



International  
**Transplant Nurses**  
Society

A Guide to Your Health Care

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# After Liver Transplantation

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**Liver Transplant Handbook: A Guide for Your Health Care after Liver Transplantation (2016)**

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**Liver Transplant Handbook: A Guide for Your Health Care after Liver Transplantation (2007)**

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**Liver Transplant Handbook: A Guide for Your Health Care after Liver Transplantation (2003)**

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Congratulations on your recovery following liver transplantation! This manual provides important information about your care as you and your family prepare for discharge from the hospital. As you are learning by now, liver transplantation is far more than the operation you recently experienced. 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 your active participation in your care will lead to a successful recovery.

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## Purpose

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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. **It is always important to check with your transplant coordinator when you have questions or concerns about your care.** Review this handbook with your nurse, transplant coordinator, or clinical nurse specialist and know your center's specific guidelines.

**Your transplant center's specific guidelines should always be followed.**

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## Your Responsibilities

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You are the most important caretaker of your transplanted liver. To have the best outcome as a transplant recipient you should:

- Know all your medications: doses, times and why you are taking them.
- Follow your medication schedule daily and make changes only as ordered by your transplant provider.
- 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.
- Have blood tests drawn routinely as required.
- Monitor your weight, blood pressure, and temperature as required.
- Maintain a healthy lifestyle that includes a balanced diet, regular exercise, and routine check-ups.

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# Your Transplant Team

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Maintaining regular contact with your transplant team is important. Team members will continue to provide medical care, advice, and support for you and your family throughout the transplant process. Team members vary in each transplant center but usually include:

## You!

You are the most important member of the transplant team. You should have a good understanding of your medical care and be actively involved in your care through clinic appointments and communicating with members of the team.

## 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): \_\_\_\_\_ Transplant Office number: \_\_\_\_\_

## 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: \_\_\_\_\_ Office number: \_\_\_\_\_

Management varies by transplant center, so you may have follow-up care with a transplant physician or other provider, transplant surgeon, and/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.



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## Advanced Practice Registered Nurse (APRN) [Nurse Practitioner (NP) or Clinical Nurse Specialist (CNS)] or Physician Assistant (PA)

An advanced practice registered nurse (APRN) is a licensed registered nurse who has completed advanced education, either a master's or doctorate degree, and has training in the diagnosis and management of medical conditions and chronic illnesses. Advanced practice registered nurses may be prepared as a nurse practitioner or clinical nurse specialist. Physician Assistants are non-physician clinicians who are licensed to practice medicine under a physician's supervision. Most PAs also have a master's degree.

APRNs and PAs provide a broad range of health care services. They provide some of the same care as physicians while working closely with the transplant team. An APRN or physician assistant working at a transplant center might manage your daily medical care when you are in the hospital or may follow your progress in the outpatient clinic.

My APRN or PA: \_\_\_\_\_ Phone: \_\_\_\_\_

## Transplant Coordinator (RN, CCTC)

Transplant Coordinators are usually licensed registered nurses (RN). They have extensive experience in the care and management of transplant recipients, both before and after transplant. Your coordinators will be involved in preparing you for discharge and will also follow your care after you return home. Your coordinators 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. The initials CCTC after your coordinator's name means that your coordinator has passed a transplant certification examination as 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 licensed registered nurse with an advanced practice degree (master's or doctorate) in a nursing specialty. The transplant clinical nurse specialist may be a care provider as is discussed above in the advanced practice registered nurse (APRN) section. In addition, the 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 in preparing you for discharge. This advanced practice nurse may be involved with your care while you are in the hospital and after discharge.

My CNS: \_\_\_\_\_ Phone: \_\_\_\_\_

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## 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 pharmacist: \_\_\_\_\_ Phone: \_\_\_\_\_

My pharmacy: \_\_\_\_\_ Phone: \_\_\_\_\_

## Dietitian

A dietitian specializes in helping patients maintain good nutrition. Your dietitian will help manage your nutrition before and after transplant. The dietitian 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 dietitian: \_\_\_\_\_ Phone: \_\_\_\_\_

## Other members of my Transplant Team:

Name/Title	What they do	Contact information

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# Medications

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One of the most important responsibilities you will have after transplant is taking your medications as they are prescribed. You will learn a lot about your medications before you leave the hospital.

## What you should know about your medications

- **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. For example, tacrolimus and Prograf® are the same medication. Tacrolimus is the generic name and Prograf® is the brand name.

- **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. For example, fluconazole is a medication used to treat fungal infections, but it can also be used to increase tacrolimus blood levels.

- **What each medication looks like**

You must be able to recognize each medication by color, shape, and size. Many medications have a similar appearance with only slight differences. They must be looked at closely at the time they are picked up from the pharmacy to be sure the correct medication is being taken. Magnesium oxide, sodium bicarbonate, and some generic forms of Bactrim® are all large, round, white pills. If you look closely, though, you will see some differences.

- **When to take each medication**

Some medications, such as the anti-rejection medications tacrolimus and cyclosporine, must be taken on time daily so that the appropriate level of that medication is maintained. It is important to know what time you need to take each medication. Work with your coordinator, nurse, or pharmacist 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, coordinator, or pharmacist. Some pills should not be crushed because breaking up the pill may decrease its effectiveness or could be harmful to non-transplant patients if the medication powder is inhaled or handled without gloves.

- **How long each medication is prescribed**

Some medications may be prescribed for only 7 to 14 days, such as antibiotics. Others, like your anti-rejection medications, are usually prescribed for your lifetime. Some medications may be discontinued if a complication or significant side effect occurs.

- **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 medications. Discuss any special instructions for your medications with your nurse, pharmacist, or coordinator.



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- **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, pharmacist, or social worker will help you find the most convenient way to order your medications. As you are preparing for discharge, have your caregiver get your medications at the hospital's outpatient pharmacy, at a retail pharmacy in the area, or from a mail order pharmacy, depending on the rules of your transplant center and your insurance. Be sure that you have a month's supply of all your medications 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. Your insurer may also specify how many refills can be ordered. After the prescription has been submitted to your pharmacy, you may call for refills/ repeat prescriptions. However, all new prescriptions and any changes in the medications you are already taking must be called in or sent to your pharmacy by your provider. 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 at least a one week supply of medications.

- **What is the cost for your medications?**

It is important to know your financial responsibility for your medications so you can plan ahead. In the United States, some medications may be completely covered by insurance, while others have co-payments. Often, insurance companies have a deductible you must meet before their coverage begins. It may be helpful for you or a family member to call your insurance 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 by country. You should discuss the possible cost of your prescriptions with your transplant coordinator, pharmacist, social worker and/or transplant financial counselor.

## Medication Guidelines

### *Call your transplant 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
- notice 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
- would like to take Tylenol® (acetaminophen) or Advil® (ibuprofen) for fever
- would like to take an over-the-counter cold remedy, cough suppressant, diet aid, herbal medicine, natural supplement, or medication that you have not previously discussed with your provider.
- are prescribed or given any new medications by your local care provider or if any changes or new medications are added by another provider.

### *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 convenient. A convenient schedule will improve your success for taking all your medications at the right time every day.
- Some people find it helpful to follow a written schedule or a check-off list.
- Pill reminder containers (medi-sets) 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. Medication alarms can be set on cell phones and other electronic devices 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 provider'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 transplant provider about the possibility of changing the dosage so that it may be taken less frequently. In some cases, the dosage frequency may be able to be decreased.

## 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 medications in a cool, dry place away from sunlight. Do not store them in the bathroom because moisture may interfere with the effectiveness of some medications.
- Do not store medications in a refrigerator unless instructed to do so by your pharmacist.
- Keep all medications in a safe place, out of reach of children and pets.
- 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, in their office, or with the school nurse in case of an emergency.
- When traveling, be sure you have enough pills for the time you are away from home.
- It is helpful to bring your medications, filled medication container and/or medication list with you for clinic visits or if you are admitted to the hospital. This will ensure that you won't miss any doses.

## Commonly Prescribed Medications Following Liver Transplantation

This section contains information about commonly prescribed medications following liver transplantation. It 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 transplant team to be aware of your center's recommendations and specific medication protocols.

If you are pregnant or planning to become pregnant, your transplant provider and obstetrician/gynecologist should be consulted to review and discuss your current medication routine and your medication history. Some medications may be harmful to the developing fetus, so adjustments may need to be made.

## Anti-Rejection Medications

### Tacrolimus (Prograf<sup>®</sup>, Hecoria<sup>™</sup>, Astagraf XL)



**Purpose:** Tacrolimus is used to prevent or treat rejection after liver transplant. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Tacrolimus may be used by itself or in combination with other anti-rejection medications to prevent rejection.

**Dosage:** Tacrolimus is available in 0.5 mg, 1 mg, and 5 mg capsules. Tacrolimus may be dosed once or twice a day, as directed by your transplant team. It is important to take tacrolimus on time every day and exactly as directed to ensure a stable level of drug in your blood. Most transplant centers advise that patients take their tacrolimus no more than one hour earlier or one hour later than it is scheduled.

**Side effects:** The side effects of tacrolimus vary and are often related to the blood level of the drug. Side effects are more commonly seen when levels are high,

particularly in the early weeks after transplant and during treatment for rejection. The most common side effects include:

**Nervous system side effects (neurotoxicities):**

These side effects are more commonly seen with a high tacrolimus level (>15 ng/mL). They 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. Difficulty speaking (aphasia), seizures, and confusion are very rare side effects, but have occurred.

- **Kidney dysfunction (nephrotoxicity):** Tacrolimus 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 (an elevated blood urea nitrogen [BUN] and creatinine). Long term kidney dysfunction and damage may occur.
- **Infection:** If you are taking tacrolimus your immune system is suppressed. Your body's natural ability to fight infections is decreased. Therefore, you may be more likely to develop 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 and other anti-rejection medications.
- Other side effects that may be experienced with tacrolimus are nausea, diarrhea, high blood sugar, high blood pressure, 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 provider.
- 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. Although management of immunosuppression varies by transplant center, tacrolimus level may be run 6 to 12 ng/ml in the early post-operative period

or during treatment for rejection. Levels may be decreased to 3 to 10 ng/ml after one to two years if the patient has stable liver function.

- Tacrolimus levels should be drawn before taking a dose and about 10 to 12 hours after the previous dose. This is called a trough level and is the lowest level of tacrolimus that is present in the blood. Check with your transplant center for the timing of the trough. For example, if your transplant center wants you to have the trough at 12 hours, and you take tacrolimus at 8:00 AM and 8:00 PM, then have your trough level drawn at 8:00 AM prior to taking that dose. On days when you are having blood work, be sure to have your labs drawn before taking tacrolimus so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- Your dose of tacrolimus may be increased if you are experiencing liver rejection. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Food may affect the tacrolimus level. Some transplant centers prefer that patients not eat for an hour before or after taking tacrolimus. It is best to take tacrolimus in a consistent manner to decrease the variability of tacrolimus absorption. Please check with your coordinator or transplant pharmacist for your center's guidelines.



- Take your tacrolimus dose in the same way and at the same time every day to maintain a stable level.
- You should not eat grapefruit or pomegranates or drink grapefruit juice while taking tacrolimus. Chemicals in these fruits can interfere with the enzymes that break down tacrolimus and will increase tacrolimus levels.
- An increased tacrolimus level increases your risk of infection and serious side effects.
- Some medications should not be taken with tacrolimus.
  - Two hours from tacrolimus: sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®)
  - Two to four hours from tacrolimus: sodium bicarbonate (Bicitra®, Polycitra®)
- 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 and away from the reach of children and pets.
- If you are planning to become pregnant, discuss the use of tacrolimus with your transplant provider and obstetrician/ gynecologist.

## Cyclosporine (Sandimmune®, Neoral, Gengraf®)



**Purpose:** Cyclosporine is used to prevent or treat rejection after transplant. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Cyclosporine may be used by itself or in combination with other anti-rejection medications to prevent rejection.

**Dosage:** Cyclosporine is available in two formulations that are not identical. These are cyclosporine (Sandimmune®) and cyclosporine-modified (Neoral® and Gengraf™). Cyclosporine is made by several pharmaceutical companies. Your body absorbs them in different ways. Because of this difference in absorption, be sure that your pharmacy always gives you the correct formulation of cyclosporine that has been prescribed for you.

Neoral® and Gengraf™ are also available as a liquid. 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 and soft plastic cups should not be used since some cyclosporine could cling to the foam container or plastic. Hard plastic containers are acceptable for safety reasons with small children.

Cyclosporine is usually dosed once or twice daily and should be taken at the same time each day to ensure a stable level of drug in your blood. Most transplant centers advise that patients take their cyclosporine no more than one hour earlier or one hour later than it is scheduled.

**Side effects:** The side effects of cyclosporine vary and are usually related to the blood level of the drug. Side effects are more commonly seen when levels are high, particularly in the early weeks after transplant and during treatment for rejection. The most common side effects include:

- **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), and numbness and tingling of the hands and feet.

- **Kidney dysfunction (nephrotoxicity):** 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 (an elevated blood urea nitrogen [BUN] and creatinine).
- **Infection:** While taking cyclosporine, your immune system is suppressed. Because your body's natural ability to fight infections is decreased, you may be more likely to get infections. You are at greatest risk for developing infections when your cyclosporine level is high, particularly during the first three months after transplant, and if you are being treated for rejection with increased immunosuppression.
- **Cosmetic side effects:** Cyclosporine can cause some changes in your appearance. Excessive hair growth (hirsutism) can occur. Patients may also develop swelling, tenderness, and bleeding of the gums. This overgrowth and gum enlargement is known as gingival hyperplasia. Acne may develop or worsen in patients taking cyclosporine.

### Additional information:

- Do not change the dose of cyclosporine or take it more or less often than prescribed for you by your transplant provider. Cyclosporine levels are monitored through blood tests. Levels are monitored daily in the early postoperative period, then less frequently over time. Most patients have a cyclosporine level checked monthly by the time they are several months post-transplant. Although management of immunosuppression varies by transplant center, levels usually range from 200-250 ng/ml in the early post-operative period or during treatment for rejection. Levels may be decreased to 100-150 ng/ml after one to two years if the patient has had no recent rejection episodes and has stable kidney function.
- Cyclosporine levels are usually drawn before taking a dose and about 10 to 12 hours after the previous dose. This is called a trough level and is the lowest level of cyclosporine that is present in the blood. Check with your transplant center for the timing of the trough. For example, if your transplant center wants you to have the trough at 12 hours, and you take cyclosporine at 8:00 AM and 8:00 PM, then have your trough level drawn at 8:00 AM prior to

taking that dose. On days when you are having blood work, be sure to have your labs drawn before taking cyclosporine so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose. Alternatively, some transplant centers monitor cyclosporine as a C2 level which means your level is checked 2 hours after you take your morning dose. Always get cyclosporine drawn as instructed by your transplant center.

- Your dose of cyclosporine may be increased during an episode of rejection or to prevent rejection if your level is low. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Take your cyclosporine dose in the same way and at the same time every day to maintain a stable level.
- You should not eat grapefruit or pomegranate or drink grapefruit juice while taking cyclosporine. Chemicals in these fruits can interfere with the enzymes that break down cyclosporine and will increase cyclosporine blood levels. An increased cyclosporine level increases your risk of infection and serious side effects.
- Cyclosporine interacts with some other medications, causing higher or lower levels. Always check with your transplant coordinator or pharmacist before starting any new medication to be sure that it does not interfere with cyclosporine.
- 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 and away from heat and direct sunlight. An opened bottle of cyclosporine liquid may be used for up to two months. Be sure to keep cyclosporine and all medications out of the reach of children and pets.
- If you are planning to become pregnant, discuss the use of cyclosporine with your transplant provider and obstetrician/gynecologist.

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## Prednisone (Deltasone®) or Prednisolone (Orapred®)



**Purpose:** Prednisone is a steroid used to help prevent or treat rejection in organ transplantation. It prevents rejection by inhibiting the cells in the immune system that cause rejection and is given with tacrolimus, cyclosporine, or sirolimus. Although some patients require prednisone for life, many transplant recipients are being weaned from steroids within weeks to a few months after transplant. Some centers use steroids only as needed to treat rejection.

**Dosage:** Prednisone is available in several strengths including 1 mg, 2.5 mg, 5 mg, 10 mg, 20 mg, and 50 mg tablets. It is also available in a liquid form called prednisolone. Prednisone is usually prescribed once daily and should be taken in the morning. If taken at night, it can affect your sleep. If prednisone is prescribed twice daily, you can take a dose in the morning and the second dose with dinner.

**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 high blood sugar, an increased appetite, 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 occur with higher dosages over a longer period of time include bruising, high blood pressure, high cholesterol levels, muscle weakness, night sweats, bone weakening, delayed wound healing, cataracts, glaucoma, and growth retardation in children. Steroid medications can contribute to bone loss (osteopenia or osteoporosis). Patients are encouraged to take calcium with vitamin D supplements in order to minimize bone loss.

### Additional information:

- Be sure you know your correct dose of prednisone and that you have the correct strength of the medication. Because prednisone is available in several strengths, it is easy to get confused.
- Do not change the dose of prednisone or take it more or less often than prescribed.
- If prescribed once a day, prednisone should be taken in the morning so that you don't have trouble sleeping at night.

- If prednisone is to be stopped, the dose must be decreased slowly over several weeks. If prednisone is stopped suddenly, serious complications may occur.
- Prednisone should be taken with food because this medication can cause stomach upset or ulcers.
- If you miss a dose of prednisone, 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, missing doses could make you sick.
- If you are taking prednisone, 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 provider may advise you to avoid concentrated sweets like candy bars and soda while taking prednisone. High blood sugar levels can develop with higher doses of steroids. Patients who already have diabetes may find it more difficult to control their blood sugar when they are taking prednisone.
- If you are taking prednisone, you will usually be taking an antacid or an acid blocker so that you do not get a stomach ulcer. If you develop a stomach ulcer from prednisone, you may have an upset stomach or abdominal pain. Sometimes stomach ulcers can cause bleeding which may 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®)



This drug is commonly used in the treatment of liver transplants although it has not been FDA research approved for this purpose.

**Purpose:** Sirolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Sirolimus may be the only immunosuppressant that is prescribed for you or it may be prescribed to be taken with tacrolimus, cyclosporine, or prednisone.

**Dosage:** Sirolimus is available in 0.5, 1 mg and 2 mg tablets. It is also available in a liquid. Sirolimus is usually taken once

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daily and should be taken on time to ensure a stable level of immunosuppression. The liquid form of sirolimus should be mixed with two ounces of water or orange juice in a glass or plastic cup. Do not use a styrofoam or paper cup because sirolimus may cling to the container. Sirolimus should not be taken with apple or grapefruit juice. 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 blood level of the drug. The most common side effects are an increased risk of infection, nausea, diarrhea, a low red blood cell count (anemia), high cholesterol and/or triglyceride levels, a low white blood cell count, headache, acne, mouth sores, arthritis, muscle cramping, and delayed wound healing. Side effects usually resolve as the dose is reduced. A rare side effect includes hepatic artery thrombosis, or blockage of the artery providing blood flow and oxygen to the liver.

### Additional information:

- Do not change the dose of sirolimus or take it more or less often than prescribed for you by your transplant provider.
- 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 four 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-rejection medications because it can impair wound healing. Patients may be prescribed cyclosporine or tacrolimus for the first six to twelve weeks after transplant, then changed to sirolimus. In some cases, sirolimus may be added.
- Due to the effects of sirolimus on wound healing, always notify your transplant team prior to having any surgery.
- The dosage of sirolimus may be increased during an episode of rejection or to prevent rejection if your level is low. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Sirolimus levels are monitored through blood tests. Levels are monitored one to two times weekly in the early postoperative period, then less frequently over time. Most patients have a sirolimus level checked monthly by the time they are several months post-

transplant. The desired sirolimus level depends on whether it is the only immunosuppressant you are taking or if you are taking it with tacrolimus or cyclosporine. Although management of immunosuppression varies by transplant center, levels usually range from 5 to 15 ng/ml if used with tacrolimus or cyclosporine; 12 to 24 ng/ml if used alone.

- Sirolimus levels should be drawn one to four hours before taking a dose or about 20 to 24 hours after the previous dose if it is taken once a day. This is called a trough level and is the lowest level of sirolimus that is present in the blood. Check with your transplant center for the timing of the trough that they want. On days when you are having blood work, be sure to have your labs drawn before taking sirolimus so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- 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 two ounces of orange juice or water in a glass or plastic cup. Do not use a styrofoam or paper cup because sirolimus may cling to the container. Rinse the container with another ounce of water or orange juice and swallow that amount as well. It is also advisable to rinse your mouth with more water or orange juice after swallowing the medicine. Some patients have developed mouth ulcers from the liquid form. These ulcers have resolved over time or with decreased dosing.
- Store sirolimus tablets at room temperature and out of the reach of children. The liquid form of sirolimus must be refrigerated before it is opened. Once opened, sirolimus liquid can be used for 1 month if it continues to be refrigerated. Opened bottles of sirolimus stored at room temperature (and not in the refrigerator) must be used within 15 days.
- If you are planning to become pregnant, discuss the use of sirolimus with your transplant provider and obstetrician/gynecologist.

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## Azathioprine (Imuran®)

This drug is commonly used in the treatment of liver transplants although it has not been FDA research approved for this purpose.



**Purpose:** Azathioprine is used to help prevent rejection in organ transplant recipients. Azathioprine is a “helper” immunosuppressant and may be given with tacrolimus, cyclosporine, and/or prednisone.

**Dosage:** Azathioprine is available as a 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 platelets, which are cells that help your blood clot. Other side effects may include nausea, vomiting, and rash. Azathioprine may also be harmful to the liver resulting in an increase in the liver function tests (LFTs). It can also cause an inflammation of the pancreas (pancreatitis).

### Additional information:

- Do not change the dose of azathioprine or give it more or less often than prescribed.
- The dose of azathioprine 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 complaints or complications due to side effects of the medication.
- 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 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 provider has prescribed this medication for you.
- If you are taking azathioprine and considering becoming pregnant, consult your transplant provider and obstetrician-gynecologist.

## Mycophenolate mofetil (Cellcept®) Mycophenolate sodium (Myfortic®)

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

**Dosage:** two formulations: CellCept® and Myfortic®. Myfortic is enteric-coated to help decrease stomach upset and other gastrointestinal (GI) side effects. Mycophenolate mofetil (Cellcept) is available in 250 mg capsules and 500 mg tablets. It can be prescribed up to four times a day but is generally given twice daily. Mycophenolate 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 platelets which help your blood clot. Other side effects may include nausea, stomach irritation, vomiting, and diarrhea. Side effects may decrease over time or resolve with a lower dose of mycophenolate.

### Additional information:

- Do not change the dose of mycophenolate or take it more or less often than prescribed.
- Mycophenolate can be taken with food to prevent stomach upset.
- The dose of mycophenolate may be increased during an episode of rejection or to prevent rejection if your immunosuppression level is low. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Mycophenolate capsules should be swallowed whole and should not be opened. The powder inside the capsule may be harmful if inhaled. Mycophenolate tablets should also be swallowed whole and not be chewed, crushed, or cut.
- 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, you must discuss the use of mycophenolate with your transplant provider and obstetrician/



gynecologist. Women of childbearing age should use contraception while on this medication and for six weeks after discontinuing mycophenolate. New laws now require your healthcare provider to give you, “Mycophenolate REMS Overview & Your Birth Control Options” booklet. You will sign a form stating that you received this booklet and that this information was discussed with you. There is a higher risk of losing the pregnancy (miscarriage) in the first 3 months and a higher risk that the baby will have birth defects. If of childbearing age, pregnancy tests will be performed before starting and during mycophenolate treatment. If pregnancy does occur while on this medication, notify your healthcare providers (transplant and OB/GYN) immediately. If this does occur, your healthcare provider is required to report any pregnancies to the Mycophenolate Pregnancy Registry at [www.mycophenolaterems.com/PregnancyRegistry.aspx](http://www.mycophenolaterems.com/PregnancyRegistry.aspx)

### Antithymocyte globulin (ATG, Thymoglobulin®, Atgam®)

This drug is commonly used in the treatment of liver transplants although it has not been FDA research approved for this purpose.

**Purpose:** Antithymocyte globulin (ATG) is an immunosuppressant given in some transplant centers as a “pre-conditioning” agent immediately before transplant surgery. If given, one dose of ATG is given about four hours before transplant surgery to reduce the body’s immune response and possibly reduce the risk of rejection. Some transplant centers also use ATG to treat rejection that does not respond to steroids.

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

**Side effects:** During the ATG infusion, patients may have fever, chills, rash, low blood pressure, increased heart rate, or difficulty breathing. To minimize this “infusion reaction,” patients are usually treated with methylprednisolone (Solumedrol®), acetaminophen (Tylenol®)/ paracetamol, and diphenhydramine (Benadryl®) 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.

Other side effects that can occur later include a low white blood cell count, a low platelet count, pain, headache, fever, abdominal pain, diarrhea, high blood pressure, nausea, swelling of the hands and feet, and an increased level of potassium in the blood.

### OKT3 (Orthoclone®, muromonab-CD3)

**Purpose:** OKT3 is an immunosuppressant that is used to treat moderate to severe rejection of the liver.

**Dosage:** 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 the severity of this reaction. Within 30 minutes to 6 hours, and up to 24 hours after the first dose, OKT3 may cause: low blood pressure, a high heart rate, fever, chills, and/or flu-like symptoms. Patients may also experience 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 to 48 hours after the first dose.

Other side effects include headache, 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 to prevent or treat a type of pneumonia called *Pneumocystis carinii* pneumonia (PCP) or *Pneumocystis jiroveci* pneumonia (PJP). Patients who have a suppressed immune system are at greater risk for this type of pneumonia.

**Dosage:** To prevent PCP/PJP, patients are prescribed Bactrim® or Septra® once daily or three times a week (usually on Monday, Wednesday, and Friday) depending on the dosage. Bactrim® and Septra® are available as a tablet or liquid.

**Side effects:** Patients who are allergic to sulfa drugs will have an allergic reaction to Bactrim® or Septra®. They usually develop a rash, itching, and/or hives. If you are allergic, your transplant provider will usually prescribe another medication to prevent PCP/PJP, usually pentamidine or dapsone. Some transplant centers may have you try a sulfa desensitization protocol if you did not have a serious side effect (such as anaphylaxis) to sulfa in the past to see if you can tolerate this medication.

Other side effects include nausea, vomiting, diarrhea, mouth ulcers, a low red blood cell count (anemia), a low white blood cell count, or a low platelet count. Bactrim can cause an increase in liver and kidney function tests in some patients. If this occurs, another medication will be prescribed instead of sulfamethoxazole.

### **Ganciclovir (Cytovene®) Valganciclovir (Valcyte®) Acyclovir (Zovirax®)**

This drug is commonly used in the treatment of liver transplants although it has not been FDA research approved for this purpose.



**Purpose:** Ganciclovir, valganciclovir, and acyclovir are medications (also called antivirals) used to prevent or treat certain viruses that commonly occur in patients who have a suppressed immune system. Cytomegalovirus (CMV), herpes simplex infections (HSV), and Epstein Barr Virus (EBV) infections are usually treated with antivirals, depending on transplant center protocols.

**Dosage:** Ganciclovir is often 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. An oral form of antiviral similar to ganciclovir, called valganciclovir, is available as a tablet. A liquid form of valganciclovir can be prepared and is often used for children. For patients at high risk of contracting CMV infections, valganciclovir is ideal. For patients at low risk of contracting CMV/HSV infections, acyclovir is often given instead.

Some transplant centers give a preventative course of intravenous (IV) therapy of ganciclovir for 14 days following transplantation, particularly if the patient is at high risk for developing CMV. The oral form, valganciclovir, may be prescribed for an additional three to six months after transplant to prevent CMV in patients who are at risk for the virus. In patients at low risk for CMV/HSV infections, acyclovir is often given for one to four months.

Acyclovir may be used to treat herpes simplex infections (HSV-1, HSV-2) and varicella-zoster infections (chickenpox, shingles). Acyclovir helps decrease the pain caused by the herpes lesions (sores) and also helps them heal. The dose of acyclovir depends on the type of herpes simplex infection and kidney function of the patient.

**Side effects:** Side effects may include: nausea, vomiting, headache, pancreatitis, irritation from the IV infusion (phlebitis), confusion, and seizures. Ganciclovir and valganciclovir can affect the white blood cell count and platelet count, but this usually resolves by decreasing the dose or by stopping the medication. These medications are eliminated by the kidneys, so patients with kidney dysfunction receive a lower dose. Studies in animals 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:**

- If you are diagnosed with CMV, the first few doses of IV ganciclovir are usually given in the hospital. If you are doing well, you will be discharged to complete the IV treatment at home with home care nursing support or the medication will be changed to the oral antiviral, valganciclovir (Valcyte®).
- 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 drink two to three liters of fluid daily (unless fluid restricted) while taking valganciclovir.
- Avoid handling crushed or broken tablets. Wash the affected area thoroughly if your skin comes into contact with the powder.
- There is an increased risk of infection while on ganciclovir and valganciclovir therapy. Call your transplant coordinator if you have fever, chills, unhealed sores, or white plaques in your mouth.
- If you have herpes, acyclovir will not prevent you from spreading herpes to others. Sex should be avoided when symptoms of genital herpes are present or when there are active lesions (sores) in the genital area. Condoms may help prevent the spread of genital herpes.

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## Cytogam® (Cytomegalovirus Immune Globulin)

**Purpose:** Cytogam® is a medication used to prevent and treat CMV and EBV disease in patients who are immunosuppressed. It provides antibodies against CMV.

**Dosage:** Cytogam® is given through an IV infusion in the hospital or clinic. There is no oral form. The dose and frequency vary depending on transplant center protocols. It can be given to treat an active infection or to help prevent infection.

**Side effects:** Side effects are uncommon, but if present can include flushing, sweating, muscle cramps, back pain, nausea, vomiting, wheezing, chills, and fever.

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



**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, the vaginal area, or on the skin.

**Dosage:** Antifungal medications are prescribed to prevent or treat fungus. Fluconazole may be prescribed once weekly to prevent a fungal infection. Nystatin, a liquid antifungal, can be prescribed if a patient has fungus or thrush in the mouth. The liquid should be swished in the mouth for several minutes, then swallowed. Sometimes a lozenge (Mycelex®) is prescribed to be dissolved in the mouth. Vaginal creams, suppositories, powders, 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 mouth irritation, a stinging sensation, and increased liver function tests.

### Additional information:

- Nystatin oral solution should be swished and held in the mouth for as long as possible before swallowing.
- Clotrimazole lozenges should be dissolved slowly in the mouth.
- Patients should not eat or drink for about 15 to 30 minutes after taking the liquid or lozenge so that the medication can be absorbed into the tissue of the mouth and esophagus.

## Gastrointestinal (GI) Agents, Antacids and Acid Inhibitors

### GI Agents and Antacids:

Sucralfate (Carafate®)

Antacids: Mylanta®, Tums®, Roloids®, Maalox®, Di-Gel®

### H2-Blockers:

Famotidine (Pepcid®) Cimetidine (Tagamet®) Ranitidine (Zantac®)

### Proton-Pump Inhibitors (PPIs)

Omeprazole (Prilosec®) Lansoprazole (Prevacid®) Pantoprazole (Protonix®)

**Purpose:** Following transplantation, patients are at risk for developing stomach irritation and ulcers. This can be caused by steroids and also stress which may increase the amount of acid in your stomach. You may be prescribed one or two GI agents and/or antacids after transplant. Sucralfate works by coating existing ulcers and the lining of the stomach. This coating protects the tissue from irritation by stomach acid. Other types of antacids (H2 blockers and PPIs) work by blocking the mechanism that produces acid so you have a decreased amount of acid in your stomach.

**Dosage:** Each antacid is dosed differently. Your risk for developing stomach ulcers and the length of time after transplant will determine what GI agents, antacids and/or acid blockers are prescribed for you.

**Side Effects:** Most patients are able to take these medications without any problems. Side effects are rare but can include headache, diarrhea, nausea, vomiting, and abdominal pain.

### Additional Information:

- Antacids may increase or decrease the absorption of many medications. Antacids (Carafate®, Mylanta®, Tums®, Roloids®, Maalox®, Di-Gel®) should be taken two hours away from other medications, particularly tacrolimus, cyclosporine, and sirolimus.
- Sucralfate (Carafate®) should be taken before meals or on an empty stomach to be most effective.
- Omeprazole (Prilosec®) and lansoprazole (Prevacid®) capsules should be swallowed whole, not chewed, since these capsules contain time-released granules. Prevacid® is also available as a tablet that dissolves in the mouth (solutab) and as granules that are mixed with water before taking.

## Medications for Electrolyte Imbalances

**Purpose:** Sometimes medications can cause imbalances in the body’s electrolytes. Electrolytes are substances your body needs to maintain fluid balance and to help with other functions of your body. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body.

Medications to treat or prevent electrolyte imbalances may be needed for several reasons. Sometimes these imbalances are due to side effects of other medications. For example, tacrolimus can cause magnesium levels in your blood to be lower than normal. Sometimes imbalances can occur if your kidneys are not working well. If you have a lot of diarrhea because of an infection or as a side effect of a medication, your sodium blood levels may be high and your bicarbonate blood levels may be low. When electrolytes are higher or lower than the normal range, medications such as the ones listed below are used to treat or prevent imbalances.

Medication	Use	Possible Side Effects
Magnesium oxide Magnesium gluconate (Magonate®)	to treat or prevent low magnesium level	diarrhea, abdominal cramping, muscle weakness, high magnesium level, low blood pressure
Fludrocortisone (Florinef®)	to treat or prevent high potassium levels	high blood pressure, edema, headache, rash, low potassium
Sodium bicarbonate, sodium citrate, citric acid (Bicitra®)	to treat or prevent low bicarbonate levels	edema, increased gas, abdominal distention, low levels of potassium and/or calcium, high levels of sodium
Sodium and potassium phosphate (Neutra-Phos®) Potassium phosphate (Neutra-Phos K®)	to treat or prevent low phosphorus levels	low blood pressure, a high phosphorus level, nausea, vomiting, high potassium levels, diarrhea
Potassium chloride (K-Dur®)	to treat or prevent low potassium levels	high potassium, nausea, vomiting, diarrhea, abdominal pain, muscle weakness, heart problems

## Blood Pressure Medications



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

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

Medication	Possible Side Effects
<b>ACE inhibitors</b> Enalapril (Vasotec®) Lisinopril (Prinivil®) Ramipril	headache, low blood pressure, dizziness, faint feeling, fatigue, vertigo, insomnia, dry cough, high potassium, increased creatinine levels, anemia. Notify your transplant team if you develop swelling around lips and/or eyes.
<b>Calcium Channel Blockers</b> Amlodipine (Norvasc®) Nifedipine (Procardia®) Isradipine (DynaCirc®) Diltiazem (Cardizem®) Verapamil (Isoptin®)	swelling, headache, flushing, palpitations, low blood pressure, affects levels of some immunosuppressant medications (especially diltiazem and verapamil)
<b>Beta Blockers</b> Atenolol (Tenormin®) Metoprolol (Lopressor® Toprol XL®)	low heart rate, low blood pressure, fatigue, dizziness, chest pain, swelling
<b>Diuretics</b> Furosemide (Lasix®) Hydrochlorothiazide (Diuril®)	dry mouth, dizziness, thirst (dehydration), low blood pressure, low potassium levels, high blood glucose levels, weakness, palpitations, tinnitus (ringing in ears), rash
<b>Alpha Blockers</b> Doxazosin (Cardura®) Prazosin (Minipress®)	dizziness (especially when standing suddenly), allergic reaction, chest pain, palpitations, rash

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## Over-the-Counter (OTC) Medications

After transplant, patients may have complaints about common every day illnesses, just like the general population. People often take over-the-counter (OTC) medications to treat common illnesses such as the flu, colds, and diarrhea. If you want to take an OTC medication for any cold or flu symptoms, be sure to contact your provider or transplant coordinator before taking any of these remedies. Some OTC medications can contain multiple drugs and could interact with your transplant medications. You should always read the label and know what medications are included. It is also important that your transplant team knows when you are ill because your illness could be related to your transplant, rather than being a routine community-acquired illness.

**Always contact your transplant center before starting any new medications.**

### • OTCs for Diarrhea

Diarrhea may occur after transplant as a side effect of some commonly prescribed medications. Magnesium often causes diarrhea. In addition, mycophenolate can cause GI upset and diarrhea. You may have diarrhea if you eat foods that are spoiled or that you do not tolerate well. Food allergies cause diarrhea in some people. Diarrhea also can be a symptom of an infection by a fungus or bacteria in your gastrointestinal (GI) tract, or the result of a common virus.

If you have diarrhea for more than 24 hours or if you develop fever with diarrhea, contact your transplant coordinator or provider. If you have diarrhea, your transplant medications may not be absorbed well in your intestine. This could result in lower levels of your anti-rejection medicines. If this level is lower than desired, you may be at risk for rejection.

Your provider will prescribe the appropriate medication if you have diarrhea. However, usually a stool sample is first sent to the lab. If you have a bacterial infection in your GI tract, an antibiotic may be prescribed. Do not take an OTC medication for diarrhea unless told to do so by your provider.

### • OTCs for Constipation

If you are constipated, you may get some relief by increasing fiber in your diet. Eat plenty of bran, whole grains, fresh fruits, and vegetables. Drinking plenty of fluids can also help. Talk to your provider about this if you are fluid-restricted. Activity also helps. Gradually increase your activity level and try to exercise daily.

Contact your provider and/or transplant coordinator if constipation continues to be a problem. Do not take any OTC medications for constipation unless told to do so by your provider. The most commonly used OTC medications for constipation include Metamucil®, Fiber-Con®, Senokot®, and Colace® (docusate). Enemas to lubricate the intestine can also be helpful in some patients who are constipated but some transplant centers do not recommend them.

### • OTCs for Headache and Muscle Aches

If you have a headache or muscle aches that do not occur with fever, most transplant centers recommend taking acetaminophen (Tylenol®) / paracetamol, but often in lower doses than the general population.

Check with your provider or transplant coordinator for the recommended dose of acetaminophen/ paracetamol and the frequency of dosing. Be sure you know your center's guidelines about using acetaminophen/ paracetamol. If your headaches worsen or become more frequent, or if your headache presents with fever or vomiting, contact your provider or transplant coordinator.

### NSAIDs (non-steroidal anti-inflammatories)

Ibuprofen products (Motrin®, Advil®, Nuprin®, Midol®) and naproxen products (Naprosyn® or Aleve®) are common OTC medications used to treat headaches, muscle aches, and joint pain. However, these products are not recommended by most transplant centers, particularly in the first few months after transplant. These medications can affect the kidneys and the liver. They can also cause ulcers and bleeding in the stomach and GI tract. Although ibuprofen or naproxen may be appropriate medications to take for pain in the general population, be sure to talk to your provider before using these medications.

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- **OTCs for Colds, Coughs, and the Flu**

If you have cold or flu symptoms, particularly with fever, call your provider or transplant coordinator. Be sure you know your center's guidelines for what to do if you have a cold or the flu. If your provider thinks your symptoms might be related to a transplant illness, you may be asked to come for a check-up and/or have labs drawn. If you are thought to have a common community-acquired cold or flu, ask what OTC remedy you can take to relieve your symptoms. Many OTC cold and flu medications contain a combination of medications such as an antihistamine to dry your secretions and help you sleep, acetaminophen for aches and fever, and/or a cough suppressant. Always check the ingredients in OTC cold and flu medicines because some contain alcohol or non-steroidal anti-inflammatory medications. Alcohol-containing cold and flu remedies should always be avoided because they can affect your liver.

- **OTCs for Seasonal or Environmental Allergies**

Over-the-counter allergy medications can help relieve the symptoms of seasonal allergies such as hay fever or allergies to pollen, dust, animal dander, or certain foods. There are several OTC medications that can be used to relieve the symptoms of allergies. If you have an allergy, contact your transplant coordinator for your center's recommendations.

- **Nutritional Supplements**

After transplant, some patients may be advised to take a daily multivitamin, vitamin supplements, and/or mineral supplements. This is usually because they had poor nutrition before transplant due to chronic liver disease or they had a difficult recovery after transplant. Your dietitian will give you guidelines for eating healthy after transplant and will discuss your specific dietary needs. Always check with your provider or transplant coordinator before taking any nutritional supplement that has not been prescribed for you.

- **Herbal Products**

Herbal products, herbal remedies, and some herbal teas should be avoided after transplant. Most transplant centers strongly recommend that transplant recipients stay away from any herbal products. In the United States, herbal products are classified as dietary supplements by the Food and Drug Administration (FDA), so these products have not been well-tested for effectiveness, side effects, drug interactions, and contaminants. Product safety and doses are not regulated. Herbal remedies may interact with transplant medications or affect the transplanted liver.

St. John's Wort is an example of an herbal remedy that can cause complications in transplant recipients. St. John's Wort is a well-known herbal supplement used to treat depression, anxiety, fatigue, and generalized pain, among other uses. This herb increases the metabolism, or breakdown, of medications. In transplant patients, this increase in metabolism causes a decrease in cyclosporine or tacrolimus levels. Lower levels of tacrolimus or cyclosporine will increase your risk of rejection.

Herbal supplements should be avoided. If you are interested in taking any herbal products, discuss with your transplant coordinator. Never take an herbal supplement without telling your provider or transplant coordinator. These products can interact with your medications and lead to significant problems with your liver transplant.

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# Complications Following Liver Transplantation

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## Surgical and Post-operative Complications

Although liver transplantation is a successful treatment for end stage liver disease, complications can occur. Risks that can occur with any surgery include bleeding, pneumonia, breathing problems, stroke, or wound infections. Surgical complications that can occur following liver transplantation include:

### **Bleeding**

Bleeding can occur with any surgery because the body tissues and blood vessels are cut. If bleeding occurs after liver transplant surgery, it is usually detected within the first 12 to 24 hours following the operation. The patient may be returned to the operating room to repair the bleeding blood vessel. Transplant recipients are monitored very closely for any symptoms of bleeding during the early post-operative time.

### **Vascular Thrombosis**

Vascular thrombosis is a rare but very serious complication after transplant. This occurs when blood clots form in the blood vessels of the liver, causing a blockage of blood flow to or from the liver. If you have a risk for developing blood clots, your providers will prescribe medications to keep your blood “thinner” and will follow you closely for any symptoms.

### **Biliary Stenosis (narrowing of the bile duct)**

Occasionally, the bile duct narrows and may eventually become blocked. If this occurs, the patient will become jaundiced and labs will become abnormal. Your transplant team will decide if surgery, endoscopy, or an interventional radiology procedure may become necessary to correct it.

Knowing the common symptoms of these complications, reporting the symptoms to your provider or coordinator, and getting early treatment will lead to an improved outcome. The transplant team will watch you closely for complications and will prescribe medications and/or treatments to prevent and control any potential problems.

### **Diabetes**

Diabetes is an increased level of sugar in the blood. Even if someone does not have diabetes prior to a liver transplant, the medications and stress of the surgery cause the blood to have increased sugar levels. These higher levels of sugar need to be managed and brought to normal levels for proper healing and recovery. Often this higher blood sugar level is temporary, but sometimes it will continue for life. You will receive specialized teaching and ongoing follow up about how to deal with this problem.

Signs of diabetes may include extreme thirst, frequent urination, blurred vision, drowsiness, or confusion. Notify the transplant team if you notice any of these signs. In some cases, high blood sugar can be reduced and managed by weight loss, careful diet, and exercise. However, you may need an oral diabetes drug or insulin injections.

If left untreated or uncontrolled, diabetes can lead to heart disease, stroke, nerve damage, eye damage, kidney disease, and foot damage.

# Fever

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

It is very important to call your transplant coordinator if you have a 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.

## What is fever?

Fever is an increase in body temperature that is above the normal body temperature of 98.6° Fahrenheit (F) or 37° Celsius (C). Fever is not an illness, but is a symptom of an illness. Fever can be caused by a minor illness as well as a serious infection. Fever after transplantation is often defined as a **body temperature greater than or equal to 100.4° F or 38.0° C**. Check with your transplant center for the temperature that they consider a fever.

## Why would I get a fever?

In the general population, fever could be a symptom of a cold, the flu, or another type of infection. Now that you have had a liver transplant, your immune system is suppressed so that your transplanted liver will not be rejected. If you get a fever after liver transplant, it could be from a community-acquired cold or the flu. But fever after transplant can also be a symptom of rejection or a specific infection related to having a suppressed immune system.

If you have a fever, most transplant centers recommend that you:

- call your transplant coordinator or provider immediately if your fever is 100.4° F/38° or greater (or the temperature your transplant team has indicated is a fever).
- do not take any medications to treat your fever until told to do so.



Depending on how high of a fever you have and other symptoms of your illness, you may be told to take acetaminophen (Tylenol®) or paracetamol. Be sure to take the recommended dose at the appropriate time interval, usually every 4 to 6 hours. You may also be instructed to have blood tests drawn or to go to your Transplant Clinic, provider's office, or local Emergency Room for an examination.

Ibuprofen products (for example, Motrin®, Advil®) are sometimes used to treat fever. These products should not be taken by liver transplant recipients unless advised to do so by your transplant provider. Although ibuprofen can treat high fevers effectively, ibuprofen can affect liver and kidney function. Ibuprofen can also cause stomach irritation, ulcers, and GI bleeding.

## My responsibilities in monitoring for 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®) or paracetamol to take for fever if I am instructed to do so.
- After I am discharged from the hospital, I should take my temperature every \_\_\_\_\_
- I should call my transplant coordinator or primary provider if my temperature is greater than or equal to \_\_\_\_\_° F or \_\_\_\_\_° C.
- If I am told to take acetaminophen (Tylenol®) or paracetamol my dose is: \_\_\_\_\_mg or \_\_\_\_\_ tablets every \_\_\_\_\_ hours as needed for fever greater than or equal to \_\_\_\_\_.
- I should not take more than \_\_\_\_\_ doses in a 24 hour period.
- I should not take any ibuprofen products, such as Motrin® or Advil® unless instructed to do so by my transplant team.



# 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 common for your body's immune system to try to reject the liver within the first three months after transplant. Many patients experience at least one mild to moderate rejection episode during this early period, but rejection can happen at any time.

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

Rejection occurs as your body's immune system responds to the presence of the transplanted liver. Rejection actually shows that your immune system is working. However, in transplant recipients, this immune response needs to be suppressed to protect the transplanted liver so that it is not rejected.

Rejection can be *acute* meaning that it develops quickly as your immune system attempts to destroy the liver cells. If the rejection process is not completely resolved and continues slowly over time, it is called *chronic* rejection. Chronic rejection can be more difficult to treat because of 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 liver enzymes into the bloodstream. An injury to the liver cells could be caused by rejection, infection, side effects of medications, or problems with blood/bile flow. Measuring the liver function tests (LFTs) regularly and watching the pattern of the results can help your transplant team decide what is happening to your liver.

Liver rejection is usually diagnosed by looking at the liver function tests. Your transplant team may suspect that you have rejection if any of these numbers are increased from the normal range.

Measurement ranges of blood tests vary by center. Adjust the normal ranges in the table below to your center's guidelines. If your blood test results are out of the normal range, your transplant provider or transplant coordinator will discuss the results 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 and UK measurements.)

Test	Normal Adult Range (US)	Normal Adult Range (UK)	Indicates
ALT alanine aminotransferase	1–30 u/l	5–41 u/l	↑ may be rejection
AST aspartate aminotransferase	0–35 u/l	5–43 u/l	↑ may be rejection
Total Bilirubin	0.1–1.2 mg/dl	70–330 u/l	↑ may be rejection, biliary obstruction
GGTP Gamma-glutamyl transferase	males 11–50 u/l females 7–32 u/l	males 11–50 u/l females 10–40 u/l	↑ may be rejection, biliary obstruction
AP Alkaline phosphatase	20–140 u/l	1–22 umol	↑ biliary obstruction ↓ malnutrition

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## What are the symptoms of rejection?

While you are in the hospital, the transplant team will be monitoring your liver function tests daily to watch for rejection. If you reject your liver during this time, you may not feel differently or have any noticeable signs of rejection. This is because rejection is detected early through frequent blood tests, usually before you have any symptoms.

- 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 greater than 100.4° F/38.0° C
- increased liver function lab tests (AST, ALT, Bilirubin, GGT, Alkaline Phosphatase)
- flu-like symptoms such as chills, nausea, vomiting, diarrhea, loss of appetite, headaches, dizziness, body aches, tiredness
- abdominal pain or tenderness

If you have any of these symptoms, your liver function tests will be obtained to monitor for rejection. In addition, you may have an abdominal ultrasound to check blood flow in your liver. Additionally, your transplant team may want you to have a liver biopsy to confirm that your symptoms are caused by rejection.

If you do not report these early symptoms to your provider or coordinator and fail to get your lab tests as directed, rejection and symptoms will worsen over time. Later symptoms may be similar to problems you had before your liver transplant and may include:

- yellowing of the skin and eyes (jaundice)
- dark, tea-colored urine
- light, clay-colored stools
- confusion
- increased fatigue
- abdominal swelling with fluid (ascites)



## How is rejection treated?

Mild to moderate rejection is treated by increasing immunosuppression. The amount and/or frequency of your anti-rejection medications are usually adjusted. If you are taking prednisone, the dose may be increased. If you are not taking prednisone, it may be prescribed for a few weeks to treat the rejection. Sometimes the IV form of prednisone is given for several days to treat rejection that does not resolve with oral prednisone. Another way to treat rejection is by adding or combining other anti-rejections medicines, such as mycophenolate mofetil, sirolimus, or azathioprine.

Severe rejection is treated as described above, but other agents that more strongly affect the immune system are often used. The most common medications used for severe rejection of the liver is antithymocyte globulin (ATG, Thymoglobulin®, Atgam®). These medications are given by IV in the hospital, and patients are monitored closely to be sure that the rejection is resolving.

As rejection resolves and your liver recovers, the doses of these additional anti-rejection medications may be decreased or stopped. The level of your primary anti-rejection medication, usually tacrolimus or cyclosporine, may be reduced. Lower immunosuppression also contributes to a decreased risk of infection and other side effects from high levels of the immunosuppressive medications, particularly poor kidney function. Your transplant team's goal is to have you on the lowest amount of immunosuppression possible so that you do not reject your liver and have good liver function.

Rejection of the liver can usually be treated successfully if it is detected early. It is important to take all your medications exactly as prescribed to help avoid rejection.

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## **What is a liver biopsy?**

Although your symptoms and liver function test results 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.

The biopsy procedure is usually done as an outpatient or short-stay admission at the hospital. To prepare you for the biopsy, an area on your right side will be cleaned with an antiseptic solution. 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 provider will advance a special needle into the liver to take out a small piece of tissue. It may look like a short piece of string. The actual biopsy only takes a few seconds. The tissue is placed into a special solution and taken to the pathology lab to be processed and viewed under the microscope. Your biopsy results may be ready later that day. If you have been discharged from the hospital, you will be called with the results or asked to return to Clinic to discuss your results and whether treatment is necessary.

Following a liver biopsy, you will need to lie on your right side for at least one hour and must rest in bed for four to six hours. Your nurse will take your vital signs frequently during this time to monitor for a high heart rate or respiratory rate and a low blood pressure. Some transplant centers order a chest X-ray and blood tests before discharge to be sure that there is no internal bleeding from the biopsy. Most patients feel fine after a liver 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 liver transplant.

## **To decrease my risk for rejection and to monitor symptoms of rejection, I should:**

- know and understand the signs and symptoms of liver rejection
- take all my medications as prescribed
- make sure I always have a supply of my medications
- stay in regular contact with my transplant coordinator or transplant team 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 provider if I think I am experiencing any symptoms of rejection
- avoid alcohol, recreational/illegal drugs, and any herbal remedies or supplements



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## Infection

### *Why am I at risk for getting infections?*

Liver transplant recipients require anti-rejection medications to suppress their immune system so that the transplanted liver is not rejected. Because the immune system is suppressed by these medications, transplant recipients are always at risk for infection. This risk is highest in the first three to six months after transplant. Infections can also occur when higher levels of immunosuppression are needed to treat rejection.

If you are doing well, have good liver function, and have not had any episodes of rejection, your transplant provider may slowly lower your level of immunosuppression after a few months. Using less immunosuppression, when possible, will help minimize your risk of infection.

### *How can I decrease my risk of infection?*

There are many ways to stay healthy after transplant and avoid infections.

Discuss how you can prevent the risk of infection with your transplant team. Know your center's specific guidelines. The following guidelines are commonly recommended for transplant recipients.

#### **Hand washing:**

- Practice good hand washing techniques. Use warm water and soap and scrub vigorously for one minute. Be sure to scrub between your fingers and under your nails as well.
- Wash your hands well before eating and preparing food, after going to the bathroom, after changing diapers, and after playing with pets.
- Encourage any family and friends who are in contact with you to practice good hand washing 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 putting your fingers or hands in or near your mouth, particularly if you have not washed your hands recently.



#### **Contacts:**

- Avoid close contact with people who have obvious illnesses such as colds and flu.
- Avoid crowds, particularly when in a closed area, during cold and flu season, or when you are highly immunosuppressed.
- Do not share eating utensils, cups, and glasses with others since many viral illnesses are spread through saliva and mucous.
- Do not share razors or toothbrushes.

#### **Pets:**

- If you have pets, be sure that they are healthy and have had all recommended vaccines.
- Do not handle animal waste. Do not clean bird cages, fish or turtle tanks, or change cat litter.
- Some types of pets should be avoided such as reptiles, turtles, amphibians (frogs), hamsters, and guinea pigs. These animals can carry infections that could cause you to become ill. Some transplant centers also recommend that transplant recipients avoid having caged pet birds in their homes, such as parrots or parakeets.
- Discuss getting any new pets with your transplant team, especially in the first 6 months following transplant.

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## Gardening:

- Wear gloves when working in the garden and in soil.
- Wash your hands frequently when gardening.
- Some transplant centers request that gardening be avoided for about three to six months after transplant until the patient's immunosuppression level is lower. Other transplant centers may recommend no gardening for life.
- Avoid compost piles, wet leaves, and rotting organic matter. These materials can carry mold which can cause significant respiratory infections in immunosuppressed patients.

## Swimming:

- Liver transplant recipients may swim in chlorinated pools after their incision and wounds are healed and all drainage tubes are removed.
- Small standing bodies of water such as ponds or small lakes that may contain infectious organisms should be avoided.
- Swimming in oceans or large lakes may be permitted at three to six months after transplant if the water is tested to be safe for the general population by the local health department.
- Public hot tubs should be avoided.

## Sexual Activity:

- Practice safe sex and use barrier methods of contraception

## What infections are most common?

There are 3 types of organisms that cause infections: bacteria, fungus, and virus.

### Bacterial Infections

Bacterial infections usually occur very early after transplant surgery and can be caused by central vein catheters, infections inside the abdomen, or wounds. Patients can develop pneumonia, particularly if they had complications during or early after surgery and had 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 and cause infection. Another type of bacterial infection is cholangitis, an infection in the bile ducts of the liver.

If you have an infection caused by bacteria, your provider will determine where the infection is and what type of bacteria is causing that infection. You will be given an antibiotic for several days to treat the bacterial infection. The antibiotic may be given through an IV or as an oral medication depending on the type and severity of the infection.

### Fungal Infections

Fungal (yeast) infections are most common in the first three months after transplant. *Candida albicans*, the most common fungus, 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 thrush is not treated, it can spread to the esophagus, stomach, and intestines. Most Candida infections resolve after treatment with a topical antifungal agent.

Fungus can cause vaginal infections (vaginitis) in women. The vaginal area may become very itchy and often produces a thick yellow or white discharge.

Transplant recipients who are highly immunosuppressed or taking high doses of prednisone are at risk for getting fungal infections. Most fungus infections are non-invasive, meaning that they do not get into the bloodstream. Fungal infections in the blood are rare, and can be treated with IV anti-fungal medications.

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## Viral Infections

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

Acute CMV infection most commonly occurs within two to three 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 have received a CMV-positive liver or CMV-positive blood products.
- have received high levels of immunosuppression.
- have received treatment for 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 taking a preventative medication for three to six months after transplant. Using these treatments to prevent CMV has decreased the rate of this infection. When possible, maintaining a lower level of immunosuppression will also decrease the risk of getting this virus.

Symptoms of CMV include fever, a low white blood cell count, and a low platelet count. If CMV infects the lungs, common symptoms include fever, coughing, shortness of breath, or wheezing. If CMV develops in the gastrointestinal (GI) tract, it can cause diarrhea, nausea, vomiting, abdominal pain, and/or bloody stools. If CMV infects the liver, the liver function tests may increase. Because increased liver function tests may also indicate rejection, it is important that the exact diagnosis is determined so that appropriate treatment is provided.

To check for a CMV infection, your provider will complete a physical examination, obtain blood tests, ask you about your symptoms, and assess your risk factors for getting this virus. The diagnosis is confirmed through a special blood test called the CMV-PCR. This test detects CMV in your blood. Sometimes a liver biopsy is completed if the liver function tests are increased to see if this increase is caused by CMV or rejection. Depending on the patient's symptoms, biopsies can also be taken of lung tissue or intestine tissue to determine if the virus has infected that particular organ.

A CMV infection is usually treated with intravenous (IV) ganciclovir for 14 days or longer until the CMV-PCR

shows that the virus has resolved. Some transplant centers prescribe an additional few weeks of oral valganciclovir (Valcyte®) after the course of IV ganciclovir is completed. In some cases, immunosuppression may be lowered during treatment for CMV to help the immune system fight the virus.

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

Epstein-Barr Virus or EBV is a common virus of the herpes family of viruses. Most adults have been exposed to this virus at some point in their lives. In fact, over 80% of adults in the United States will test positive for EBV antibodies which means that they have been exposed to the virus.

Transplant recipients have a greater risk for developing or reactivating an acute EBV infection if they:

- are EBV-negative and received a EBV- positive liver
- have received high levels of immunosuppression
- have received treatment for rejection.

Acute EBV infection can occur at any time following transplant but most commonly occurs within the first year. It is usually a mild to moderate viral illness but in rare cases can become a more serious condition.

Patients who are at high risk of developing EBV-related complications are monitored closely through a blood test called the EBV-PCR. This blood test is obtained regularly to check for EBV, particularly in patients who have an increased risk. Symptoms of EBV infection include:

- high fever
- extreme tiredness and lethargy
- swelling of the lymph nodes in the neck area, armpits, and/or groin.

The more serious form of EBV is called PTLD, or post-transplant lympho-proliferative disease. PTLD is a type of cancer. Tumor growth or lymphoma is seen with PTLD. Treatment for EBV and PTLD varies by transplant center but usually includes decreasing immunosuppression and administering IV medications to help control the virus. Patients are monitored very closely during this time when their immunosuppression is decreased so that if they begin to reject their liver, immunosuppression can be resumed or increased.

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# Taking Care of Yourself and Your Liver

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## Transplant Clinic

After discharge from the hospital, you will be followed as an outpatient at your center's Transplant Clinic. Most patients are seen one to two times every week for up to a month, then less frequently as they improve and return home. Long-term patients who have good liver function usually have check-ups once a year and labs every one to two months. Most transplant centers will continue to manage immunosuppression and the patient's local care provider will manage routine care.

Clinic routines vary by center. Discuss the following questions with your coordinator before you leave the hospital.

- When is my first clinic appointment?  
\_\_\_\_\_
  
- Where is clinic?  
\_\_\_\_\_
  
- What should I bring with me to clinic?
  - a list of my medications
  - my medications
  - my Liver Handbook
  - a record of my blood pressure measurements
  - a record of my daily temperatures
  - a record of my blood sugar (for patients with high blood sugar)
  - a family member or caregiver
  - \_\_\_\_\_
  - \_\_\_\_\_

## What is the usual Clinic routine? What will happen in Clinic?

Every transplant center has a slightly different clinic routine. Patients are usually examined by a provider, blood tests are obtained, the plan of care is reviewed, and questions or concerns are discussed. A typical routine for a clinic appointment includes:

- Report to the Transplant Clinic and register for your appointment as instructed.
- Have your blood tests drawn before taking your morning dose of tacrolimus or cyclosporine.
- Have a physical examination by the transplant surgeon or another provider on the transplant team.
- Review blood test results and medications with your provider.
- Meet with your transplant coordinator to:
  - review your medical care
  - answer questions or concerns
  - be aware of and understand any changes in care or medications
  - get prescriptions or have any new meds or med changes ordered.
- Schedule or report for additional procedures or tests (biopsy, X-ray, etc.) that might be needed.
- Meet with other members of the transplant team as needed (social worker, clinical nurse specialist, dietitian, pharmacist).
- Attend support group meetings.



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## Vital Signs

When you leave the hospital, you may be asked to regularly check your temperature, pulse, and blood pressure — 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 Emergency Services (911 in the United States and Canada) and ask to be taken to the nearest Emergency Room. If you have these life-threatening symptoms, never try to drive yourself or have a caregiver take you to the hospital. You may require care as soon as possible and your caregiver may not be able to help you if he/she is driving. Always call Emergency Services in this case.

I should call \_\_\_\_\_  
in the event of an emergency.

## 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 two numbers, for example: 120/80. The systolic blood pressure is the “top number”. It measures the force of 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.

Your center will provide you with a blood pressure cuff or instruct you on where you can 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 the blood pressure cuff used by your nurse in the hospital or 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 side effects of some medications or kidney problems. It can usually be managed well with blood pressure medications and/or some adjustments in your diet, such as a low sodium diet.

### What you should know about your blood pressure:

- A normal blood pressure for me ranges from a low of \_\_\_\_\_/\_\_\_\_\_ to a high of \_\_\_\_\_/\_\_\_\_\_
- I should take my blood pressure \_\_\_\_\_ times every day and before I take blood pressure medicine. I will be taking my blood pressure at: \_\_\_\_\_ AM \_\_\_\_\_ PM or as needed every \_\_\_\_\_ hours
- I should call my coordinator if my blood pressure is greater than \_\_\_\_\_/\_\_\_\_\_ or less than \_\_\_\_\_/\_\_\_\_\_
- I should record my blood pressure as instructed and bring this record to clinic.

## 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 infection.

### What you should know about your temperature:

- How often should I take my temperature?  
\_\_\_\_\_
- I should call my transplant coordinator or provider if my temperature is \_\_\_\_\_° F or \_\_\_\_\_° C or higher.
- If I am told to take acetaminophen (Tylenol®) or paracetamol my dose is: \_\_\_\_\_ mg or \_\_\_\_\_ tablets every \_\_\_\_\_ hours as needed for fever greater than or equal to \_\_\_\_\_.
- I should not take more than \_\_\_\_\_ doses in a 24 hour period.
- I should not take any ibuprofen products (NSAIDs such as Motrin®, Advil®) unless instructed to do so by my transplant provider or coordinator.



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## 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 heart rate.

What you should know about 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 two to three times a week to monitor for any losses or gains. Your weight will also be monitored at every clinic visit. When you are home, you should check your weight as often as instructed on the same scale at the same time each morning. After you go to the bathroom, but before you eat breakfast is a good time. You may be asked to record your weight so that your provider can follow any changes in your weight. 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 holding in 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.

What you should know about your weight:

- My ideal body weight is \_\_\_\_\_ lbs/kg.
- My weight at discharge from the hospital is \_\_\_\_\_ lbs/kg.
- I should call my provider or transplant coordinator if I have a sudden weight gain of greater than \_\_\_\_\_ lbs/kg within \_\_\_\_\_ days.

## 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, infection, recent changes in your medications, or have had other complications.

When you return home, you will have your blood tests done locally. Depending on your transplant center, it may be your responsibility to arrange this. Your coordinator will let you know 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 to help follow your care.

What I should know about my blood tests:

- I will get my blood tests done every \_\_\_\_\_
- When I am at the transplant center, where will I get my labs drawn? \_\_\_\_\_
- When I am at home, where will I get my labs drawn? \_\_\_\_\_
- My lab results should be faxed to: \_\_\_\_\_
- Who should I call to be sure my lab results have been reviewed? \_\_\_\_\_
- If a tacrolimus or cyclosporine level is being drawn, I should have my labs drawn just before taking the morning or evening dose. I should not be more than one hour late in taking my dose.
- Special instructions about my labs: \_\_\_\_\_

Measurement ranges of blood tests vary by center or lab. **Adjust the normal ranges in the tables below to your center's guidelines.** If your blood test results are out of the normal range, your provider or transplant coordinator will discuss the results 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 and UK 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, problems with blood flow to or from the liver, and/or blockage of the bile ducts.

Test	Name	Result	Normal Range (US)	Normal Range (UK)
Bili, TB	Total bilirubin	↑ bile duct obstruction, or problem with blood flow ↑ may be a sign of rejection or infection	0.1 – 1.2 mg/dl	7-330 u/l
Alk Phos	Alkaline phosphatase	↑ bile duct obstruction, rejection, infection, or problem with blood flow, bone loss ↓ malnutrition	Adults 20 – 140 IU/l	1-22 umol
ALT	Alanine aminotransferase	↑ liver injury, rejection	1-30 u/l	5-41 u/l
AST	Aspartate aminotransferase	↑ liver injury, rejection	0-35 u/l	5-43 u/l
GGT or GGTP	Gamma-glutamyl transpeptidase	↑ liver injury, rejection, bile duct obstruction, alcohol consumption, drug effects, cardiovascular disease/heart failure	Males: 11-50 u/l Females: 7-32 u/l	Males: 11-50 u/l Females: 10-40 u/l
Alb	Albumin (serum)	↓ malnutrition, problem with liver function	3.5-5. g/dl	9-40 u/l
TP	Total protein	↓ malnutrition, chronic liver dysfunction	6-8.4 g/dl	60-80g/l
PT/INR	Prothrombin time/ International Normalized Ratio	↑ liver injury, rejection, liver not functioning, if taking Coumadin (warfarin)	0.8 – 1.2	0.8 – 1.2

## Tests that Monitor Kidney Function and Electrolytes

These tests monitor kidney function and fluid balance. Anti-rejection medications can sometimes affect how well your kidneys work, so it is important that kidney function tests are checked regularly. If your kidneys are not working well, you may also have abnormal electrolyte levels. Your provider will treat any problems with adjustments in your immunosuppression and/or other medications to correct electrolyte imbalances.

Test	Name	Result	Normal Range (US)	Normal Range (UK)
BUN, Urea	Blood urea nitrogen	<p>↑ kidney dysfunction, dehydration, high protein diet, side effect of some anti-rejection medications</p> <p>↓ liver disease; over-hydration</p>	8-25 mg/dl	3.4-8 mmol/L
Cr	Creatinine	<p>↑ kidney dysfunction, side effect of some medications, dehydration</p> <p>↓ muscle wasting</p>	<p>Males: 0.6 - 1.3 mg/dl</p> <p>Females: 0.5-1.2 mg/dl</p>	134-146 mmol/L
Na	Sodium	<p>↓ side effect of diuretics; kidney dysfunction</p> <p>↑ fluid losses, such as excessive diarrhea/vomiting</p>	135-145 mEq/L	3.4 – 5.2 mmol/L
K+	Potassium	<p>↑ side effect of medications; kidney dysfunction</p> <p>↓ side effect of diuretics; decreased intake, vomiting</p>	3.5-5.0 mEq/L	<p>60-126 umol/L</p> <p>3.4-5.2 mmol/L</p>
Mg++	Magnesium	<p>↑ kidney dysfunction</p> <p>↓ diarrhea; side effect of medications; malnutrition</p>	1.8-3.0 mg/dl	0.70-0.95 mmol/L
Glu	Glucose	<p>↑ diabetes, problems with the pancreas, side effect of some medications</p> <p>↓ occurs in liver disease or with thyroid problems</p>	70-115 mg/dl (fasting)	3.5-6.0 mmol/L
Ca++	Calcium (total)	<p>↑ high intake of calcium often caused by taking too many antacids; bone disorders; thyroid problems</p> <p>↓ kidney dysfunction, over- hydration, problems with the pancreas, severe malnutrition</p>	8.5-10.5 mg/dl	<p>2.10-2.60</p> <p>mmol/L</p>

## Complete Blood Count (CBC) or Full Blood Count (FBC)

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

Test	Name	Result	Normal Range (US)	Normal Range (UK)
WBC	White blood cell count: cells that fight infection; also involved in the rejection process	<p>↑ may indicate bacterial and viral infections</p> <p>↓ may be a side effect of some medications, stress</p>	4.5–11 WBC/mm <sup>3</sup> x 1000	4.0–10 x 10 <sup>9</sup>
Hct	Hematocrit: measures the percentage of oxygen-containing red blood cell (RBC)	<p>↑ Dehydration</p> <p>↓ can be a sign of anemia</p>	<p>Males: 40–54%</p> <p>Female: 37–47%</p>	0.37–0.47
Hgb	Hemoglobin: the oxygen-containing part of the red blood cell (RBC)	<p>↑ may indicate dehydration or a blood disorder</p> <p>↓ can be a sign of anemia</p>	<p>Males: 14–18 g/dl</p> <p>Female: 12–16 g/dl</p>	<p>Males: 14–18 g/dl</p> <p>Female: 12–16 g/dl</p>
Plt	Platelets: component of blood that helps stop bleeding	<p>↑ can make your blood “thick” and lead to clotting; common in patients without a spleen.”</p> <p>↓ may be a sign of liver disease, bleeding, anemia, enlarged spleen</p>	150,000–350,000	150,000–350,000



## Nutrition

A healthy diet is one that is made up of fruits, vegetables, whole grains, and low fat or fat free milk and milk products. It also includes lean meats, poultry (chicken, turkey), fish, eggs, nuts, and beans. A healthy diet should be low in saturated fats, trans fats, salt, added sugar, and cholesterol.

Good nutrition is an important part of a 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 dietitian 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.

During the first few weeks after transplant, some patients have trouble eating due to loss of appetite, feeling full or nauseated, or because they have changes in taste. This is quite common and will resolve over time as patients recover and activity increases.

Here are some helpful hints if you are having trouble eating:

- If you have a poor appetite, try to eat several small meals a day, snack between meals on high calorie and high protein foods, and/or drink higher calorie liquids such as milk rather than water. Your dietitian 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, 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 provider 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 seem to always have a bad taste in your mouth, drinking cold fluids or sucking on sugar free hard candies may also help.

After transplantation, your dietary guidelines are much the same as for any person who is trying to eat healthy. If you have other health problems, such as high blood sugar or high blood pressure, your transplant team will give you special instructions about your diet. Fad diets, diet supplements, and herbal products should be avoided.

The level of some anti-rejection medications is affected when taken with grapefruit or grapefruit juice. All transplant centers and pharmacists recommend that transplant recipients avoid all forms of grapefruit and any drinks that contain a significant amount of grapefruit juice if they are taking cyclosporine or tacrolimus.

### **Foods That are High in Potassium**

apricots	lentils
bananas	peas
cantaloupes	potatoes
dates	pumpkin
dried fruits	spinach
figs	squash
honeydew melons	tomatoes
kiwi	tomato sauce
nectarines	ketchup
oranges	cocoa
prunes	coffee nuts
raisins	cereals with fruits and nuts
artichokes	salt substitute
beans	
brussel sprouts	

While it is important to regain lost weight and rebuild your protein stores, your weight should stay within your appropriate weight range. Being overweight may contribute to other health complications such as heart disease and diabetes. Some patients feel better after transplant and overeat. Be careful to make wise food choices and monitor food portions. For snacks, choose fruits and vegetables over empty calories of potato chips or candy.

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 and/or too fast. If your potassium level is high, it will be controlled by medications such as fludrocortisone (Florinef®), kayexalate, or diuretics (water pills). You may also be asked to limit or avoid high potassium-containing foods. Your dietitian will advise you on how many servings of these foods you may have daily if your potassium level is high.

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## Activity

### Exercise

Exercise improves your overall health. It makes you feel better and can help control stress. Regular exercise can help you maintain a weight that is right for you. It can also help prevent bone disease (osteopenia or osteoporosis). Any physical activity that you can do is beneficial. Walking, swimming, riding a bicycle, lifting weights, playing golf or tennis, participating in yoga classes, or even doing housework counts as exercise! Staying active is key to living a full and healthy life.

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 bed rest or inactivity. You may also find that your sleep pattern is disturbed. Regular exercise and good nutrition will get you back to a more active routine and help you eventually return to your home routine, work, or school.

Transplant recipients should discuss how to start an exercise program with their transplant team so that a safe exercise plan can be developed. It is important to talk with your transplant team about increasing your activity level and when to begin an exercise routine. Your team can help you develop a plan that is right for you. 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 organize and start a simple exercise routine.

For the first six months after transplant, you may be advised to avoid any strenuous activity, heavy lifting, or more intensive exercise programs. Check with your coordinator and provider 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. Some centers restrict contact sports indefinitely.

To be healthy and fit is an important goal, but using common sense to reach this goal is just as important. Even months or years after your transplant, exercising when you are sick with a fever is not a good idea. If you ever experience any intense pain, chest pain, or shortness of breath while exercising, you should stop exercising immediately and seek medical attention or advice.



### Returning to Work or School

Transplant recipients return to work or school at various times after recovery from transplant depending on the extent of their illness before transplant, recovery time, complications, and the type of work that is done. Many patients are ready to return to work or school within three months after transplant. When possible, it can be helpful to return to work or school on a part-time basis. You can gradually increase your hours as your energy and endurance improves. Discuss returning to work or school with your transplant provider and transplant coordinator. They can help you decide on the time that is best for you based on your workplace and responsibilities.

### Driving

Many transplant recipients can resume driving about six weeks after transplant, depending on their recovery period, complications, and medications. Reflexes and judgment may be affected from a prolonged hospitalization or from certain medications, such as pain medications. It is best to discuss this issue with your provider and coordinator before getting behind the wheel. It is a good idea to practice driving in an open lot or away from other traffic for the first time as you get used to driving again. It may be helpful to have another licensed driver in the car with you for the first few times that you drive after transplant.

When driving or in a car, 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. The seat belt will provide a safe restraint in case of an accident.

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## Sexual Activity

Sexual activity is an important part of adult life. Before transplant, many patients experience a decreased desire (libido) to have sex or are unable to have sex (impotence) because of health problems. After transplant, both men and women find that their desire and ability to have sex returns. Most transplant centers advise that patients wait for six to eight weeks before resuming sexual activity. How quickly you are ready to have sex after transplant depends on how you feel. Ask your transplant provider or coordinator when it is medically safe for you to have sex. When you are ready to resume sexual activity, it may be helpful to discuss any concerns you may have with your partner.

Safe sex practices are important for everyone who is sexually active to reduce the risk of contracting sexually transmitted diseases (STD). Transplant recipients have an increased risk of getting a STD because their immune system is suppressed. Practicing safe sex is the best way to prevent STDs. 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 spermicide
- avoiding sex with anyone who has sores, a rash, or a foul discharge from their genitals
- avoiding anal sex

There are some additional considerations for transplant recipients who have 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 be tested for this virus. However, if you have been in a long-term monogamous sexual relationship and your partner/spouse does not have the virus, the risk of contracting the infection may be low. You may wish to talk to your transplant provider or coordinator if you and your partner are considering whether or not to use condoms.

## Your Lifestyle After Transplant

### Sun Exposure and Skin Cancer Screening

Transplant recipients have an increased risk of developing skin cancer. This risk is up to 65 times greater than in people who have not had a transplant. The medications that transplant recipients take to suppress their immune system cause this increased risk. Your chance of developing skin cancer is also related to how old you are at the time of transplant, the types of anti-rejection meds you have taken, how long you have taken anti-rejection medications, and the amount of immunosuppression you have received. Additional risk factors for skin cancer include having:

- fair or easily burned skin
- lots of freckling
- red or blonde hair
- blue, green or hazel eyes
- history of extensive sun exposure
- family history of skin cancer
- previous skin cancers

Almost all skin cancers can be cured if detected early. Transplant recipients should look at their skin every month. Look for any new or changing growths including pink patches or spots, scaly growths, bleeding spots, or changing moles. Your provider should thoroughly look at your skin during your annual check-up or refer you to a skin specialist (dermatologist). If you are at high-risk for developing skin cancer, you may be asked to see a dermatologist regularly. Transplant recipients should always use a sun screen with a high sun protection factor (SPF) of at least 30 to protect their skin from light rays that are damaging to the skin. Sunscreen should be used on all exposed areas of skin. It is also important to wear sunglasses, a broad-rimmed hat, and protective clothing. Outdoor activities should be avoided or limited during the time when the sun's rays are the strongest, between 10:00 AM and 4:00 PM. Transplant recipients should not use tanning booths.

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## Travel

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

If you are planning a vacation, you may be advised to have your routine blood tests taken a few weeks before you travel. Call your coordinator 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. Take enough medication to last your entire trip plus some extra pills in case your trip is extended. If you are traveling by plane, pack your medications in a carry-on bag. Check with your airline to see if there are any restrictions in taking your medications on the plane.



Taking extra medications and packing them in your carry-on bag may also be helpful should you or the airline misplace your luggage. Take your important phone numbers with you in case you need to call your transplant center while you are away. You should 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, malaria,

and rabies. If you plan to travel in this type of area, please discuss this with your transplant provider and coordinator so that you are fully informed of the risk. It would also be helpful to learn more about the health concerns in your desired area of travel through the Travelers' Health website sponsored by the Centers for Disease Control at [www.cdc.gov/travel/destinat.htm](http://www.cdc.gov/travel/destinat.htm). This site discusses current illnesses and diseases occurring in that region, required vaccinations, health risks, and how to stay healthy during your visit.

Another helpful website on travel includes the Transportation Security Administration at [www.tsa.gov](http://www.tsa.gov). Click on Our Travelers, then Air Travel, then Travelers with Disabilities and Medical Conditions.

## Safe Food Handling

Safe food handling is important for everyone. However, transplant recipients may be at an increased risk of getting a food-borne illness because their immune system is suppressed. The following guidelines will help decrease your risk of getting an infection from food:

- Always 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.
- Eat only 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.
- Avoid eating from salad bars or buffets due to possible contamination by others and unsafe food temperatures.
- Do not eat food purchased from street vendors.



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## Drinking Water

It is safe for you to drink treated 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 rapid boil for at least 1 minute before using it for drinking water. Well water should be tested by your local water authority every 6 to 12 months, even if you are not using it for drinking water. Some transplant centers advise transplant recipients to boil well water if they are using it for brushing teeth, washing fresh fruits and vegetables, or for making ice cubes or cold drinks. If you have any concerns about your drinking water, contact your local health department. They will be able to advise you about the safety of your water and the need for further testing.

## 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 will be decreased.

- 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. If your pet is ill, have him examined by your veterinarian as soon as possible.
- Groom and/or bathe your pet regularly. If you have a cat, have your vet trim your cat's claws regularly.



- If possible, avoid your pet's bodily fluids (urine, feces, vomit). If your pet has an accident, ask someone else to clean the area. If not, wear gloves and clean the area with a disinfectant. Wash your hands well after cleaning.
- Do not let your pet lick your face.
- Do not change your cat's litter box if possible. The litter and liner should be replaced frequently. The litter box should be cleaned at least monthly with a disinfectant or boiling water. If you need to clean the litter box, wear a mask and disposable gloves.
- Avoid cleaning fish tanks. If you must clean your fish tank, wear disposable gloves.
- Contact your provider immediately if you are bitten by any animal.
- Avoid stray or sick animals and exotic animals.
- Some pets should be avoided by transplant recipients. The following animals are considered high-risk animals by the Centers for Disease Control for people who are immunosuppressed:
  - Reptiles, including lizards, snakes, and turtles
  - Baby chicks and ducklings
  - Exotic pets, including monkeys

Some transplant centers also restrict having amphibians (frogs), hamsters, guinea pigs, and caged birds as pets in the home.

## Plants and Gardening

Many centers recommend that transplant patients avoid exposure to live plants, cut flowers, and soil for three to six months after transplant. Other transplant centers recommend no gardening at all after transplant. If you have a cut on your skin while working in your garden, 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. Avoid working around compost piles, wet leaves, and rotting organic matter when possible. These materials may contain mold which can cause significant respiratory infections in immunosuppressed patients. Check with your transplant coordinator for your center's guidelines about gardening.

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## Routine Screenings and Examinations

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When you return home, you will resume routine health care with your local provider 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 whom to call when you have any signs or symptoms of illness. You may be told to see your local provider and then return to the transplant center for further evaluation. Your local provider may be asked to perform certain blood tests and send the report to the transplant center.



## 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 is a nonprofit membership organization in the United States 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 patients who are unable to communicate their health issues. Your coordinator can provide you with information about Medic-Alert or you can contact them at 1-800-432-5378 or through the website at [www.Medicalert.org](http://www.Medicalert.org) to become a member. As a member, you can order Medic-Alert tags and submit information about your liver transplant, allergies, your current medications, and other health conditions that will be included in your file.

## Your Local Primary Care Provider (PCP)

Your local provider may be an internal medicine physician (internist), an advanced practice registered nurse (NP or CNS), a physician's assistant (PA), or a hepatologist who will see you for routine medical care and follow the recommendations of the transplant center. This provider 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 provider within the first few weeks of returning home.

Your transplant coordinator should have the contact information for your local provider before you leave the transplant center. The coordinator will forward information to your local provider about your transplant surgery, post-operative complications, and your current care. The transplant center will also discuss its role in your care and how the providers can work cooperatively to be sure you do well. Your local provider plays an important role in examining you for any possible complications. Be sure to see this provider regularly and have reports of those visits forwarded to your transplant coordinator.

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## Dental Care

Maintaining healthy teeth and gums is an important part of your care after transplant. As in the general population, transplant recipients can develop gum disease, tooth decay, mouth ulcers, dry mouth, and mouth infections. Some dental problems may be related to side effects of some of the medications you take after transplant. You can also develop infections more easily because your immune system is suppressed. Bacteria that are commonly in the mouth can cause infection.

It is important to visit your dentist and dental hygienist for regular check-ups and cleanings every six months. If you develop problems, you may need check-ups every three or four months. Examine your mouth regularly and call your provider and/or dentist if you have chipped or cracked teeth, tooth pain, swellings or sores in your mouth, red or swollen gums, bleeding, or white patches on your tongue or the lining of your mouth. Be sure to brush your teeth at least twice a day, particularly after meals and before going to sleep. Floss between your teeth daily to remove food particles and plaque.

If you are having your teeth cleaned or having a procedure that may injure your gums, some transplant centers recommend taking an antibiotic before the procedure to prevent infection. This is called infection prophylaxis. Your dentist will prescribe the appropriate antibiotic. Contact your transplant coordinator about your center's protocol for infection prevention before dental procedures.



## Eye Care

Eye and vision examinations are important for everyone. Vision screenings (checking how well you see) can be completed regularly by a health care professional to detect problems. The need for a dilated eye examination by an eye doctor (ophthalmologist) is usually determined by age or a specific eye problem. For this test, the eye doctor uses eye drops to temporarily enlarge the pupil (the black center) of the eye. When the pupil is enlarged, the eye doctor can see the inside of the eye more easily. The dilated eye examination can detect serious problems such as glaucoma, cataracts, diabetes, infection, and cancer.

Transplant recipients may have an increased risk of developing eye problems because their immune system is suppressed and as a side effect of some medications. Discuss the risk of developing eye problems with your transplant provider or transplant coordinator. Some transplant centers recommend ophthalmology exams every year for those at risk. You and your provider should decide on the frequency of an examination by an eye doctor that best meets your needs as a transplant recipient. Diabetic patients should have a dilated eye examination with an eye doctor at least once a year.

The most common eye problems seen after transplant include cataracts, changes in the pressure of the eye (*intraocular pressure*) leading to glaucoma, scarring in the layer of blood vessels behind the retina, and damage to the small blood vessels in the retina due to diabetes (*diabetic retinopathy*). Eye infections have also been reported but are not as common now due to improved anti-rejection protocols and treatments to prevent infection.

Call your primary care provider and/or eye doctor if you have any symptoms of eye problems including:

- eye pain
- changes in vision such as blurring, double vision, or fading of colors
- flashes of light
- sensitivity to light
- seeing spots
- the appearance of dark spots in your vision
- distorted or wavy lines or edges of objects
- dry eyes with redness, itching, and/or burning

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## Gynecologic Care

*Recommendations for routine gynecologic and breast examinations vary by country, so it is important that you follow your provider's advice and guidelines.*

Many transplant centers advise their female transplant recipients who are 18 years of age or older and/or are sexually active to have a gynecologic examination every year. This examination is the same as for the general population and should include a pelvic exam to detect any abnormalities of the uterus, a breast examination to evaluate changes in the breast tissue, and a Papanicolaou's smear (Pap smear) to detect any abnormalities of the cervix. Women ages 18-39 should have a professional breast exam every three years, or as needed, and should perform monthly breast self-examinations. Women 40 years of age and older should also have a yearly mammogram and perform monthly breast self-exams. Providers may advise women who have a family history of breast cancer or other risks to have a mammogram before the age of 40 and more frequently than traditional guidelines.

## Sexual and Reproductive Concerns

### **Fertility and libido**

Fertility for both men and women may return quickly after transplant. Studies report that regular menstrual cycles start within a few months to a year after transplant for most women. Many men who had difficulty with sexual activity before transplant report improvements in erections. It is common for men and women before transplant to have low levels of sexual activity because of their illness and low desire (libido). Although some differences are reported with the type of organ transplant, most men and women report an improvement in their desire for sexual activity and in their sexual functioning after they have recovered from transplant.

There are many reasons why patients can have problems with sexual activity. Difficulties could be from complications related to their original disease, medications, or problems in their relationship with their partner. If you have any questions or concerns about resuming sexual activity, be sure to talk with your providers.

### **Birth control and pregnancy**

When you resume sexual activity after transplant, an appropriate method of birth control should be used. Barrier methods (condoms, diaphragms, and spermicidal jellies) are most often advised. When one or more barrier methods are used, it is possible to prevent conception as well as provide protection from sexually transmitted diseases. Some transplant centers have approved the use of low-dose oral contraception ("the pill"). However, oral contraceptive pills place the transplant recipient at greater risk for blood clots, high blood pressure, gastrointestinal (GI) problems, coronary artery disease, and depression. Cyclosporine levels may be higher in patients who take cyclosporine and oral contraception. Additionally, it is important to remember that the pill prevents pregnancy when taken correctly, but it does not protect against STDs.

Generally, becoming pregnant or fathering a child can be safe and successful for many women and men who have received solid organ transplants. Pre-pregnancy counseling is important so that you can plan your pregnancy to achieve the best possible outcome for you and your baby. Most transplant centers advise that female transplant recipients wait one to two years following transplant to become pregnant. This allows for a reasonable amount of time to be sure that the transplanted organ is healthy and functioning well. Immunosuppression levels should be stable and at a maintenance level.



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**Whether male or female, it is especially important that you plan any pregnancies if you are taking mycophenolate mofetil. This drug has shown to cause birth defects and should not be taken when attempting to conceive or during pregnancy.**

When considering pregnancy, female liver transplant recipients should have:

- stable function of the transplanted liver
- stable level of immunosuppression
- good kidney function
- normal blood pressure or well-controlled high blood pressure
- normal blood glucose levels or well-controlled diabetes
- overall good health

If you are thinking about getting pregnant after your transplant, it is important to remember that each pregnancy has its own unique concerns and possible risks. There are many issues to consider about your current health, the function of your transplanted organ, and your medications. Planning with a complete understanding of the issues and with appropriate medical care before, during, and after pregnancy can lead to the best outcome for you and your child.

Pregnancy outcomes of transplant recipients in the United States are being followed through the National Transplantation Pregnancy Registry (NTPR). You may contact the NTPR through the registry's toll free number at 877-955-6877 to request additional information. Your transplant team can discuss the findings of this group in greater detail with you if you are considering becoming pregnant.

For more information about pregnancy, refer to *Pregnancy and Parenthood After Transplant; What You Should Know*. Published by the International Transplant Nurses Society. Available at: [www.itns.org/education/patient-materials](http://www.itns.org/education/patient-materials)

## Prostate screening

The prostate is a walnut-sized gland that is part of the male reproductive system. It is located in front of the rectum and below the bladder. The prostate makes the fluid that carries sperm. Prostate cancer is one of the most common forms of cancer in men. Although the cause of prostate cancer is not known, some risks have been identified. These include:

- **Age:** The risk of getting prostate cancer is greater as men get older.
- **Family history:** A man is more likely to develop prostate cancer if his father or brothers had prostate cancer.
- **Race:** Prostate cancer is more common in some racial and ethnic groups. It is more common in African American men than Caucasian men. Men of Hispanic, Asian, Native American, or Pacific Islander descent are less likely to develop prostate cancer than Caucasians.

A blood test called the prostate-specific antigen test (PSA) is used to screen for prostate cancer. This test measures the level of a substance (enzyme) produced by the prostate and checks whether or not this level is within the normal range. Another test used to screen for prostate cancer is the digital rectal examination (DRE). For this examination, the provider inserts a gloved lubricated finger gently into the rectum to feel the back of the prostate. The provider checks the size of the gland and feels for any irregularities.

The screening recommendations for prostate cancer based on scientific studies are unclear. Some providers who support regular screening believe that the research shows that finding and treating prostate cancer early may save lives. These providers recommend that all men who expect to live for at least 10 more years should be given the opportunity to have the PSA blood test and DRE every year, starting at age 50. Men who are African American or have a family history should be tested earlier. However, some providers do not recommend regular screenings because they believe that finding and treating prostate cancer early may not save that person's life. They believe that the side effects of treatment are worse than the possible benefits because most prostate cancers grow very slowly and may never affect the man's life.

It is important that you discuss prostate screening with your provider. You should know your risk factors for prostate cancer and the pros and cons of screening to make the best decision for you.

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## Colorectal Screening

*Recommendations for colorectal screening vary by country, so it is important that you follow your provider's advice and guidelines.*

Colorectal screening (examination of the large intestine and rectum) is recommended for both men and women 50 years of age and older to detect signs of colorectal cancer. This cancer is an abnormal growth of tissue that occurs in the colon (large intestine) or rectum. It is the third most common cancer after prostate cancer and lung cancer in men. In women, it is the third most common cancer after breast cancer and lung cancer. Colorectal cancer is very treatable when diagnosed at an early stage. It can be prevented through regular screening tests that can find abnormal growths (*precancerous polyps*). These growths, or polyps, can be removed before they turn into cancer. Screening is important because polyps and colorectal cancer may not cause any symptoms, particularly in the early stages.

There are several tests or procedures used to screen for colorectal cancer. Your provider will advise you about when you should be screened for colorectal cancer and which test or tests are right for you. In addition to routine screening, it is very important to tell your doctor about any changes in your stools or bowel routine including:

- an increased or decreased amount of stool
- a change in stool color
- a change in the firmness or texture of your stool (hard stools or liquid/watery stools)
- the appearance of blood

## Bone Density Screening

Osteopenia and osteoporosis are diseases in which the bones become less dense, fragile and more likely to break or fracture. Most people think that low bone density (osteopenia or osteoporosis) occurs only in women, but men can develop this condition as well. Although any bone can be affected by osteoporosis, the bones of the hip, spine, and wrist are at greatest risk. Low bone density can progress painlessly until a bone breaks if not prevented or if left untreated.

Risks factors for developing low bone density include:

- **Pre-transplant condition:** Many patients with liver disease also have low bone density.
- **Age:** Your bones become weaker and less dense as you age.
- **Gender:** Women are more likely to develop osteoporosis because of the effects of menopause and because they have less bone tissue than men.
- **Family history:** Osteoporosis tends to run in families.
- **Race:** Caucasian and Asian women are at greater risk. Hispanic and African-American women have a lower risk.
- **Bone structure and weight:** Small framed women weighing less than 127 pounds/58 kilograms are at greater risk for osteoporosis.
- **Menopause:** Women lose up to 20% of their bone mass within the first five to seven years after menopause.
- **Life style:** Smoking, high alcohol intake, not getting enough calcium in your diet, not exercising, or having an inactive lifestyle can contribute to low bone density.
- **Medications:** Certain medications, such as steroids, can increase the risk of low bone density.
- **Chronic disease:** Some long-term health conditions, such as chronic kidney disease, can increase the risk of osteopenia and osteoporosis.

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Transplant recipients are at an increased risk for developing low bone density. Some anti-rejection medications can cause this, particularly in the first 6 to 12 months after transplant when immunosuppression levels are high. Prednisone, cyclosporine, and tacrolimus are all associated with low bone density. Your chance of developing osteoporosis depends on your general risk factors as well as the amount of immunosuppression and length of time you are prescribed high levels of these medicines.

There are several things you can do to prevent low bone density.

- Eat a well-balanced diet that is rich in calcium and vitamin D. Talk to your transplant dietitian for advice on the amounts and types of foods that are right for you, particularly if you have additional health problems.
- Be active! Exercise daily and include aerobic and weight-bearing exercises in your routine.
- Live a healthy lifestyle. Do not smoke. Avoid alcohol.
- Ask your provider about your need for having a bone mineral density (BMD) test. Recommendations for having this test are based on your age, risk factors, and any recent fractures. Some transplant centers recommend annual BMD. A BMD measures the density of your bones, or bone mass, and is painless, safe, and noninvasive.
- Medications may be helpful in some people. Although osteoporosis can not be cured, there are several types of medications that treat this condition.

Your transplant team will always monitor your immunosuppression levels and your risks for developing low bone density. In some cases, medications or doses may be changed to decrease your risk. Never discontinue or change these medications on your own. Talk to your transplant team about your risks for developing low bone density after transplant.

## Immunizations

Immunizations are an important part of routine healthcare for everyone. Adult transplant recipients have usually received all required immunizations before transplant but infants and young children may not because of their age or being too ill. If a transplant recipient needs immunizations, there are some important exceptions. Transplant recipients can not receive immunizations that contain a live virus. Receiving a live vaccine may cause serious health complications because a transplant recipient could develop the virus that he/she is being immunized against. This is because live vaccines contain a small amount of the live virus that is weakened.

There are several live vaccines. The most common live vaccines that immunosuppressed patients should never receive include:

- **Oral polio (Sabin):** The oral polio (Sabin) vaccine contains a live but weakened form of the polio virus that is given to provide immunity against the polio virus (poliomyelitis). The Salk injection is an inactivated polio vaccine that contains “killed” polio virus. This “shot” form of the polio vaccine should be used in all immunosuppressed patients instead of the oral vaccine. This injection does not pose a risk to someone who is immunosuppressed. Some centers recommend that transplant recipients avoid contact with anyone who has had the oral polio vaccine for up to eight weeks since the virus might be shed in their stool and saliva. Transplant recipients who have infants should be sure that their child receives the Salk injection.
- **MMR (measles, mumps, rubella):** The MMR is a live vaccine given to children at 12 to 15 months of age, again at four to six years of age, and possibly again as an adult. You do not need to avoid a child who has recently received the MMR but some centers recommend to try not to change their diapers because the live virus may be in the stool.
- **Varivax® (chickenpox or varicella vaccine):** This is a live vaccine given to children at one year of age to immunize them against chickenpox (varicella). People who are immunosuppressed should not receive this vaccine. Some centers advise transplant recipients to avoid close contact with a child who has received the Varivax® injection. Check with your coordinator for your center’s guidelines.

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- **Zostavax® (Shingles vaccine):** This live vaccine is given to protect against shingles, caused by the herpes zoster virus. It is not recommended for people who are receiving drugs that affect the immune system such as transplant recipients. Discuss this vaccine with your transplant team.

## The Tetanus Vaccine

The general public as well as transplant recipients are advised to get a tetanus booster every 5 to 10 years. If you get a dirty injury or cut or are bitten or scratched by an animal, you should get the tetanus vaccine.

## The Influenza Vaccine (“flu shot”)

The flu shot or injection is an inactivated (killed) vaccine that usually contains three influenza strains (types) that are expected to be seen most often in that year. People who want to decrease their risk of getting the flu should get the flu shot. Older people, very young children, and people with certain health conditions are at high risk for becoming very sick with the flu.

Transplant recipients are usually advised to get the flu shot every year. Ask your transplant team for your center’s recommendations. The best time to get the vaccine is in October or November, although your provider may advise you to get it earlier. It takes about 2 weeks for protection to develop in your body and this can last for almost a year. Most transplant centers recommend that caregivers and other people in the household who have close contact with the transplant recipient also get the flu vaccine.

People should **not** get the influenza vaccine if they have had:

- a severe allergic reaction to eggs
- an allergic reaction to the flu shot in the past
- Guillain-Barré Syndrome (a disease that results in muscle weakness and sometimes paralysis)

Check with your transplant team about getting the flu shot if you are within the first three months after transplant or if you have recently been treated for rejection. You should not get the influenza vaccine if you have a fever when you visit the provider’s office for your shot. Be sure to reschedule an appointment to get the vaccine at a later date when you are feeling better.

A newer form of the flu vaccine that is given as a nasal spray has been available since 2003 for use in healthy people, ages 5 through 49 years. Transplant recipients and people with suppressed immune systems should not get this form of the flu vaccine. The nasal spray flu vaccine contains weakened live influenza viruses instead of killed viruses. This live vaccine may place them at high risk for complications from the flu.





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## Other Health Concerns

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### Smoking

Smoking is a risk to everyone's health with both active and passive contact. 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 or are required to quit. 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. Levels of these medications may be lower in smokers.

Your transplant coordinator or social worker can help you find local support groups to help you stop smoking. You can also contact the American Heart Association ([www.Americanheart.org](http://www.Americanheart.org)), American Lung Association ([www2.lungusa.org](http://www2.lungusa.org)), or the American Cancer Society ([www.cancer.org](http://www.cancer.org)) for additional information and support. If you are interested in using any medications to help you stop smoking, 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. Liver cells may be destroyed with the additional stress of breaking down alcohol as well as your medications.

If you have had a problem with alcohol dependency in the past, this was probably discussed at your transplant evaluation. You may have attended counseling sessions or 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 team and local providers can help you recover and continue to do well after transplant.

### Recreational/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 transplant medications. Additionally, marijuana is known to carry a mold or fungus called *Aspergillus* which can cause a serious, life-threatening illness in people who have a suppressed immune system.

The illegal use of drugs is not tolerated by any transplant center. If you have had problems with recreational/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.

### Understanding Your Emotions After Transplant

The transplant process can be a very difficult emotional experience. Some transplant recipients experience more emotional difficulties and stress before transplant when they are waiting for an organ. Others have more stress after transplant as they learn to cope with the changes in their life. In the early months after transplant, transplant recipients can experience a variety of emotions including anger, frustration, guilt, and depression.

These feelings can affect you for different reasons and in different ways. What is emotional or stressful for you may not be as stressful for another person. Some common symptoms people experience when they are dealing with emotional problems may include:

- feeling sad, depressed, angry, anxious, or overwhelmed
- crying frequently or easily
- being unable to focus or concentrate
- not sleeping well, sleeping too much, or being unable to fall asleep
- mood changes
- changes in appetite

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Feeling emotional can also be related to side effects of medications or even an underlying medical problem. Talk to your provider and transplant team about how you feel. They will consider how you are feeling emotionally when reviewing your blood tests, medications, physical examination, and reports from procedures. It is always important to check for any medical problem that can affect how you feel. Support and therapy is available to you if you feel you need additional help.

You can also help yourself! It is important to develop strategies to deal with your emotions and feelings after transplant. Some things you can do to help yourself include:

- Exercise regularly and be as active as possible.
- Participate in social activities with friends and family at home and in your community.
- Eat a healthy diet.
- Establish a good sleeping routine. Get adequate rest.
- Find a way to relax through music, social activities, arts and crafts, yoga, and/or meditation and deep breathing.
- Recognize and understand how you feel.
- Let your family and friends know that you need their support. Talk to them about how you feel. Talking or just spending time with them can be helpful.



- Talk to other transplant patients through support groups. Sometimes it is helpful to talk to other people who have shared the same experience.
- Talking to a professional counselor may also be helpful. Your transplant team can refer you to someone who can help.

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# Glossary of Terms

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## A

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<b>ABO testing</b>	blood tests that classify human blood into one of four groups: A, B, O or AB
<b>albumin</b>	a protein made by the liver that helps maintain fluid balance in the body.
<b>anemia</b>	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 is decreased in patients with anemia.
<b>antibody</b>	a protein produced by the immune system in response to specific antigens. Antibodies help the body fight organisms that cause infection and any foreign substances.
<b>antigen</b>	a substance usually found on the surface of cells that identifies the cell as “self” or “non-self;” causes an immune response through antibody production against the antigen.
<b>arteriogram</b>	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.
<b>ascites</b>	an abnormal accumulation of fluid in the abdomen

## B

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<b>B cells</b>	a type of lymphocyte, or white blood cell that develops in the spleen that is responsible for the body’s immunity. B cells produce antibodies which help fight infection and foreign substances.
<b>bile</b>	a digestive juice secreted by hepatocytes (liver cells) and stored in the gallbladder; aids in the digestion of fats
<b>bile ducts</b>	the tubes in the liver through which bile flows
<b>bilirubin</b>	a substance made from the breakdown 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.
<b>biopsy</b>	a procedure that provides a small amount of tissue from an organ, tumor, bone, or other body 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 a puncture with a special 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.
<b>blood urea nitrogen (BUN)</b>	a test that indicates kidney function. The BUN is a product of protein breakdown, or a waste product, normally excreted by the kidney.

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## C

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<b>calcium</b>	a mineral measured in the blood that is required for bone growth and for blood clotting; also needed for the heart and nerves to function
<b>catheter</b>	a flexible tube that enters or exits the body. Catheters may be used to drain body fluids (for example, a urinary catheter drains urine) or to administer fluids or medications through a vein (such as a central venous catheter).
<b>cholangitis</b>	a bacterial infection in the bile ducts of the liver
<b>cholestasis</b>	an accumulation of bile in the liver caused by medications, an injury to the liver, liver disease, total parenteral nutrition (TPN), or gallstones
<b>cholangiogram</b>	a test that examines the bile ducts in the liver for any leaks or blockages
<b>chronic</b>	having a disease for a long period of time. Chronic disease may worsen slowly over time.
<b>cirrhosis</b>	a condition in which scar tissue forms in the liver decreasing its ability to function
<b>coagulation</b>	the process of blood clotting. The ability of the blood to clot is assessed by several blood tests including the prothrombin time (PT), partial thromboplastin time (PTT), and platelet count.
<b>coagulopathy</b>	decreased ability of the blood to clot which increases the risk of bleeding, particularly during surgery or invasive procedures
<b>complete blood</b>	a blood test that measures components of the blood count (CBC)/ full including hemoglobin (Hgb), hematocrit (Hct), platelets blood count (FBC) (Plt), and the types of white blood cells (WBC)
<b>CT scan</b>	Computed Tomography scan; a noninvasive radiologic study that shows a detailed cross-section of organ and tissue structure.
<b>Creatinine</b>	a test indicating kidney function. Creatinine 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.
<b>crossmatch</b>	a test that examines the compatibility of the transplant recipient's blood with that of the donor. A high positive crossmatch 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 and recipient.
<b>cytomegalovirus</b>	CMV; a type of herpes virus commonly seen following transplantation that can cause an infection in the gastrointestinal tract, blood, liver, lungs, and/or eyes.

## D

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<b>diabetes</b>	a chronic disease originating in the pancreas related to insulin production that causes high levels of glucose (sugar) in the blood
<b>dialysis</b>	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.
<b>diastolic</b>	the “bottom number” of blood pressure measurement when the heart muscle is at rest, expanding and filling with blood
<b>diuretic</b>	a medication that helps remove excess fluid from the body usually increasing urine output

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## E

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<b>edema</b>	tissue swelling, particularly in the face, hands, legs, and ankles
<b>electrolytes</b>	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 the body.
<b>encephalopathy</b>	confusion or an altered mental status that is seen in patients with end- stage liver disease
<b>electrocardiogram EKG/ECG</b>	a noninvasive test that records the electrical activity of the heart
<b>enzyme</b>	a protein made in the body that is capable of changing a substance from one form to another
<b>ERCP</b>	endoscopic retrograde cholangiopancreatogram. Test that examines the drainage system or ducts of the gallbladder, pancreas, and liver (the biliary tree)

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## F

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<b>fibrosis</b>	the presence of fibrous tissue in the liver that causes scarring and liver dysfunction. Fibrosis develops into cirrhosis.
<b>fulminant</b>	liver failure a severe form of liver disease with a very rapid onset

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## G

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<b>gall bladder</b>	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.
<b>gastroenterologist</b>	a medical doctor who specializes in the diagnosis, treatment, and management of diseases of the digestive system, including the liver
<b>gastroesophageal varices</b>	swollen veins of the esophagus and stomach caused by portal hypertension from liver disease
<b>gingival hypertrophy</b>	swelling or enlargement of the gums; a side effect of cyclosporine and some seizure medications
<b>glucose</b>	a type of sugar in the blood that supplies energy to the cell. Glucose levels vary with diet, medications, stress, and organ dysfunction.
<b>graft</b>	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.

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## H

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<b>hematocrit</b>	a measurement of the amount of red blood cells in the blood
<b>hematoma</b>	a bruise or swelling caused by the accumulation of blood in tissue
<b>hemoglobin</b>	a substance in red blood cells containing iron and protein that gives blood its characteristic red color; carries oxygen from the lungs to the tissues and carbon dioxide from the tissues to the lungs
<b>hepatic</b>	a term referring to the liver or having to do with the liver
<b>hepatic artery</b>	the blood vessel that carries oxygenated blood to the liver from the heart
<b>hepatic vein</b>	the blood vessel that carries deoxygenated blood from the liver to the heart
<b>hepatitis</b>	an inflammation of the liver, usually caused by infection hepatologist a medical doctor specialized in treating diseases of the liver hepatomegaly a term to describe an enlarged liver, usually felt below the rib cage herpes a family of viruses that cause infection in humans
<b>hirsutism</b>	excessive hair growth; a common side effect of cyclosporine seen in both male and female transplant recipients who receive cyclosporine
<b>histology</b>	the study of living tissue; determined by examining a piece of tissue from a biopsy under a microscope
<b>hyperlipidemia</b>	high level of fats (triglycerides or cholesterol) in the blood; can be caused by diet, genetic disorders, or medications
<b>hypertension</b>	high blood pressure

## I

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<b>immune system</b>	a specialized system of cells and proteins that protect the body from organisms that may cause infection or disease
<b>immunity</b>	the ability of the body to resist a specific disease
<b>immunization</b>	a vaccination that provides the body with protection from certain diseases
<b>immunosuppressed</b>	describes the immune system of a transplant recipient which is weakened or inhibited by certain medications so that the transplanted organ is not rejected
<b>infection</b>	a condition in which organisms such as bacteria, fungi, and viruses invade the body and reproduce causing a variety of symptoms
<b>insulin</b>	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.
<b>intravenous (IV)</b>	within the blood stream. Fluids and medications may be given intravenously as well as by mouth (PO).

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## J

**jaundice** a yellow appearance of the skin and eyes commonly seen in patients with liver disease; results from an increased blood level of bilirubin

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## L

**liver function tests** LFTs; blood tests used to determine how well the liver is functioning; includes the ALT, AST, GGTP, bilirubin, and alkaline phosphatase

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

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## M

**magnesium** a mineral required for normal bodily function; involved in nerve, skeletal muscle, heart, and cell function; also involved in blood clotting and the metabolism of carbohydrates and proteins

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## N

**nephrologist** a medical doctor who specializes in the diagnoses, treatment, and management of kidney diseases

**nephrotoxicity** kidney damage usually as a result of medications or other substances

**nonadherence** failure to follow instructions for medical care after transplantation including not taking medications as prescribed, not obtaining labs as instructed, or missing clinic appointments and tests; a significant post-transplant issue that often results in rejection, infection, an ultimately loss of the graft

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## P

***Pneumocystis carinii pneumonia* (PCP)** a bacterial infection of the lungs. Patients who are immunosuppressed carry a higher risk for developing PCP.

**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** increased pressure in the portal system, the veins that collect blood from the stomach, spleen, pancreas, and intestines

**portal vein** the vein that collects blood from the stomach, spleen, pancreas, and intestines and carries that blood to the liver; carries about 70% of the blood flow 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") to a type of lymphoma, or cancer of the lymph nodes; a complication of a suppressed immune system. Treatment includes lowering immunosuppression and administering antiviral medications.

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<b>potassium</b>	a mineral required for normal body functioning; important in helping the heart, nerves, and muscles function properly; helps change carbohydrates into energy and in forming proteins
<b>prophylaxis</b>	medications given to prevent an infection in patients who are at greater risk for developing that infection
<b>pruritis</b>	itching. Patients with liver disease may have increased itching because of an accumulation of bile salts in their skin.

## R

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<b>renal</b>	a term referring to the kidney or having to do with the kidney
<b>rejection</b>	a process in which the body's immune system attacks the transplanted organ, usually resulting in damage to that organ

## S

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<b>sodium</b>	a mineral needed by the body to keep body fluids in balance
<b>shingles</b>	a viral infection caused by the herpes zoster virus that usually affects an area by a nerve, resulting in fluid-filled blisters and pain; most commonly seen on the neck, abdomen, and legs; can also affect the nerves of the eye
<b>spleen</b>	an organ located under the rib cage on the left side of the abdomen that removes old or deformed red blood cells, white blood cells, and platelets; also makes lymphocytes, a type of white blood cell, that help produce antibodies. The spleen may enlarge (splenomegaly) in patients with liver disease since the portal vein can not easily carry blood through the liver due to cirrhosis. The blood backs up into the portal vein (portal hypertension) and then into the spleen.
<b>splenomegaly</b>	a term used to describe an enlarged spleen; can cause a decreased platelet count that may increase the risk of bleeding
<b>steroids</b>	corticosteroids; natural hormones secreted by the adrenal gland, located above the kidney; can also be manufactured and prescribed through medications such as prednisone/prednisolone. Steroids can help prevent or treat rejection.
<b>systolic</b>	the "top number" of blood pressure measurement that measures the pressure as the heart muscle contracts to pump blood around the body



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## T

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- T cells** a type of lymphocyte, or white blood cell, that develops in the thymus gland located in the upper chest in front of the heart; associated with 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 that is placed inside the common bile duct to drain bile from the liver to the outside of the body into a drainage bag
- thrush** *Candida albicans*, yeast; a fungal infection that looks like white plaques or spots in the mouth (oral mucosa), throat, and on the tongue

## U

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- ultrasound** a test that displays internal bodily organs, blood vessels, and ducts using sound waves; 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

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- varices** swollen or enlarged blood vessels, particularly in the stomach and esophagus
- vital signs** the measurement of temperature, blood pressure, heart rate, and respiratory (breathing) rate

## W

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- wean** to slowly withdraw or reduce. Immunosuppression, particularly steroids, may be weaned slowly over time in patients who have stable function of the transplanted liver.
- white blood cell** a type of blood cell that fights infection

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# Vital Signs Form

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Name: \_\_\_\_\_

Date/Time	Temp	Blood Pressure	Pulse	Weight	Comments

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# Appointment Diary

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Name: \_\_\_\_\_

Date/Time	Test/Place	Reason for Appt.	Results

# My Transplant Team

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

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

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

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

Website: \_\_\_\_\_

	Name	Phone	Email	Fax (if needed)
<b>Transplant Coordinator</b>				
<b>Transplant MD</b>				
<b>Clinical Nurse Specialist</b>				
<b>Hepatologist</b>				
<b>Social Worker</b>				
<b>Pharmacist</b>				
<b>Physical Therapist</b>				
<b>Psychologist</b>				
<b>Dietitian</b>				

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# My Local Healthcare Team

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Name: \_\_\_\_\_

	Name	Phone	Email	Fax
Internist (PCP)				
Hepatologist				
Dentist				
Ophthalmologist				
OB/Gyne				
Pharmacist				
Physical Therapy				
Lab				