enzymes, muscle aches, and kidney dysfunction.

**Additional information:**

If you have herpes, acyclovir will not prevent you from spreading herpes to others. Condoms may help prevent the spread of genital herpes. Sex should be avoided when there are any herpes symptoms or active lesions.

**CytoGam®  
(Cytomegalovirus Immune Globulin,  
CMV-IGIV)**

**Purpose:** Cytogam is an immune globulin used to treat CMV and EBV disease in patients who are immunosuppressed. It provides antibodies against CMV.

**Dose:** Cytogam is given through an IV only. The dose and frequency vary depending on different transplant center protocols. It can be given to treat an active infection or to help prevent infection.

**Side effects:** The most common side effects are flushing, sweating, muscle cramps, back pain, nausea, vomiting, wheezing, chills, and fever.



## Antifungal Agents

### Nystatin (Mycostatin®) and Clotrimazole (Lotrimin®, Mycelex®)



**Purpose:** When you are taking anti-rejection medications, particularly prednisone, there is a greater risk for getting an infection from fungus. This infection usually develops in the mouth and throat, vaginal area, or on the skin.

**Dose:** An antifungal is prescribed to treat fungus at the site of the infection. Nystatin, a liquid antifungal, is prescribed if a patient has fungus or thrush in the mouth. The dose is usually 5 cc swished and swallowed 2 to 4 times a day. Sometimes a lozenge (Mycelex®) is prescribed to be dissolved in the mouth. Vaginal creams, suppositories, and ointments are also available for vaginal or skin infections.

**Side effects:** Side effects are uncommon, but may include nausea, vomiting, and diarrhea. Side effects of clotrimazole also include irritation, a stinging sensation, and increased liver function tests.

#### **Additional information:**

- The oral liquid should be swished and held in the mouth for as long as possible before swallowing.
- Patients should not eat or drink for about 15-20 minutes after taking the liquid or lozenge.
- The clotrimazole lozenge should be dissolved slowly in the mouth.

## Antacids and Acid Inhibitors

### Famotidine (Pepcid®) Cimetidine (Tagamet®) Ranitidine (Zantac®) Omeprazole (Prilosec®) Pantoprazole (Protonix®) Lonesprazole (Prevacid®) Sucralfate (Carafate®) Mylanta®, Tums®, Rolaids®, Maalox®, Di-Gel®

**Purpose:** Following transplantation, patients are at risk for developing stomach irritation and ulcers. This can be caused by steroids and also stress (stress gastritis) which may increase the amount of acid in your stomach. You may be prescribed 1 or 2 of these antacids after transplant.

**Dose:** The dose varies according to the medication prescribed. Some medications coat stomach ulcers while others inhibit the amount of acid that is being released in the stomach.

**Side effects:** Most patients are able to take these medicines without any problems. The most common side effects of each medication include:

famotidine: headache, heart palpitations, high blood pressure, dizziness, weakness, diarrhea  
cimetidine: headache, low blood pressure, low heart rate, dizziness, confusion  
ranitidine: headache, low or high heart rate, dizziness  
omeprozole: headache, diarrhea, nausea,



- vomiting, abdominal pain
- lansoprazole: headache, diarrhea, nausea, vomiting, abdominal pain
- sucralfate: dizziness, sleepiness, vertigo, rash, itching, constipation
- antacids: side effects vary according to the minerals or electrolytes in the medication.
- antacids containing sodium — fluid retention
  - antacids containing aluminum — confusion, constipation
  - antacids containing magnesium — diarrhea

#### **Additional information:**

- Antacids may increase or decrease the absorption of many medications. Antacids should be taken 1-2 hours away from other medications.
- Omeprazole (Prilosec®), lansoprazole (Prevacid®) and pantoprazole (Protonix®) capsules should be swallowed whole, not chewed.
- Sucralfate (Carafate®) should be taken before meals or on an empty stomach. It should be given 2 hours away from tacrolimus or cyclosporine.

## Medications for Electrolyte Imbalances:

**Magnesium (Magnesium Oxide, Magnesium Gluconate)**  
**Fludrocortisone (Florinef®)**  
**Sodium Citrate, Citric Acid (Bicitra®)**  
**Neutra-Phos**

**Purpose:** Sometimes medications can cause imbalances in the body's electrolytes, the substances needed by your

body to maintain fluid balance and many other functions. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body. When electrolytes are higher or lower than the normal range, medications such as the ones listed above are used to correct the levels.

**Magnesium Oxide (Mag-Ox 400) or Magnesium Gluconate (Magonate®):** used to treat a low magnesium level. Side effects of magnesium supplements include diarrhea, abdominal cramping, muscle weakness, a high magnesium level, and low blood pressure.

**Fludrocortisone (Florinef®):** used to treat a high potassium level. Side effects include high blood pressure, swelling of the hands and feet, headache, rash, and low potassium.



**Sodium Citrate, Citric Acid (Bicitra®):** used to treat low CO<sub>2</sub> levels, often resulting from diarrhea. Side effects include swelling of the hands and feet, increased gas, abdominal distention, and low levels of sodium, potassium and/or calcium.

**Neutra-Phos®:** a phosphorus supplement. Side effects include low blood pressure, a high phosphorus level, nausea, vomiting, high potassium levels, and diarrhea.



## Blood Pressure Medicines



**Nifedipine (Procardia®)**  
**Isradapine (DynaCirc®)**  
**Amlodipine (Norvasc®)**  
**Atenolol (Tenormin®)**  
**Labetalol (Normodyne®)**  
**Enalapril (Vasotec®)**

**Purpose:** Patients may develop high blood pressure after liver transplantation as a side effect of medications, particularly immunosuppressants. High blood pressure can also be a symptom of kidney dysfunction. Your transplant doctor will prescribe blood pressure medications to control high blood pressure.

**Dose:** Blood pressure medications may be prescribed 1 to 4 times daily, or when the patient's blood pressure is above a certain range. A variety of blood pressure medications are available and your doctor will choose the medication or the combination of medications that are best for you.

## Over the Counter (OTC) Medications

After liver transplant, patients may have complaints about common “every day” problems. There are some over-the-counter (OTC) medications that may be taken to treat these. However, these recommendations vary by physician and transplant center. Please check with your transplant center for the OTC medications that you are permitted to use.

## Diarrhea

Diarrhea may occur after transplant as a side effect of some commonly prescribed medications such as magnesium oxide (Mag-Ox) or magnesium gluconate (Magonate®). Although diarrhea may also result from certain foods that you do not tolerate very well, it may also be a symptom of a viral or bacterial infection. If you have diarrhea for more than 48 hours or if you develop fever with diarrhea, contact your transplant coordinator. Diarrhea may affect the absorption of your medications and result in lower than desired levels of immunosuppression. After evaluating your symptoms, your transplant team may recommend an OTC medication.

## Constipation

If you are constipated, you may get some relief by increasing your fluid intake as well as the fiber content of your diet. Eat plenty of bran, whole grains, fresh fruits, and vegetables. Gradually increase your activity level. Medications and fiber supplements that may help resolve constipation include Metamucil®, Fiber-Con®, Senekot®, and Colace®. If constipation continues to be a problem, contact your transplant coordinator.

## Headache and Muscle Aches

If you have a headache or muscle aches that do not occur with fever, acetaminophen (Tylenol®) may be taken. Check with your transplant coordinator for the recommended dose of acetaminophen and the frequency of dosing. Most centers advise 1-2 tablets every 4-6 hours, not to exceed 3 doses per day. If your headaches worsen and/or become more frequent, or if your headache



presents with fever or vomiting, contact your transplant coordinator. Most transplant centers recommend that patients do not take ibuprofen products such as Motrin<sup>®</sup>, Advil<sup>®</sup>, Nuprin<sup>®</sup>, or Midol<sup>®</sup>, and Naproxen products such as Naprosyn<sup>®</sup> or Aleve<sup>®</sup>. Ibuprofen can cause kidney dysfunction and also stomach irritation.

### **Upper Respiratory Infections and Seasonal Allergies**

Although OTC medications may be taken for cold symptoms, these symptoms, particularly when occurring with fever, should be reported to your coordinator. If it is determined that you have a community-acquired cold, ask your coordinator what cold remedy may be taken. Most OTC cold medications contain an antihistamine, acetaminophen and/or a cough suppressant. However, some cold remedies contain alcohol. Alcohol-containing cold remedies should be avoided.

If you require an OTC antihistamine to relieve and treat the symptoms of a seasonal allergy, contact your coordinator for your center's specific recommendations.

### **Nutritional Supplements**

Patients are often advised to take a daily multivitamin, vitamin supplements, and/or mineral supplements after transplantation, particularly if their nutritional status was poor before transplant or if they have had a difficult recovery with complications following surgery. Your dietician will advise you about how to maximize your nutrition following transplant. Check with your transplant coordinator before taking any nutritional supplement that has not been prescribed for you.

### **Herbal Products**

Most transplant centers strongly recommend that transplant recipients avoid taking any type of herbal products/remedies or teas. In the United States, these products are classified as dietary supplements by the Food and Drug Administration (FDA), so the manufacturers do not have to test them for effectiveness, side effects, drug interactions, or safety, and doses are not regulated.

St. John's Wort is a well-known herbal supplement that is used to treat depression. This herb increases the metabolism, or breakdown, of medications which in transplant patients, can decrease cyclosporine and tacrolimus levels. Decreased levels place the patient at risk for rejection.

Grapefruit juice is sold as an herbal supplement called paradisapfel, pomelo, and toronja. A substance found in grapefruit and grapefruit juice decreases the metabolism of some medications. Patients who are taking cyclosporine or tacrolimus may develop a very high level of their medication if grapefruit juice is taken anytime of day. Any form of grapefruit, including the herbal supplement, should be avoided if you are prescribed tacrolimus or cyclosporine.

Before taking any herbal supplement or remedy, you should check with your transplant team for the best advice. Do not take any herbal supplements without telling your physician or transplant coordinator. These products can interact with your medications and lead to problems with your liver transplant.



# Complications Following Liver Transplantation

## Fever



### What is fever?

Fever, or a high body temperature, is a symptom of the body's reaction to an organism not considered as "self" by the immune system. Fever can be caused by minor illnesses as well as serious infections and is usually defined as a body temperature greater than 101 degrees Fahrenheit (F) or 38.4 degrees Celsius (C).

### Why would I get a fever?

Healthy adults may have an occasional fever throughout the year due to colds, influenzas, or other community-acquired infections. However, since your immune system is now suppressed so that the transplanted liver will not be rejected, episodes of infection with fever may be more common, particularly when you are more highly immunosuppressed during the

first 3-6 months after transplant or during periods of treatment for rejection. A high temperature can also be a symptom of rejection.

### What should I do if I have a fever?

It is very important to call your doctor and/or transplant coordinator if you have a temperature of 101°F (38.4°C) or greater. Since the temperature range may vary by center, check with your transplant coordinator about when to call for fever. Be sure that you have a thermometer when you leave the hospital and that you are able to read it. Digital thermometers are also available if you have trouble reading a glass thermometer.

If you have a fever, call your transplant coordinator or physician as instructed at discharge. Although acetaminophen (Tylenol®)/paracetamol may be used to treat fever after transplant, do not take any fever medication until you have talked to your coordinator.

If you are instructed to take acetaminophen (Tylenol®)/paracetamol, take the recommended dose at the time interval prescribed. You may also be instructed to have blood tests drawn or to come to Transplant Clinic or your physician's office for an examination.

Ibuprofen (Motrin®, Advil®) is another medication used to treat fever, but should not be taken by liver transplant recipients since it can affect liver and kidney function. It can also cause stomach irritation and ulcers.



### My responsibilities for taking care of fever:

- I must have a working thermometer that my caregiver or I can read before I leave the hospital.
- I should have a supply of acetaminophen (Tylenol®)/paracetamol on hand to take for fever if I am instructed to do so.
- After I am discharged from the hospital, I should take my temperature every \_\_\_\_\_.
- After \_\_\_\_\_ weeks, I should take my temperature only if I feel ill or think I might have a fever.
- I should call my transplant coordinator or physician if my temperature is greater than \_\_\_\_\_ °F or \_\_\_\_\_ °C.
- The dose of acetaminophen/paracetamol that I should take if instructed to do so by my physician is: \_\_\_\_\_ mg or \_\_\_\_\_ tablets every \_\_\_\_\_ hours as needed for fever greater than \_\_\_\_\_. I should not take more than \_\_\_\_\_ doses in a 24 hour period.
- I should not take any ibuprofen products (Motrin®, Advil®) unless instructed to do so by my physician.



## Rejection



### What is rejection?

Your body's immune system is designed to seek and destroy any foreign object that it finds in your body, such as a cold virus, a flu virus, or a transplanted organ! The process of destroying the foreign object — the transplanted organ — is called rejection. It is very common for your body's immune system to try to reject the liver within the first month after transplant, usually at 7-10 days. Most patients experience at least one mild to moderate rejection episode during this time. This is a normal reaction between your body's immune system and the transplanted liver and shows that your immune system is working. However, in order to protect the transplanted liver and maintain good function of your liver, your immune system will need to be suppressed a little more so that the rejection resolves.

Rejection may be called “acute”, meaning that it develops quickly as your immune system attempts to destroy the liver cells. If the rejection process continues slowly over time, it is called chronic rejection. Chronic rejection can be more difficult to treat than acute rejection because of the more permanent changes in the liver tissue.



## How do I know I am rejecting my liver?

Any injury to the liver can cause the release of normal liver proteins, or enzymes, into the bloodstream. An injury could be caused by rejection, infection, or drug toxicities. Measuring these enzymes, called the liver function tests (LFTs), regularly and watching the pattern of the results can help your doctor decide what is happening to your liver.

Liver rejection is usually diagnosed by looking at the liver function tests. Your physician may suspect that you have rejection if any of these numbers are increased from the normal range. *(Lab values are US measurements and may vary slightly by transplant center.)*

Test	Normal Adult Range	Indication
ALT alanine aminotransferase	1-30 U/L	↑ rejection
AST aspartate aminotransferase	0-35 U/L	↑ rejection
Total Bilirubin	0.1 - 1.2 mg/dl	↑ rejection, bile duct obstruction
GGTP Gamma-glutamyl transferase	males 11-50 U/L females 7-32 U/L	↑ rejection, bile duct obstruction
AP Alkaline phosphatase	30-120 U/L	↑ bile duct obstruction ↓ malnutrition

## What are the symptoms of rejection?

While you are in the hospital, the transplant team will be monitoring your liver function tests (LFTs) daily to watch for rejection. If you reject your liver during this time, you may not have any noticeable symptoms because rejection was diagnosed early through your blood test results.

After you leave the hospital, your blood tests will be monitored less frequently. If rejection occurs, you may experience some mild symptoms, although some patients

may continue to feel fine for a while. The most common early symptoms include:

- Fever/high temperature over 101°F or 38.4°C
- flu-like symptoms such as chills, nausea, vomiting, diarrhea, headaches, dizziness, body aches, tiredness
- abdominal pain or tenderness
- increased LFTs

Later symptoms may be similar to problems you had before your transplant and may include:

- yellowing of the skin and eyes (jaundice)
- dark, tea-colored urine



- light, clay-colored stools
- confusion
- increased fatigue
- abdominal swelling (ascites)

### How is rejection treated?

Rejection does not mean that you will lose your liver, but it is very important to begin treatment as soon as possible to avoid further complications. Rejection can usually be treated successfully if it is detected early.

Rejection is usually treated by increasing the doses of your anti-rejection medications or by adding or combining different anti-rejection medications. Your transplant team may want to perform a liver biopsy to confirm that your symptoms are caused by rejection before they make any changes to your medications. You may be prescribed an increased dose of prednisone/prednisolone daily or given solumedrol, the IV form of prednisone. Sometimes another anti-rejection medicine, such as mycophenolate mofetil, sirolimus, or azathioprine may be added.

When your liver recovers, your doses of these additional anti-rejection medications may be decreased or discontinued. The level of your primary anti-rejection medication, usually tacrolimus or cyclosporine, may be reduced. Your transplant team's goal is to have you on the lowest amount of immunosuppression possible so that you do not reject your liver, have good liver function, and have minimal risk of infection and other side effects.

### What is a liver biopsy?

Although liver function tests and your symptoms help diagnose rejection, a liver biopsy confirms that the liver is being

rejected. A small piece of liver tissue is examined under a microscope for signs of rejection

Biopsies are usually done as short-stay procedures at the hospital. To prepare you for the biopsy, an area on your right side will be cleaned with an antiseptic solution, such as betadine. You will be given an injection of a local anesthetic, or numbing medicine, into the area where the biopsy will be done. Sometimes an ultrasound is done to determine the best place to insert the biopsy needle. After the area is numb, the physician will advance a special cored needle into the liver to take out a small cylindrical piece of tissue. The actual biopsy only takes a few seconds. The piece of liver tissue may look like a small piece of string. It is placed into a special solution, and then taken to the pathology lab to be processed and viewed under the microscope. Your biopsy results may be ready later that day, or you may be asked to return to clinic to discuss your biopsy results or any treatment that may be necessary.

Following a liver biopsy, you will need to lay on your right side for at least 1 hour, and you must rest in bed for 4-6 hours. Your nurse will take your vital signs every 15-30 minutes during this time to watch for a high heart rate or respiratory rate and a low blood pressure. You may also have a chest X-ray and some blood tests before you leave to be sure that there is no bleeding internally from the biopsy site. Most patients feel fine after the biopsy. Sometimes the biopsy site may be a little tender, like a bruise, for a day or two.



### **Will I always have to be concerned about rejecting my liver?**

The risk of rejection decreases over time, but can occur at any time. Taking good care of yourself, taking your medications as prescribed, and having your blood tests done as requested will help decrease your risk of rejection. Good communication with your transplant team and following your care routine are key factors for a successful outcome after transplant. Rejection can be successfully treated due to advances in immunosuppression and combinations of anti-rejection medications.

### **My responsibilities for monitoring the symptoms of rejection and decreasing my risk for rejection:**

- know and understand the signs and symptoms of liver rejection
- take all medications as prescribed
- make sure I always have a supply of my medications
- stay in regular contact with my transplant coordinator for any changes in my immunosuppression
- have my blood testing done as instructed
- follow-up on my blood test results with my transplant coordinator
- call my transplant coordinator or physician if I think I am experiencing any symptoms of rejection
- avoid alcohol, illegal drugs, herbal supplements, and alternative medicines
- maintain good communication with my transplant team

## *Infection*

Patients who have had liver transplants require anti-rejection medications, usually for their lifetime, to suppress their immune system so that the liver is not rejected by the body. Since your immune system is inhibited by these medications, transplant recipients always have an increased risk of getting infections. This risk is highest in the first 3-6 months after transplant or when higher levels of immunosuppression are prescribed to treat rejection.

### **How Can I Decrease My Risk of Infection?**

If you are doing well, have good liver function, and have not had any episodes of rejection, your transplant doctor will gradually lower your immunosuppression level over time. This will help minimize your risk of infection.

These guidelines may help decrease your risk of infection:

- Practice good handwashing techniques by using warm water, soap, and vigorous scrubbing for 1 minute. Be sure to scrub between your fingers as well.
- Wash your hands well before eating and preparing food, and after going to the bathroom.
- Avoid putting your fingers or hands in or near your mouth, particularly if you have not washed your hands recently.
- Encourage any family and friends who are in contact with you to practice good handwashing techniques.
- Wash your hands well before caring for any wounds or doing any dressing



changes. Report any changes in the wound (increased redness, swelling, or drainage) to your transplant coordinator.

- Avoid close contact with people who have obvious illnesses such as colds and flu.
- Avoid any “live” vaccines including the chickenpox (varicella) vaccine, MMR (measles, mumps, rubella), and the oral polio vaccine. If for any reason you are told to get one of these immunizations, contact your transplant coordinator.
- Get a tetanus injection as needed if you have a skin wound from an object that could potentially cause an infection such as a piece of wood or a rusty nail.
- Consider getting the influenza vaccine every fall. Your close family contacts should also get this vaccine.
- Take the recommended antibiotics before dental work or any invasive procedures as instructed by your transplant team.
- Do not share eating utensils, cups, and glasses with others since many viral illnesses are spread through saliva and mucous. Also, do not share razors or toothbrushes.
- Do not handle animal waste. Do not clean bird cages, fish or turtle tanks, or change cat litter.
- Practice safe sex.

### What infections are most common?

There are 3 types of organisms that cause infections: bacteria, fungi, and viruses.

#### Bacterial Infections

Bacterial infections usually occur very early after transplant surgery and may be caused by central vein catheters, infections inside the abdomen, or wounds. Patients may develop pneumonia, particularly if they had complications during or early after surgery and required a prolonged stay in the

intensive care unit. Urinary tract infections may occur from having a urinary catheter to drain urine. Although rare, abscesses can develop in the liver if the patient develops clots in the major liver arteries and veins. Another type of bacterial infection is cholangitis, or an infection in the bile ducts of the liver.

If you develop a blood infection, blood specimens will be sent to the lab to find out what type of bacteria is causing the infection. Your doctor will prescribe a specific antibiotic to treat that bacterial infection.

#### Fungal Infections

Fungal, or yeast, infections are most common in the first 3 months after transplant. These infections usually do not get into the bloodstream. The most common fungus, *Candida*, looks like a white plaque or coating on the tongue and inside the mouth. This infection is also called thrush. It may make your mouth tender and sore and you might have difficulty swallowing if it is coating your throat as well. If thrush is not treated, it can also infect the esophagus, stomach, and intestines.

Women may get a vaginal infection with *Candida*. The vaginal area may become very itchy and there may also be a thick yellow or white discharge from the vagina.

These types of fungus infections are often seen when patients are taking high doses of prednisone. They usually resolve when treated with topical medications such as nystatin, lotrimin, or clotrimazole.



## Viral Infections

**Cytomegalovirus (CMV)** is a common community-acquired virus and is not a serious illness for most people who are healthy. However, CMV may be of more concern to people who are taking immunosuppressive medications.

CMV is a common infection that usually occurs within 2-3 months after transplant. Some patients are more at risk for CMV than others. The patients who are at highest risk are those who:

- are CMV-negative and received a CMV-positive liver or CMV-positive blood products
- received high levels of immunosuppression
- received OKT3 to treat rejection

Because CMV is such a common infection, transplant centers usually have treatments to prevent this infection, particularly in patients who are considered to be at high risk for getting the virus. Most treatment plans to prevent CMV include ganciclovir. Some centers continue preventative treatment for up to 3 months after transplant. Using these treatments to prevent CMV has decreased the rate of this infection.

Symptoms of CMV include fever, a low white blood cell count and a low platelet count. A CMV infection in the lungs can cause fever, coughing, shortness of breath, or wheezing. If CMV develops in the gastrointestinal (GI) tract, it causes diarrhea, nausea, vomiting, abdominal pain, and/or bloody stools. If CMV infects your liver, your LFTs may increase and you may think you have rejection. A liver biopsy will confirm if the diagnosis is rejection or

a CMV infection. CMV is suspected if you have fever and any of these symptoms, but is confirmed through a special blood test.

The medical management of CMV infection after liver transplant varies by transplant center; however, the treatment usually includes a 14 day course of intravenous ganciclovir followed by 6-10 weeks of oral valganciclovir (Valcyte®).

Additionally, immunosuppression may be lowered during the infection so that the immune system helps fight the virus.

## Epstein-Barr Virus (EBV) and Post-Transplant Lymphoproliferative Disorders (PTLD)

EBV is a very common virus and most adults have been exposed to it at some point in their lives. In patients who are immunosuppressed, EBV can occur at any time after transplant, but most commonly occurs within the first year. This virus ranges from “mono” (infectious mononucleosis) to a more serious disease, PTLN, which can cause tumors or a lymphoma. The virus causes some cells to multiply or proliferate at a higher rate than usual. This can lead to the development of a lymphoma.

Some transplant centers monitor patients who are at high risk of developing EBV-related complications. Since being immunosuppressed has caused the virus to develop, the best treatment is to lower or stop immunosuppression until the virus resolves. Patients are monitored very closely during this time so that if they begin to reject, immunosuppression can be resumed or increased. Intravenous medications to treat the virus are also given.



# Taking Care of Yourself and Your Liver

## Clinic

After discharge from the hospital, you will be seen regularly as an outpatient at your center's Transplant Clinic. Most patients are seen 1-2 times every week for 2-4 weeks, then less frequently as they improve and return home. Long-term patients who have good liver function may be seen only once a year. Most transplant centers will manage the patient's immunosuppression for the rest of their lives, with the patient's local physician managing routine care.

Clinic routines vary greatly by center. It may be helpful for you to discuss the following questions with your coordinator.

### When should I come to Clinic?

My first clinic appointment is:

\_\_\_\_\_

Clinic is held every:

\_\_\_\_\_

### Where is Clinic?

Clinic is located:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### What should I bring to Clinic?

- Medication list or record
- Vital signs record (if requested)
- Blood sugar records (if you are a diabetic)
- Your liver handbook
- A family member or caregiver
- Any medications that need to be taken during clinic times
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### What is the usual Clinic routine?

- Registration
- Blood tests
- Waiting room
- Examination by my transplant doctor with a review of my blood test results and medications
- Meet with my coordinator to:
  - ✓ review care
  - ✓ answer my questions or concerns
  - ✓ be aware of and understand any changes in my care or medications
  - ✓ get prescriptions or have any new meds or med changes ordered
- Schedule or report for any additional procedures (biopsy, X-ray, etc.)
- Meet with my Social Worker if needed
- Attend support group meetings if scheduled



# Vital Signs

When you leave the hospital, you may be asked to regularly check your temperature, pulse, and blood pressure — called your “vital signs”. Understanding what each vital sign means and what your normal range is for each vital sign is important.

If you experience difficulty breathing or any chest pain or pressure, call 911 (Emergency Services) and ask to be taken to the nearest Emergency Room. Never try to drive yourself or have a caregiver take you to the hospital if you have these symptoms. You may require care as soon as possible and your caregiver may not be able to help you while driving. You should always call 911.

## Blood Pressure

Blood pressure is the measure of force in your arteries. It is a measure of two types of pressure, the systolic and the diastolic. The blood pressure measurement is written as 120/80. The systolic blood pressure is the “top number” of blood pressure measurement and measures the force of the muscle contraction of the heart as blood is pumped out of the chambers of the heart. The diastolic blood pressure is the “bottom number” and is when the heart muscle is at rest between beats, expanding and filling with blood.

If you are asked to record your blood pressure, you and your caregiver will be taught how to take your blood pressure before you leave the hospital. Your center will provide you with a cuff or instruct you on where you may purchase one. Cuffs may be manual (you pump them yourself) or digital (automatic). If you have a digital

cuff, be sure to measure how accurate it is with a cuff used by your nurse or in the clinic. Accuracy varies in some of the digital pumps.

High blood pressure (hypertension) may occur early on after liver transplant and is usually related to the side effects of some medications or kidney dysfunction. It can usually be managed well with blood pressure medications and/or some adjustments in your diet, such as low sodium diets. A common symptom of high blood pressure is headache.

- ✓ My blood pressure may range from \_\_\_\_\_/\_\_\_\_\_ to \_\_\_\_\_/\_\_\_\_\_.
- ✓ I should take my BP \_\_\_\_\_ times every day at \_\_\_\_\_ and before I take any blood pressure medicine.
- ✓ I should call my coordinator if my BP is greater than \_\_\_\_\_/\_\_\_\_\_.
- ✓ I should record my BP on the Vital Signs Form (see page 59).





## Temperature

Normal body temperature is 98.6° F or 37° C. If your temperature is rising, you may feel hot or cold, achy, and/or develop chills or sweat. Fever is an important symptom and can occur with rejection or infections (see Fever, page 24).

- ✓ I should take my temperature \_\_\_\_\_ times daily or whenever I feel ill.
- ✓ I should call my transplant coordinator or physician if my temperature is greater than \_\_\_\_\_ ° F or \_\_\_\_\_ ° C.
- ✓ The dose of acetaminophen/paracetamol that I should take if instructed to do so by my physician is: \_\_\_\_\_ mg or \_\_\_\_ tablets every \_\_\_\_\_ hours as needed for fever greater than \_\_\_\_\_.
- ✓ I should not take more than \_\_\_\_\_ doses in a 24 hour period.
- ✓ I should not take any ibuprofen products (Motrin®, Advil®) unless instructed to do so by my physician.

## Pulse

Your pulse is created by your heart beat. When you take your pulse, you are feeling the pressure of your blood in an artery from the beating of your heart. The pulse rate is the number of times your heart beats in a minute, for example 72 beats per minute (bpm).

Your pulse can be felt in your wrist or neck. You can also listen to your pulse with a stethoscope over your heart. You may be

advised to take your pulse when you take your blood pressure or if you feel like your heart is beating too fast or “racing”. You may also be asked to take your pulse if you are on certain heart medications that affect your pulse rate.

- ✓ My normal pulse when resting is:  
\_\_\_\_\_.
- ✓ My normal pulse when active is:  
\_\_\_\_\_.
- ✓ I should call my coordinator if my pulse is greater than \_\_\_\_\_ or less than \_\_\_\_\_.

## Weight

You may be asked to weigh yourself daily or 2-3 times a week to monitor for any losses or gains. Your weight will also be monitored at every clinic visit. You should check your weight as often as instructed on a bathroom scale at the same time each morning. After you go to the bathroom, but before you eat breakfast is a good time. Record your weight on the Vital Signs Form (page 59). Gaining or losing weight, particularly if this happens suddenly, can be a sign of problems in your recovery. A sudden weight gain could mean that you are retaining fluids. This could be a side effect of medications or a sign that your kidneys are not working well. A sudden loss could mean you are dehydrated which can be harmful to your heart and kidneys. Call your transplant coordinator with any sudden weight changes.

# Blood Tests



Monitoring blood tests is another way your transplant team follows your recovery and checks how your transplanted liver and other important body systems are functioning. Your medications may be adjusted based on your test results.

Blood tests are done frequently after transplant while you are in the hospital to monitor your recovery and progress. As you improve, your blood tests will be checked less often. Your blood tests may be repeated more frequently if you have rejection, infections, or other complications. When you return home, you may be asked to have your blood tests done locally.

Depending on your transplant center, it may be your responsibility to arrange this. Your coordinator will advise you on where to go and how to have your results sent to the transplant center. You may also want to keep a record of your results (page 37).

✓ My blood tests should be checked every:

✓ I will get this done at:

✓ Results should be faxed to:

✓ Any special instructions:

Lab values of blood tests vary by center. **Please adjust the normal ranges in the tables below to your center's guidelines.** If your lab results are out of the normal range, your physician or transplant coordinator will discuss these with you. Some abnormal lab values may be acceptable as you recover from transplant or a related complication and should improve over time. *(Lab values are US measurements.)*

## Tests that Monitor Liver Function

Your liver function tests (LFTs) will be monitored to check how well your new liver is working and to watch for any signs of rejection, infection, and/or blockage of the bile ducts.

Test	Name	Result	Normal Range (US Values)
Bili	Total bilirubin	↑ Bile duct obstruction ↑ May be a sign of rejection or infection	0.1 - 1.2 mg/dl
Alk Phos	Alkaline phosphatase	↑ Bile duct obstruction ↓ Malnutrition	30 - 120 U/L
ALT	Alanine aminotransferase	↑ Liver injury, rejection	1-30 U/L
AST	Aspartate aminotransferase	↑ Liver injury, rejection	0-35 U/L
GGTP	Gamma-glutamyl transpeptidase	↑ Liver injury, rejection, bile duct obstruction	Males: 11-50 U/L Females: 7-32 U/L
Alb	Albumin (serum)	↓ Malnutrition	3.5-5. g/dl
TP	Total protein	↓ Malnutrition, chronic liver dysfunction	6-8.4 g/dl



## Tests that Monitor Kidney Function and Electrolytes

These tests are important to follow to be sure your kidneys are functioning properly and that the fluid balance in your body is correct. Anti-rejection medications can

sometimes effect how well your kidneys work, so it is important that kidney function tests are also checked regularly. If your kidneys are not working well, you may also have abnormal levels of your electrolytes. Your physician will treat any problems with adjustments in your immunosuppression and/or other medications to treat electrolyte imbalances.

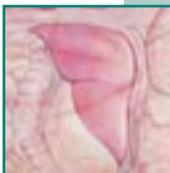
Test	Name	Result	Normal Range (US Values)
BUN	Blood urea nitrogen	↑ Kidney dysfunction, dehydration, high protein diet, side effect of some anti-rejection medications ↓ Liver disease; over-hydration	8-25 mg/dl
Cr	Creatinine	↑ Kidney dysfunction, side effect of some medications, dehydration ↓ Muscle wasting	Males: 0.6 - 1.3 mg/dl Females: 0.5-1.2 mg/dl
Na	Sodium	↓ Side effect of diuretics; kidney dysfunction	135-145 mEq/L
K+	Potassium	↑ Side effect of medications; kidney dysfunction ↓ Side effect of diuretics; decreased intake, vomiting	3.5-5.0 mEq/L
Mg <sup>++</sup>	Magnesium	↑ Kidney dysfunction ↓ Diarrhea; side effect of medications	1.8-3.0 mg/dl
Glu	Glucose	↑ Diabetes, problems with the pancreas, side effect of some medications ↓ Occurs in liver disease or with thyroid problems	70-115 mg/dl (fasting)
Ca <sup>++</sup>	Calcium (total)	↑ High intake of calcium often caused by taking too many antacids; bone disorders, thyroid problems ↓ Kidney dysfunction, over-hydration, problems with the pancreas, severe malnutrition	8.5-10.5 mg/dl



## Your Blood Count (CBC)

The Complete Blood Count (CBC) will be monitored with your routine labs to check for infection, the effects of anti-rejection drugs, anemia, and to make sure you have the normal range of each type of blood cell.

Test	Name	Result	Normal Range (US Values)
WBC	White blood cell count	Cells that fight infection and are also involved in the rejection process. ↑ Bacterial and viral infections ↓ Side effect of some medications, stress	4.5-11 WBC/mm <sup>3</sup> x 1000
Hct	Hematocrit	Measures the percentage of oxygen-containing RBCs. ↑ May cause blood clotting ↓ Sign of anemia	Males: 40-54% Female: 37-47%
Hgb	Hemoglobin	The oxygen-containing part of the RBC. ↑ May indicate dehydration or a blood disorder ↓ Anemia	Males: 14-18 g/dl Female: 12-16 g/dl
Plt	Platelets	Component of blood that helps stop bleeding. ↑ Can make your blood “thick” and lead to clotting ↓ May be a sign of liver disease, bleeding, anemia	150,000 - 350,000



# Lab Tests

<b>DATE</b>																				
Prograf level																				
Bili																				
ALT																				
AST																				
GGTP																				
Alk Phos																				
BUN																				
Creat																				
Sodium																				
Potassium																				
Magnesium																				
Calcium																				
Glucose																				
WBC																				
Hematocrit																				
Platelets																				

# Nutrition



Good nutrition is an important part of your complete recovery following liver transplant. As you recover, your body has increased nutritional needs for wound healing, to regain any weight you lost due to liver disease and the stress of surgery, and to help your body fight infection. After liver transplant, patients need a diet high in calories and protein to rebuild muscle tissue and restore protein levels. Dietary requirements are different for everyone, so your dietician will meet with you after transplant to discuss your specific nutritional and caloric needs and any dietary restrictions you may have. Most patients will need to increase calories as well as calcium and protein intake. Some patients may have to limit intake of sugar, salt (sodium), or potassium-containing foods.

Transplant recipients may also be at greater risk for bone fractures due to poor nutrition before transplant, chronic liver disease, or long-term use of steroids (prednisone). A bone density test may be ordered to check for calcium loss and weakness in your bones. Your physician and dietician may recommend that you take calcium supplements and increase your dietary intake of calcium. Good sources of calcium include: yogurt, low fat milk products (ricotta cheese, skim or low-fat milk, provolone cheese, mozzarella cheese), sardines, salmon, dark green leafy vegetables, and calcium-fortified orange juice. Regular exercise will also help prevent bone weakness.

During the first few weeks after transplant you may have some trouble eating due to loss of appetite, feeling full or nauseated, or you may have changes in taste. This is



quite common and will resolve over time as you recover and your activity increases. While your appetite is low, you might try eating several small meals a day, snack between meals on high calorie and high protein foods, and/or drink higher calorie liquids such as milk or juice rather than water. Your dietician can help you plan your meals and snacks. If you feel full or bloated, try to eat frequent small meals, avoid foods that may cause additional gas, eat foods that are high in carbohydrates and proteins rather than fats, or sip on fluids between meals instead of during meals. If you are nauseated during your recovery, foods high in carbohydrates such as pasta, cereal, bread, pretzels, and fruit may help. Nausea may also be decreased by drinking ginger ale and lemon-lime sodas. Spicy and fatty foods should be avoided if you are nauseated. If you continue to have problems with nausea, your physician may order a medication to help decrease this feeling. If you are experiencing changes in taste, try using seasonings and spices to enhance the flavors of your food.

Marinating meat, poultry, or fish can also be helpful. If you continually have a bad taste



in your mouth, drinking cold fluids or sucking on hard candies may also help.

Patients often have high potassium levels in their blood following liver transplant. An increased potassium level (hyperkalemia) could be due to anti-rejection medications or kidney dysfunction. High levels of potassium may cause the heart to beat irregularly. If your potassium level is high, it will be controlled by a medication called fludrocortisone (Florinef®) and/or dietary limits of high-potassium foods. Some high potassium-containing foods include: apricots, bananas, cantaloupes, dates, dried fruits, figs, honeydew, kiwi, nectarines, oranges, prunes, raisins, artichokes, beans, brussel sprouts, lentils, peas, potatoes, pumpkin, spinach, squash, tomatoes, ketchup, cocoa, coffee, nuts, cereals with fruits and nuts, and salt substitute. Your dietician will advise you on how many servings of these foods you may have daily if your potassium level is high.

While it is important to regain lost weight and to rebuild your protein stores, you should also be careful not to gain too much weight once you have returned to your recommended weight. Being overweight may contribute to other health complications such as heart disease and diabetes. Regular low-impact exercise such as walking or riding a bicycle can be very helpful. You should start all activities slowly then gradually increase your activity as your endurance improves.

The recommended weight range for my height is: \_\_\_\_\_ lbs to \_\_\_\_\_ lbs  
(\_\_\_\_\_ kgs to \_\_\_\_\_ kgs).

### Safe Food Handling

Safe food handling is important for everyone. However, you may be at an increased risk of getting a food-borne illness since you are taking anti-rejection medications. The following guidelines will help decrease your risk of getting an infection from food.

- Follow the safety instructions on food packaging.
- Avoid raw or undercooked meat, fish (sushi, oysters), poultry, or eggs.
- Foods should be cooked thoroughly and served hot.
- Always check labels on meats, fish, and dairy products for freshness and “sell by” dates.
- Buy pasteurized milk, cheese, and fruit juices.
- Store foods appropriately. Place foods in the refrigerator or freezer as soon as possible if they require cold storage.
- Wash your hands thoroughly with warm water and soap before and after preparing food and particularly after you touch raw meat, fish, or poultry.
- Wash all surfaces that come in contact with raw meat, fish, or poultry.
- Scrub all raw fruits and vegetables before cooking or eating them.
- Some centers caution patients not to eat food from salad bars due to possible contamination by others or from buffets if the food temperature is not hot enough.

# Activity



## Exercise

It is common to feel tired or weak as you recover from liver transplant. If you have been hospitalized for a long time before or after your transplant, you may have lost some muscle mass from prolonged bed rest. You may also find that your sleep pattern is disturbed. Regular exercise and good nutrition will help get you back to a normal, active routine and an eventual return to your home routine, work, or school.

While you are in the hospital, you may receive physical therapy to help you regain strength and increase your activity level. Your physical therapist can help you start a simple exercise routine. Walking for short periods several times a week can be the start of a good exercise routine once you leave the hospital. Regular exercise is important for everyone to control weight, improve cardiovascular health, increase endurance, and even to reduce stress.

For the first 6 months after transplant, you may be advised to avoid any strenuous activity, heavy lifting, or more intensive exercise programs. Check with your coordinator and physician for your center's guidelines. The best activity in the first few weeks after transplant is walking. Most centers recommend that any activities or sports with a high risk of injury like football, wrestling, skiing, water skiing, or motorcycling, should be avoided for at least one year after transplant although some centers restrict contact sports indefinitely.

Liver transplant patients may swim in chlorinated pools after all drainage tubes are removed and their incision and wounds

are healed. Patients should avoid small standing bodies of water such as ponds or small lakes that may contain infectious organisms. Patients may swim in oceans or large lakes if the water is tested to be safe by the local health department. Public hot tubs should be avoided.

## Returning to Work or School

Patients return to work or school at various times depending on the extent of their illness before transplant, recovery time, complications, and the type of work that is done. Most patients are ready to return to work or school within 2-3 months after transplant. It is often helpful to return on a part-time basis and increase your hours slowly as your energy and endurance improves. Discuss your return with your transplant doctor and coordinator to decide the time that is best for you based on your workplace and responsibilities.





### Driving

Most patients can resume driving within 4-6 weeks after transplant, but this also depends on your recovery period and medications. Your reflexes and judgment may be affected from a prolonged hospitalization or from certain medications, so it is best to discuss this with your transplant doctor and coordinator before getting behind the wheel. It may be helpful to have another licensed driver in the car with you for the first few times that you drive after transplant. You may also want to practice driving in an open lot or away from other traffic for the first time as you get used to driving again. It is important that you always wear a seat belt even if you still have an open wound. Padding your abdomen with a towel or small pillow will help cushion your abdomen from the seat belt while providing a safe restraint in case of an accident.



### Sexual Activity

Sexual activity is an important part of normal adult life. Your desire and sexual function may have been very limited before your transplant due to your liver disease and illness. Both men and women may find as they recover from liver transplant that their desire for sexual activity has returned. Most centers advise that patients wait for 6-8 weeks before resuming sexual activity because of the stress on the abdominal muscles, but how quickly patients feel ready for sex after transplant is different with every person. Ask your transplant doctor or coordinator when it is medically safe for you to have sex. Also discuss any concerns with your spouse/partner so that he/she understands your feelings about resuming sexual activity.

### Sexually Transmitted Diseases

Since transplant recipients are immunosuppressed, they are at higher risk for contracting sexually transmitted diseases (STD), particularly if they are not in a monogamous (one partner) relationship. If you are not in a monogamous relationship, it is imperative that latex condoms are used to decrease the transmission of STDs during sexual activity.

Practicing safe sex is the best way to prevent STDs and is important for everyone who is sexually active. Safe sex practices include:

- Having sex with only one partner (a monogamous relationship)
- Washing your genitals before and after sex.
- Always using latex condoms with a spermicide
- Avoid having sex with anyone who has sores, a rash, or a foul discharge from their genitals
- Avoid anal sex.



There are some additional considerations for patients who have received transplants for hepatitis B or hepatitis C. Sexual partners of patients who have hepatitis B may wish to be tested for the virus and should be vaccinated if they are not immune. Sexual transmission of hepatitis C is rare but can occur. Sexual partners may also be tested for this virus. However, if this is a long-term sexual relationship and partners do not have the virus, the risk of contracting the infection may be low. You may wish to talk to your transplant doctor or coordinator if you and your partner are considering whether or not to use condoms.

### **Birth Control and Pregnancy**

Female transplant patients who did not menstruate before transplant because of liver disease and illness, often begin to ovulate or menstruate within a few weeks to months after liver transplant. Most transplant centers recommend that women avoid getting pregnant for 1-2 years following liver transplant .

Birth control barrier methods using latex condoms with spermicidal jelly or cream with nonoxynol-9, or the sponge or diaphragm with spermicide are recommended. Patients with multiple partners should always use a condom as well. Before using birth control pills, the Norplant, or getting an injection of Depo-Provera, you should contact your gynecologist and transplant coordinator. These methods may be used in some cases, but recommendations vary by transplant center. Most centers recommend that barrier methods be used for several months until the liver function is stable and

there are no further complications with infections. Oral contraceptives or implantable devices may then be considered.

For female transplant recipients who are considering becoming pregnant, prenatal planning and consultation with your obstetrician and transplant team is imperative to ensure a healthy pregnancy for you and your baby. Some medications may be harmful to the developing fetus and must be stopped before you become pregnant. If you plan to become pregnant, discuss this important issue with your transplant doctor, obstetrician, and coordinator before you stop using birth control.

Generally, pregnancy after transplantation is successful. Many female transplant recipients have become pregnant and delivered healthy babies. There is however, an increased incidence of prematurity, lower birth weights, and Caesarian sections. The mother also has an increased risk of high blood pressure and preeclampsia. Breastfeeding is not recommended since some medications can be transmitted to the infant through breast milk. Outcomes of pregnancies of transplant recipients are being followed through the National Transplantation Pregnancy Registry (NTPR). Your physician can discuss the findings of this group in greater detail with you if you are considering becoming pregnant.



# Other Concerns

## Drinking Water

It is safe for you to drink treated municipal tap water after your liver transplant. If you live in an area that has well water, it is best to boil that water to a rolling boil for at least 1 minute before using it for drinking water. Well water should be tested by your local water authority every 6-12 months, even if you are not using it for drinking water. Contact your local water authority or the EPA Safe Water Hotline (in the US) at 800-426-4791.

## Travel

As you recover and return to a more normal routine, you may consider traveling or going on a vacation. Please check with your transplant coordinator for your center's guidelines on traveling early after transplant. Some centers recommend waiting for 6-12 months before you take an extended vacation, particularly one that may be remote.

If you are planning a vacation, you may be advised to have your blood tests taken a few weeks before to be sure there are no abnormal levels. You should call your coordinator if you need to review your meds, blood test results, or any specific care needs. If you are traveling to a different time zone, discuss how to adjust your medication times with your coordinator. Before you leave, be sure you know where the closest hospital and/or transplant center is located in case of an emergency. Be sure to take enough medication to last your entire trip and if flying, pack your medications in a carry-on bag. Taking extra medication and packing the extra medications

in a different bag may also be helpful. Take all your important phone numbers with you in case you need to call your transplant center while you are away. You may want to drink bottled water if you are traveling in areas where the sanitation is of concern.

Most transplant centers discourage travel to third world countries for patients who are immunosuppressed. The risk of acquiring infections in these areas is high and appropriate healthcare may not be available. Additionally, some foreign travel may require immunizations that are not safe for patients who are immunosuppressed, such as measles and smallpox. If you plan to travel in this type of area, please discuss this with your transplant doctor and coordinator so that you are fully informed of the risk.

## Medic-Alert Identification

Many centers recommend that patients wear a Medic-Alert necklace or bracelet to be identified as a transplant recipient in case of an accident and/or if emergency care is required. Medic-Alert, located in Turlock, CA, is a nonprofit membership organization that is recognized internationally. The organization's goal is to protect and save lives by providing information during emergencies. These tags are recognized by emergency operations teams as they care for accident victims. Your coordinator can provide you with information on this company or you can contact them at 1-800-432-5378 or at <http://www.Medicalert.org> to become a member, order your tag, and to update them on any medical information that you would like to have in your file.

**Pets**

Pets can be an important part of family life. Research has shown that pets help relieve stress and have positive physical and psychosocial benefits, as well as possibly improving our quality of life. One study has reported that older adults who had pets were better able to handle crisis situations.

Although animals do carry a number of diseases that can be transmitted to humans, few are life-threatening. If you follow some common-sense guidelines, your risk of acquiring an infection is minimal.

- Wash your hands thoroughly after petting or playing with your pet, particularly before you eat, drink, or handle food.
- Be sure that your pet is healthy, has regular check-ups, and has received its required immunizations.
- Groom and/or bathe your pet regularly. Keep cat's claws trimmed.
- If possible, avoid your pet's bodily fluids (urine, feces, vomit). If your pet has an accident, have someone else clean it up if possible. If not, wear gloves and clean the area with a disinfectant.
- Don't let your pet lick your face.
- Do not change your cat's litter box if possible. The litter and liner should be replaced frequently and the litter box cleaned at least monthly with a disinfectant or boiling water.
- Contact your physician immediately if you are bitten by any animal.
- Avoid stray or sick animals and exotic animals.

**Plants**

Some centers recommend that transplant patients avoid exposure to live plants and soil for 3-6 months after transplant. If you have a cut on your skin, you are at greater risk of infection since many types of organisms grow in the soil. If you are a gardener, be sure to wear gloves whenever you are working in the soil. It is also helpful to wash your hands every so often while gardening as well as when you are done working. Try to avoid compost piles and rotting materials when possible. Check with your transplant coordinator for your center's guidelines.

**Sunscreen**

Transplant recipients have a higher risk of developing certain types of skin cancers. Patients should use a sun screen with a sun protection factor (SPF) of at least 15 when out in the sun. Additionally, patients should wear a hat and limit their exposure to the sun, especially when the sun is highest in the sky from 10:00 AM to 2:00 PM.



# *Routine Healthcare Follow-up*

When you return home, you will resume routine care with your local physician and other health professionals. However, most transplant centers prefer to manage immunosuppression and any transplant-related care such as episodes of rejection, liver biopsies, and some transplant-related infections. Check with your coordinator so you know who to call when you have any signs or symptoms of illness. In some cases, you may be told to see your local doctor, and then return to the transplant center for further evaluation. Your local doctor may be asked to perform certain blood tests and send the report to the transplant center.

## **Local Primary Care Physician (PCP)**

Your local physician is usually an internal medicine physician or a hepatologist who will see you for routine medical follow-up. This physician usually manages preventative healthcare, routine physical examinations, immunizations, and complications related to high blood pressure, diabetes, high cholesterol, or bone disease. You may be asked to see this physician within the first 2 months of returning home. Your transplant center should have the contact information for your local physician before you leave the transplant center. The coordinator will forward information to your local physician about your transplant surgery, post-op course, and your current care. Your coordinator will also discuss the transplant

center's role in your care and how each physician can work cooperatively to be sure you do well. Your local physician plays an important role in examining you for any possible complications. Be sure to see this doctor regularly and have reports of those visits forwarded to your transplant coordinator.



## **Dental Care**

Routine dental examinations every 6 months are essential for good dental health for everyone. However, since you are immunosuppressed, an abscessed tooth or gum infection could lead to more serious complications. Additionally, gum overgrowth (gingival hyperplasia), a side effect of cyclosporine, may lead to bleeding gums and infection. Although changes in immunosuppression may help, in some cases the overgrown gums will need to be surgically reduced.



You should visit your local dentist within 3-6 months of returning home. Your transplant coordinator can forward any medical information that the dentist needs for your health history. Preventative antibiotics are required for any invasive dental work, which may include cleaning, before the procedure. If there is any possibility that the gums will be cut, there is an increased risk of infection. Your dentist will know what to prescribe for this, but he/she can also call your coordinator for your center's protocol. Amoxicillin is usually used prior to the procedure, but check with your dentist or transplant coordinator before any invasive dental work.

### Vision Care

Routine eye examinations are usually recommended every other year. However, some patients may require exams every 6-12 months if they have any risks for vision or eye problems. Prednisone, given in high doses for prolonged periods, may lead to the development of cataracts and/or glaucoma in some patients. Visit your vision care specialist within 2-3 months of returning home so he/she is updated on your health status and can assess your risk for any complications.



### Gynecological Care

Women should have yearly check-ups as usual with their local gynecologist. Papanicolaou's smear (Pap smear) and mammograms should be completed as recommended for your age and any risk factors. After liver transplant, there may be an increased risk for cervical and breast cancers.

If you are of child-bearing age, discuss appropriate birth control methods with your gynecologist. Birth control should be started before you resume sexual activity. Barrier methods are recommended until the patient is several months to a year after transplant. At this time, oral contraceptives or implanted devices may be considered. Your coordinator can also forward information about your liver transplant to this physician and provide the center's recommendations for birth control methods. If you are planning to become pregnant, discuss this with your gynecologist before you stop using birth control.



### **Immunizations**

Immunizations are a part of routine healthcare. You have probably received all your required immunizations as a child and now may only require boosters for special reasons. Now that your immune system is suppressed, you must not receive any **live** vaccines. Receiving a live vaccine could cause serious health complications because you may develop the virus you are being immunized against. This is because these immunizations contain some of the actual virus.

### **You should never receive these live viruses:**

#### **Oral polio (Salk vaccine):**

An inactivated form of this vaccine, the Sabin injection, is now available instead of the oral vaccine. This injection does not pose a risk to someone who is immunosuppressed. Some centers recommend that transplant recipients avoid all contact with patients who have had the **oral** polio vaccine for up to 8 weeks since the virus might be shed in their stool and saliva. If you have a young child, be sure that your child receives the inactivated form of the vaccine.

#### **MMR (measles, mumps, rubella):**

This is another live vaccine given to children at 12-15 months and again at 4-6 years. As an adult, you should not need this vaccine. You do not need to avoid a child who has recently received the MMR.

### **Varivax**

#### **(chickenpox or varicella vaccine):**

This is a live vaccine given to children at 1 year of age to immunize them against chickenpox (varicella). People who are immunosuppressed should not receive this vaccine. Some centers believe you may be at risk if you are in close contact with a child who has received the vaccine. Check with your coordinator for your center's guidelines.

### **Influenza Vaccine**

The yearly "flu shot" (injection) is an inactivated vaccine to provide protection from influenza. Most transplant centers strongly encourage transplant recipients and their close family contacts to get this vaccine every year. You can receive this vaccine if it is at least 3 months since you have had your liver transplant. Influenza may be more serious in someone who is immunosuppressed. This vaccine will protect you from the 3 most common strains of influenza that are reported for that year. You should not receive the influenza vaccine if you are allergic to eggs or chicken.

### **Tetanus Toxoid**

The general public is advised to get a tetanus booster every 10 years. If you get a dirty injury or cut, or are bitten or scratched by an animal, you should get this vaccine.



# Other Health Concerns

## Smoking

Smoking is a risk to everyone's health. Smoking can cause cancer, heart disease, and lung disease. Additionally, smokers may have prolonged respiratory infections because of the effect of smoke on the lungs. Transplant recipients who smoked before transplant are strongly encouraged to stop smoking. Since nicotine is broken down or metabolized by the liver, there is a possibility that some medications, particularly tacrolimus and cyclosporine, may not be metabolized well and that levels of these medications may be lower in smokers. You should never risk losing your healthy liver for cigarettes.

Your transplant coordinator or social worker can help you find local support groups to help you stop smoking. If you would like additional information and support, contact the following organizations:

American Heart Association  
<http://www.Americanheart.org>

American Lung Association  
<http://www.2lungusa.org/>

American Cancer Society  
<http://www.cancer.org>

If you are interested in using any medications to help you stop smoking, such as the NicoDerm® patch, discuss this first with your coordinator to check on your center's recommendations.

## Alcohol

Alcohol is metabolized, or broken down, in the liver. Drinking any type of alcoholic beverages can harm your liver. Many of your medications are metabolized by the liver and with the additional stress of breaking down alcohol as well, liver cells may be destroyed.

If you have had a problem with alcohol in the past, this was probably discussed at your transplant evaluation. You may have had to attend counseling sessions or you may have been enrolled in a rehabilitation program before you received a liver transplant. It is important that you continue counseling as you recover from transplant to avoid any possible injury to your healthy liver through alcohol use. There are many ways your transplant center and local physicians can help you recover and continue to do well after transplant.

## Illegal Drug Use

Drugs such as marijuana, cocaine, LSD, and Ecstasy are toxic chemicals that are harmful to the liver as well as other organ systems. These toxic drugs will harm the sensitive liver and interfere with the break down or metabolism of your transplant medications. The illegal use of drugs is not tolerated by any transplant center. If you have had problems with illegal drugs in the past or are concerned you may want to use them again, discuss this issue with your transplant coordinator, social worker, or counselor. Help is available through counseling and support programs.



# Glossary of Terms

## A

---

### **ABO TESTING**

Blood tests that classify human blood into one of four groups: O, A, B, or AB.

### **ALBUMIN**

Albumin is a protein made by the liver that helps maintain fluid balance in the body.

### **ANEMIA**

A decreased amount of circulating red blood cells in the body. Anemia may result from blood loss, destruction of red blood cells, or a decrease in the production of red blood cells. The hemoglobin level (hgb) is decreased in patients with anemia.

### **ANTIBODY**

An antibody is a protein produced by the immune system in response to specific antigens. Antibodies help the body fight organisms that cause infection as well as any foreign substances.

### **ANTIGEN**

An antigen is a substance, usually found on the surface of cells, that identifies the cell as “self” or “non-self”. The antigen causes an immune response through antibody production against the antigen.

### **ARTERIOGRAM**

An arteriogram is a radiologic study (x-ray) or picture of the arteries in an organ system that is visualized through a special dye that is infused in the blood stream.

### **ASCITES**

An abnormal accumulation of fluid in the abdomen.

## B

---

### **B CELLS**

B cells are a type of lymphocyte, or white blood cell, that develop in the spleen and are responsible for the body’s immunity. B cells produce antibodies which help fight infection and foreign substances.

### **BILE**

Fluid made by hepatocytes, the liver cells, that is secreted into the bile ducts and then into the small intestine to help absorb fats.

### **BILE DUCT**

A vessel in the liver that carries bile from the liver cells to the common bile duct. The common bile duct then carries bile into the intestine.

### **BILIRUBIN**

A substance made from the break down of hemoglobin. Hemoglobin is a substance in red blood cells that carries oxygen to body tissues. Red blood cells are trapped and destroyed in the spleen as they wear out. When these cells are destroyed, bilirubin is released into the blood (unconjugated bilirubin). The liver then processes this type of bilirubin, combines it with another substance, and excretes the bilirubin (called conjugated bilirubin) through bile. Bile flows from the individual liver cells, through the bile ducts, and into the intestine



where it leaves the body in the feces. The characteristic brown color of feces is due to bile. Patients with liver disease often have clay-colored or tan feces since the liver may not be producing bile due to missing or blocked bile ducts. An elevated bilirubin level may also be a sign of liver rejection.

### **BIOPSY**

A biopsy is a procedure that provides a small amount of tissue from an organ, tumor, bone, or other body tissue to find out more information about that organ or tissue. A core needle biopsy is usually performed to examine liver tissue. A tiny cylinder of tissue, showing liver cells and how they are arranged, is removed through puncture with this needle. This tissue is examined under the microscope by a pathologist to determine the cause of liver disease, or to look for any evidence of rejection or infection.

### **BLOOD UREA NITROGEN (BUN)**

A test that indicates kidney function. The BUN is a product of protein breakdown, or waste product, normally excreted by the kidney.

## **C**

---

### **CALCIUM**

A mineral measured in the blood that is required for bone growth and for blood clotting. It is also needed for the heart and nerves to function.

### **CATHETER**

A flexible tube that enters or exits the body. Catheters may be used to drain body fluids (a Foley catheter drains urine) or to administer fluids or medications through a vein (a Broviac catheter).

### **CHIMERISM**

The existence of more than one genetic background within one person. Transplant recipients show chimerism through genetic markers since they have cells from the donor organ in their bodies.

### **CHOLANGITIS**

A bacterial infection in the bile ducts of the liver. Cholangitis can occur if bile flow is obstructed due to scarring of the duct or an obstruction in the duct. It can also occur in patients who had bile duct reconstruction or the Kasai procedure when bacteria from the intestine can invade the liver. Symptoms of cholangitis may include fever, an elevated bilirubin level, jaundice, and low blood pressure. Antibiotics are used to treat cholangitis. Patients with recurrent cholangitis may be prescribed a preventative dose of antibiotic daily. Treatment of the obstruction through surgery or transplantation will ultimately resolve cholangitis.

### **CHOLESTASIS**

An accumulation of bile in the liver. This can be caused by medications, an injury to the liver, total parenteral nutrition (TPN), or gallstones and may resolve over time or when the medications or TPN are discontinued. Cholestasis may also occur as a symptom of many liver diseases.

### **CHOLANGIOGRAM**

A test that examines the bile ducts in the liver for any leaks or blockages. A dye is injected into the bile ducts and then the liver is examined through an x-ray.

**CHRONIC**

Having a disease for a long period of time. Chronic disease may worsen slowly over time. It may be treatable but is usually not reversible.

**CIRRHOSIS**

Cirrhosis occurs when something destroys the liver cells causing the cells to die. When many cells die, there is scarring throughout the liver. A cirrhotic liver becomes very firm, unlike its normal spongy texture, and can be shrunken in size or enlarged.

**COAGULATION**

The process of blood clotting. A variety of factors are necessary for the blood to have a normal clotting ability. Clotting ability is assessed by several blood tests including the prothrombin time (PT), partial thromboplastin time (PTT), and platelet count. An abnormal clotting time is often seen in patients with liver disease.

**COAGULOPATHY**

Decreased ability of the blood to clot which increases the risk of bleeding, particularly with surgery or any invasive procedures such as biopsies.

**COMPLETE BLOOD COUNT (CBC) or FULL BLOOD COUNT (FBC)**

A blood test that measures many parts of your blood count including the hemoglobin (hgb), hematocrit (hct), platelets (plt), and many types of white blood cells (WBC).

**CT SCAN**

Computed Tomography scan; a noninvasive radiologic study that shows a detailed cross-section of organ and tissue structure.

**CREATININE**

The creatinine level is an indication of kidney function. It is a waste product produced by the muscles and released into the blood stream. Creatinine levels may be increased with kidney disease. Abnormal creatinine levels are also seen in patients with kidney dysfunction caused by liver disease or medications.

**CROSSMATCH**

This is a test that examines how well the transplant recipient's blood matches with that of the donor. A high positive cross-match may indicate the need for higher levels of immunosuppression for the liver recipient. A negative crossmatch means that there is no reaction between the donor's and recipient's blood.

**CYTOMEGALOVIRUS**

CMV; a virus commonly seen following transplantation that can cause an infection in the gastrointestinal tract, blood, liver, lungs, and/or eyes. CMV is a type of herpes virus.

---

**D****DIABETES**

A disease originating in the pancreas related to insulin production that causes high levels of glucose (sugar) in the blood

**DIALYSIS**

A procedure to remove waste products from the blood in patients with kidney disease. Patients with severe liver disease who develop kidney dysfunction may require dialysis until normal kidney function returns, usually following liver transplant.

**DIASTOLIC**

This is the “bottom number” of blood pressure measurement when the heart muscle is at rest, expanding and filling with blood.

**DIURETIC**

A medicine that helps remove excess fluid from the body tissue by causing the body to excrete sodium. Furosemide (Lasix®) and spironolactone (Aldactone®) are diuretics. These medications will increase urine output.

---

**E****EDEMA**

Swelling of tissue, particularly in the face, hands, legs, and ankles. Diuretics may help to decrease edema.

**ELECTROLYTES**

The dissolved form of a mineral found in the blood that helps maintain bodily functions and fluid balance. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body.

**ENCEPHALOPATHY**

Confusion or an altered mental status. Encephalopathy may be seen in patients with end-stage liver disease. Due to liver dysfunction, ammonia can not be metabolized by the liver. Ammonia builds up in the brain and interferes with oxygen getting to the tissue, causing confusion and tiredness. Medications such as lactulose, and a low protein diet can help decrease the ammonia level so that the patient does not develop encephalopathy.

**ELECTROCARDIOGRAM (EKG/ECG)**

A noninvasive test that records the electrical activity of the heart.

**ENZYME**

A protein made in the body that is capable of changing a substance from one form to another. The ALT and AST are enzymes found in liver cells.

**ERCP**

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

**FIBROSIS**

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

**FULMINANT LIVER FAILURE**

A severe form of liver disease that starts, then progresses very rapidly.

---

**G****GALL BLADDER**

A small sac-like object attached to the liver that stores bile. The gall bladder is removed from the donor liver before it is transplanted into the recipient.

**GASTROENTEROLOGIST**

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

**GASTROESOPHAGEAL VARICES**

Enlarged veins of the esophagus and stomach due to scarring in the liver that obstructs the normal flow of blood through the liver.

**GINGIVAL HYPERTROPHY**

This term describes swelling or enlargement of the gums. Gingival hypertrophy is a side effect of cyclosporine and some seizure medications. Gum overgrowth may be controlled or decreased through good oral hygiene, surgical gum reduction, and changes in immunosuppression.

**GLUCOSE**

A type of sugar in the blood that supplies energy to the cell. Glucose levels may vary with diet, medications, stress, and organ dysfunction.

**GRAFT**

An organ or tissue that is taken from one person and placed into another (transplantation). A graft between humans or the same species with different genetic material is called an allograft. A graft between different species, such as a baboon to human, is called a xenograft.

**H****HEMATOCRIT (HCT)**

A measurement of the amount of red blood cells in the blood.

**HEMATOMA**

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

**HEMOGLOBIN (HGB)**

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

**HEPATIC**

A term that refers to the liver or having to do with the liver.

**HEPATIC ARTERY**

The blood vessel that carries oxygenated blood to the liver from the heart.

**HEPATIC VEIN**

The blood vessel that carries deoxygenated blood from the liver to the heart.

**HEPATITIS**

An inflammation of the liver, usually caused by infection.

**HEPATOLOGIST**

A medical doctor who specializes in treating diseases of the liver.

**HEPATOMEGALY**

A term that describes an enlarged liver.

**HERPES**

A family of viruses that causes infection in humans.

**HIRSUTISM**

Excessive hair growth. Hirsutism is a common side effect of cyclosporine.

**HISTOLOGY**

The study of living tissue. The histology of a liver disease, for example, would be determined by examining a piece of liver tissue from a biopsy under a microscope.

**HYPERLIPIDEMIA**

A high level of fats (triglycerides or cholesterol) in the blood. This can be caused by diet, genetic disorders, or medications.

**HYPERTENSION**

High blood pressure.

**I**

---

**IMMUNE SYSTEM**

A specialized system of cells and proteins that protect the body from organisms that may cause infection or disease.

**IMMUNITY**

The ability of the body to resist a specific disease.

**IMMUNIZATION**

Providing the body with protection from certain diseases through vaccinations.

**IMMUNOSUPPRESSED**

Describes the immune system of a transplant recipient which is weakened or inhibited by certain medications. Specific medications (such as cyclosporine, tacrolimus, and prednisone) are used to lower the ability of the immune system to attack foreign cells (the transplanted tissue). Immunosuppression will help decrease the body's ability to reject the transplanted organ.

**INFECTION**

Organisms such as bacteria, fungi, and viruses that invade the body and reproduce causing a variety of symptoms.

**INSULIN**

A hormone secreted in the pancreas by the Islets of Langerhans that regulates sugar metabolism. Insulin helps the body use sugar and other carbohydrates. As insulin is released in the body, the blood glucose level decreases.

**INTRAVENOUS**

within the blood stream. Fluids and medications may be given intravenously as well as by mouth (PO).

**J**

---

**JAUNDICE**

Term used to describe a yellow appearance of the skin and eyes commonly seen in patients with liver disease. Jaundice results from an increased amount of bilirubin in the body.

**L**

---

**LIVER FUNCTION TESTS (LFTs)**

Blood tests used to determine how well the liver is functioning. These include the ALT, AST, GGTP, bilirubin, and alkaline phosphatase.

**LYMPHOCYTES**

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



## M

---

### **MAGNESIUM**

A mineral required for normal bodily function. Magnesium is involved in nerve, skeletal muscle, heart, and cell function. It is also involved in blood clotting and the breakdown of carbohydrates and proteins.

## N

---

### **NEPHROTOXICITY**

Kidney damage, usually as a result of medications or other substances.

### **NEPHROLOGIST**

A medical doctor who specializes in the diagnoses, treatment, and management of kidney diseases.

### **NONADHERENCE/NONCOMPLIANCE**

Failure to follow instructions for medical care after transplantation. This may include not taking medications as prescribed, not obtaining labs as instructed, or missing clinic appointments and tests. Nonadherence is a significant post-transplant issue that often results in rejection, infection, an ultimately loss of the graft.

## P

---

### **PNEUMOCYSTIS (PCP)**

A bacterial infection of the lungs that is more common in immunosuppressed patients. Transplant recipients are usually prescribed an antibiotic (Bactrim®/Septra®) to prevent this type of pneumonia.

### **PLATELET**

A type of blood cell that is involved in the clotting process. Platelets help stop bleeding at the site of the injury by clumping and forming a clot. If the platelet count is low, there is an increased risk of bleeding.

### **PORTAL HYPERTENSION**

This term describes increased pressure in the veins that collect blood from the stomach, spleen, pancreas, and intestines (the portal system). The blood from all the veins of these organs is collected into the portal vein, which drains into the liver. In a diseased liver that has fibrosis or cirrhosis, the blood from the portal vein may not be able to flow easily through the liver. Increased pressure then develops in the portal vein and can cause an enlarged spleen, fluid in the abdomen (ascites), and/or enlarged veins in the stomach or esophagus (varices).

### **PORTAL VEIN**

The vein that collects blood from the stomach, spleen, pancreas, and intestines and carries that blood to the liver.

### **PTLD**

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

**POTASSIUM**

A mineral required for normal body functioning. Potassium is important in helping the heart, nerves, and muscles function properly. Potassium also helps change carbohydrates into energy and in forming proteins. The kidneys excrete any extra potassium in the body. It is important to follow potassium levels after transplant because some antirejection medications can cause an increase in the potassium level.

**PROPHYLACTIC ANTIBIOTICS**

Medications that are prescribed to prevent certain infections in a specific group of patients who are at a higher risk for these infections.

**PRURITIS**

Itching. Patients with liver disease may have increased itching due to liver dysfunction since there is an accumulation of bile salts in their skin.

**R**

---

**RENAL**

A term that refers to the kidney or having to do with the kidney.

**REJECTION**

A process in which the body's immune system attacks the transplanted organ, usually resulting in damage to that organ.

**S**

---

**SODIUM**

A type of salt found in the blood and required by the body to maintain the balance between electrolytes and water.

**SHINGLES**

A viral infection caused by the herpes zoster virus that usually affects an area by a nerve, resulting in fluid-filled blisters and pain. Shingles are most commonly seen on the neck, abdomen, and legs. The virus can also affect the nerves of the eye.

**SPLEEN**

An organ located under the rib cage on the left side of the abdomen. The spleen removes old or deformed red blood cells, white blood cells, and platelets. It also makes lymphocytes, a type of white blood cell that help produce antibodies. The spleen may enlarge (splenomegaly) in patients with liver disease.

**SPLENOMEGALY**

Splenomegaly is a term used to describe an enlarged spleen. In patients with liver disease, splenomegaly results from portal hypertension. Splenomegaly can cause a low platelet count that may increase the risk of bleeding.

**SYSTOLIC**

This is the “top number” of blood pressure measurement. The systolic pressure measures the pressure as the heart muscle contracts to pump blood around the body.



---

**T****T CELLS**

T cells are a type of lymphocyte, or white blood cell, that develop in the thymus gland which is located in the upper chest in front of the heart. T cells are associated with acquired immunity, or the ability of the body to fight an infection or foreign substance that it was exposed to in the past. T cells play a major role in the rejection process.

**T TUBE**

A flexible tube may be placed inside the common bile duct to drain bile from the liver to the outside of the body into a drainage bag. Sometimes liver transplant recipients have this drainage bag for a few weeks after transplant to insure that bile is draining well from the transplanted liver.

**THRUSH**

A fungal infection that looks like white plaques or spots in the mouth (oral mucosa), throat, and on the tongue. Patients who are immunosuppressed are more at risk for developing thrush.

---

**U****ULTRASOUND**

A test that displays internal bodily organs, blood vessels, and ducts using sound waves. An ultrasound of the liver may be obtained to examine the size of the liver and spleen, the size and blood flow in the hepatic artery and portal vein, and the size and patency of the bile ducts.

---

**V****VARICES**

Enlarged blood vessels, particularly in the stomach and esophagus

**VITAL SIGNS**

The measurement of temperature, blood pressure, heart rate, and respiratory (breathing) rate

---

**W****WEAN**

To slowly withdraw or reduce; Immunosuppression, particularly steroids, may be weaned slowly over time in patients who do not reject the transplanted liver.

**WHITE BLOOD CELL**

This is a type of blood cell that fights infection.



# *Transplant*

## *Educational Resources, Support Groups, and Organizations*

ITNS is not responsible or liable for any information located as a result of visiting these websites. These sites are provided as a network resource. Information from the internet in regard to your transplant should always be discussed with your transplant team.

**American Association for the Study of Liver Diseases**

<http://www.hepar-sfgh.ucsf.edu>

**American Association of Kidney Patients (AAKP)**

<http://www.aakp.org>

**American Organ Transplant Association (AOTA)**

<http://www.a-o-t-a.org/>

**American Liver Foundation**

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

**Children's Liver Alliance**

<http://www.liverkids.tk>

**Children's Liver Association for Support Services**

<http://www.classkids.org>

**Children's Organ Transplant Association (COTA)**

<http://www.cota.org>

**Coalition on Donation**

<http://www.shareyourlife.org>

**Fujisawa Healthcare, Inc.**

<http://www.fujisawausa.com>

**International Transplant Nurses Society**

<http://www.itns.org>

**Minority Organ Tissue Transplant Education Program**

<http://www.mottep.org>

**National Council on Patient Information and Education**

<http://www.talkaboutrx.org>

**National Foundation for Transplant**

<http://www.transplants.org>

**National Transplant Assistance Fund**

<http://www.transplantfund.org>

**National Kidney Foundation, Inc.**

<http://www.kidney.org>

**Sangstat**

<http://www.sangstat.com>

**Transplant Health**

<http://www.Transplanthealth.org>

**Transplant Patient Partnering Program**

<http://www.rocheusa.com>

**Transplant Recipients' International Organization (TRIO)**

<http://www.trioweb.org>

**Transplant Speakers International**

<http://www.transplant-speakers.org>

**Transweb**

<http://www.transweb.org>

**United Network of Organ Sharing**

<http://www.unos.org>







# My Transplant Team

\_\_\_\_\_  
Patient's Name

My Transplant Center: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Fax: \_\_\_\_\_

Website: <http://www>\_\_\_\_\_

	NAME	PHONE	EMAIL	FAX (if needed)
<b>Transplant Coordinator</b>				
<b>Transplant MD</b>				
<b>Clinical Nurse Specialist</b>				
<b>Nurse Practitioner/PA</b>				
<b>Hepatologist</b>				
<b>Social Worker</b>				
<b>Pharmacist</b>				
<b>Physical Therapist</b>				
<b>Psychologist</b>				
<b>Dietician</b>				

