Duke Transplant Center

LIVER TRANSPLANT PROGRAM

After your transplant

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THE DUKE LIVER TRANSPLANT PROGRAM – LIFE AFTER LIVER TRANSPLANT

The Surgical Intensive Care Unit

Immediately following your transplant surgery, you will be brought from the operating room to the Surgical Intensive Care Unit (SICU). Once in the SICU, it will take approximately one hour for the nurses to do their initial assessments and orders and help you get comfortable. The nurses will then call in your family members so that they may see you. You will still be somewhat sleepy because of the anesthesia. You may not remember most of your time in the ICU. After that initial visit, your family may see you during the SICU regular visiting times which are 10:30 am–6:30 pm and 8:30 pm–10 pm. Once you wake up, it is normal to feel confused. Your nurses will tell you that your surgery is over, and they will tell you what day it is, what time it is, and where you are. You may also still have a breathing tube in your mouth from surgery. The breathing tubes are usually removed once you are fully awake from anesthesia.

You will have a small tube in your nose that goes to your stomach, called a nasogastric (NG) tube. This tube will drain your stomach contents and help prevent you from feeling nauseated. The NG tube will be removed after your anesthesia wears off and your stomach and intestines begin to work again. You will also have a large IV catheter in a vein in the side of your neck. This will allow us to monitor your heart function closely. You may have an IV in your arm for fluid or medication and another in your wrist to continuously monitor your blood pressure.

You will have several drainage tubes in your abdomen. These tubes, designed to drain fluid and air from the space around the new liver, will be connected to suction bulbs for a few days to help remove fluid more efficiently. These tubes will be removed within the first week after your transplant.

You will have a catheter in your bladder to drain your urine. Your nurses will measure and record your urine output every hour to ensure that you stay in good fluid balance. The bladder catheter will be removed within two to three days.

Finally, you will have a small sensor on your finger or earlobe connected to a machine at your bedside (called a pulse oximeter) to monitor your pulse rate and the oxygen level in your blood.

Every patient experiences pain after a major operation, but each person feels differently. Usually in the first few hours after surgery, you will get pain medicine through your IV. The nurses may give you this medicine or you may have a machine that lets you control when you get pain medication. Please let the nurses and doctors know if your pain is not being controlled, so that different treatment measures can be ordered.

Most patients stay in the SICU 24 to 48 hours before going to the Transplant Unit. Individualized responses and complications may extend your ICU stay.

Physical Therapy

While you are in the SICU, your nurses will help you exercise your legs to reduce the risk of blood clots. After your breathing tube is removed, you will be encouraged to turn, cough, breathe deeply, and expand your lungs to decrease the risk of pneumonia.

You will progress quickly to sitting on the side of your bed and dangling your feet, then to getting up in a chair within a day or two after your surgery. You will likely be able to walk by the second or third day. Physical therapists are available to assist you in progressive ambulation and exercise.

Intermediate and Stepdown Care

When you are ready to leave the SICU, you will be transferred to the transplant surgery stepdown unit. On this unit, you will continue to recover and regain your strength. Again, each person recovers at his or her own rate. As you recover, the IVs, drains, and dressings will be removed. You will have daily blood work so we can check for organ function and to see that your antirejection medicine is at the correct level.

Your physical activity will continue to be a priority. You should walk at least twice a day, increasing your distance each time. Most patients are able to walk one mile per day by the third or fourth week after surgery and can go back to supervised treadmill and/or bicycle therapy in even less time.

Your education about how to care for yourself when you go home will begin over the next few days. The coordinator will speak with you and your family about monitoring for infection; you will learn when to call the transplant team and other common post-surgical topics. The transplant pharmacists will teach you about your medicines, and you will begin to take your medicines with the help of the staff nurses prior to going home. You can expect to be discharged from the hospital within one to two weeks after your operation, but you may need to remain in Durham for another two weeks for frequent clinic visits. Remember that each person is different, and your recovery depends on your progress or development of complications.

Caring for Yourself after Transplant

Caring for yourself after transplant will have special considerations. These include:

- **Medications:** After a liver transplant, you will have medications to take for the rest of your life. These medications are very expensive and have some side effects. The financial coordinator will explain insurance coverage or limitations. If you have limited insurance coverage for medications, you will be asked to fund raise for your future costs. The financial coordinator will direct you to resources for fundraising. Duke Hospital is not able to provide medicines unless you are hospitalized.
- **Monitoring:** You will be asked to record your blood pressure, weight, temperature, and fluid intake and output each day.
- **Healthy habits:** After the transplant, you will be expected to maintain a well-balanced diet and exercise regularly to keep yourself in good physical condition.
- **Frequent check-up:** You will need to return to Duke frequently for outpatient tests and Liver Transplant Clinic visits. You must also be seen by your local physician to provide routine and acute care. Communication with the transplant coordinators about changes in your health before and after transplant is essential.

Your Long-Term Outlook

While a liver transplant represents a great hope for people with end-stage liver disease, various complications can occur after liver transplantation. These may include rejection, infection, technical complications, and recurrence of original liver disease. During your hospitalization, we will teach you about your medicines, and how to monitor your incisions and drains daily. Often, the first sign of liver dysfunction is seen in your lab work. That is why we ask you to come to the clinic frequently to monitor these values. Any changes in your liver function or other symptoms will be evaluated thoroughly. It is important that we carefully decide the cause of your symptoms so that we can treat you appropriately.

While complications are always a possibility, it’s important to remember that the single most important factor in the outcome of your transplant is you. Liver transplantation is a lifelong commitment, one with lasting impact on every aspect of your existence. So take your responsibility seriously --and take good care of yourself.

The Duke Liver Transplant Team knows that going through a major medical procedure like this can be a trying time, and we want very much to help you through this process. Please let us know of any way we can help ease your confusion and anxiety. We look forward to working closely with you.

MEDICATIONS

You will take many medicines after your surgery. They will be used for different reasons but all are important to your recovery and health. The transplant pharmacist will assist you in understanding the purpose of each medicine. You will take the most number of medicines during the first year after transplant. You will take some of the medicines for the rest of your life.

Please contact a pharmacist for other questions. The information below is a reference.

Safety Information about Medications

Please observe the following precautions when taking your medications. Remember that medicines can be dangerous, even fatal, if taken accidentally by a child. Make sure your pharmacy has put your prescription medications in child-proof containers, and store all your medicines out of the reach of small children. In addition:

- Keep a list of medicines and doses in your wallet or purse.
- Bring a list of your medicines to each clinic visit.
- Take each medication exactly as prescribed.
- Keep all medications in their original containers with labeling that shows the name, dosage, and expiration date. Keep your medications in a dry place away from heat and direct sunlight.
- Report any side effects of medications to the transplant team.

- Never change or skip a dose of medication unless directed. Remember, if you stop taking your immunosuppressive medications, your body will reject the transplanted liver. If you ever forget to take your medications, call your transplant coordinator as soon as you realize your mistake.
- Should you experience any vomiting that prevents you from taking your medications, or if you vomit immediately after taking your medications, call your transplant coordinator.
- Do not allow yourself to run out of your antirejection medication. Always keep at least an extra two weeks' supply on hand.
- When traveling, do not pack your antirejection medication and other medications in luggage that will be checked. Keep it with you in a carry-on bag or your hand bag. Always have your antirejection medication with you!

Other Medications

Do not take medication prescribed by other physicians until you check with us first. Because of your liver transplant and the medications you are taking, we prefer that you do not take some medications. Ketoconazole, erythromycin, diltiazem, and Dilantin are just a few of the drugs that should be avoided, due to their interference with Prograf, Rapamune, and cyclosporine. Please call your transplant nurse coordinator about any new medication prescribed for you before you get the prescription filled.

Be cautious about over-the-counter medications, too. You may take up to 4 grams per day of Tylenol as needed for minor pains, and you may take Dulcolax or glycerin suppositories as needed for constipation. In general, we ask you to avoid using nonsteroidal anti-inflammatory agents (NSAIDs) for pain. Examples of NSAIDs are Advil (ibuprofen), Anaprox, and Naprosyn (Naproxen). These medicines can make your kidneys fail if used in combination with Prograf or cyclosporine. Please do not take any other over-the-counter medications without first checking with your transplant doctor or coordinator.

Immunosuppressants

Immunosuppression is a concept you need to understand your care. Your immune system is a part of you that is able to recognize when foreign substances enter the body. Your immune system fights infection by recognizing and destroying foreign matter, such as bacteria, viruses, and fungi.

Your transplanted liver is new and foreign to your body, and your immune system can recognize this. If something is not done to stop the process, your body's immune system will "see" your new liver as foreign and soon begin to destroy it. Preventing this natural response of the body's immune system is called immunosuppression.

Prograf, Cellcept, Rapamune, cyclosporine, and prednisone are known as immunosuppressive drugs. They are given to transplant patients to decrease the body's ability to recognize and destroy foreign substances. Essentially, the body is "tricked" into thinking your new liver is not different from your old liver. Without these medications, rejection of the liver would certainly occur. It is therefore very, very important that you take these drugs exactly as prescribed for as long as you have the transplant. If you stop taking these medications, your body will reject the liver.

Being on immunosuppressive drugs does mean that you will be at greater risk for developing infections. It is important, therefore, to take some sensible precautions to avoid infection whenever possible. We will be discussing these precautions later.

Tacrolimus (also known as Prograf or FK-506)

Tacrolimus is an antirejection medication that specifically stops the action of certain immune cells called T-cells. Tacrolimus is the most common immunosuppressant medication started after liver transplant. In some cases, we may use cyclosporine or sirolimus (see information below).

It is very important that you take your cyclosporine or tacrolimus twice a day at regular intervals, 12 hours apart. These capsules should be swallowed whole; do not bite or chew the capsules. Sometimes, we may ask you to open the capsule and put the entire contents of the capsule under your tongue (sublingual administration). This may be necessary to avoid drug interactions or help with absorption of the drug.

Cyclosporine (also known as Sandimmune, Neoral, or Gengraf)

NOTE: These products (although all are cyclosporine products) are NOT interchangeable! Let your transplant doctor know if you are taking a different cyclosporine product than the product you were originally prescribed.

Cyclosporine is an antirejection medication that specifically stops the action of certain immune cells (also known as T-cells) that are involved in the rejection process.

It is very important that you take your cyclosporine or tacrolimus twice a day at regular intervals, 12 hours apart. These capsules should be swallowed whole; do not bite or chew the capsules.

*Do not remove the capsules from the foil package in which they are wrapped more than a week before you need to take them. Longer exposure to air may damage the capsule and reduce the effectiveness of the medicine.

Tacrolimus and Cyclosporine Side Effects

Unfortunately, there are side effects to any medication. The following may be side effects of Cyclosporine or Tacrolimus. Some side effects occur more often with Cyclosporine and others occur more often with Tacrolimus. (Side effects that occur with one and not the other are designated as such in the following list). Not all side effects of these medications are listed in this document. This document is simply to help you become more familiar with these medications. Please report to your transplant doctor if you experience these or any other unusual symptoms:

- **Flushing:** (cyclosporine). A brief period of warmth or redness in your face for one to two hours after taking cyclosporine. This feeling usually disappears on its own.
- **Hair growth:** (cyclosporine). Increased hair on the face, arms, and body is common, but it is usually not a problem.
- **Hair loss:** (tacrolimus). Loss of hair in specific areas, most commonly on the head or when brushing your hair and the hair comes out in wads, may occur.
- **Fine hand tremor**: (cyclosporine, tacrolimus). Some patients experience a trembling of the hands, especially in the first month. If this problem continues after that time, please notify

your transplant doctor. If your tremor is increasing, it could mean your cyclosporine or tacrolimus blood level is too high.

- **Gum swelling:** (cyclosporine) Good dental hygiene is necessary to keep gums healthy. You should brush at least twice daily with a soft toothbrush, and use dental floss daily. We recommend you see your dentist every six months. Please let your transplant doctor know if you experience swelling of the gums.
- **Numbness, tingling, burning sensation, and/or increased sensitivity in hands and feet:** These symptoms can be annoying, but they are usually not too uncomfortable.
- **Headaches:** Notify your transplant doctor if headaches are severe and bothersome.
- **High blood pressure:** (cyclosporine). If this becomes a problem, it will be treated with appropriate medication. You may be taught to monitor your blood pressure at home.
- **High blood sugar:** (tacrolimus). You may experience high blood sugar (diabetes) as a side effect (especially possible early after transplant) and need to take insulin injections as part of your post-transplant care. High blood sugar may go away after a few weeks or months post-transplant. But in some cases, you may need to take insulin for a long time. It is important to monitor your blood sugar regularly at home to avoid the consequences of high blood sugar.
- **High potassium levels:** You will need to restrict the amount of potassium in your diet. The transplant doctor will let you know if you are experiencing this rare side effect.
- **Altered kidney function:** If too much Cyclosporine or Tacrolimus is given for too long a time, it can be harmful to your kidneys. You will not usually experience any symptoms, but your creatinine level, which is a measure of kidney function, may become elevated. The transplant team will follow your lab work and Cyclosporine or Tacrolimus levels closely, and will adjust your dose accordingly. Treatment of altered kidney function as a result of too much Cyclosporine or Tacrolimus usually only involves reducing the Cyclosporine or Tacrolimus dose.

Sirolimus (also known as Rapamune)

Sirolimus is another medication that suppresses the activity of the immune system (blocking T-cell responses) but in a different way than Cyclosporine or Tacrolimus. Since it works differently than the previous antirejection medications, sometimes it may be used in combination with either Tacrolimus or Cyclosporine. Sirolimus is a good choice as an immunosuppressant drug when a patient has decreased kidney function or severe chronic rejection.

Sirolimus is taken only once a day (usually in the morning), but it should be taken at the same time each day as well.

Sirolimus Side Effects

The following may be side effects of Sirolimus. Not all side effects are listed in this document. Please report to your transplant doctor if you experience these or any other unusual symptoms.

- **Upset stomach:** You may experience nausea, vomiting, or diarrhea. Do not self-medicate yourself with over the-counter remedies for more than a day without letting your transplant coordinator know of your symptoms. Try taking the medication with food. This may decrease the possibility of upset stomach.
- **Heartburn:** You may experience a feeling of burning in your stomach or burning in the throat area. You may try taking Mylanta or Tums to stop the heartburn, but it's important not to take these medications at the same time as sirolimus (tacrolimus or cyclosporine). Mylanta or Tums may bind the antirejection medications in the stomach and decrease their absorption from the stomach.
- **Low blood cell counts:** Red blood cells (RBC), white blood cells (WBC), and platelets may be decreased while you are taking sirolimus. The only way we can tell if this is occurring is if you are having your blood drawn regularly as directed by your coordinator. Loss of RBCs (anemia) may make you feel tired and weak and loss of WBCs (neutropenia) will make you at risk for serious infections. Loss of platelets increases your chance of bleeding (nose bleeds or gums bleeding) or easy bruising. Meeting with the transplant team or your local doctor as directed by the coordinator is essential to helping you avoid these problems with sirolimus.
- **Headache:** Notify your transplant doctor if headaches are severe and bothersome.
- **High cholesterol:** You may experience high cholesterol as a side effect of sirolimus. If cholesterol is not controlled, it can increase your risk for a heart attack. It is important to have your blood cholesterol level checked regularly as directed by your coordinator. High cholesterol levels require you to eat a healthy diet rich in fiber, vegetables, fruits, and limited amounts of meats and fats. High cholesterol often means that you will need to take medications such as Zocor, Lipitor, or Pravachol to reduce your cholesterol level.
- Regardless of which antirejection medication you are prescribed (cyclosporine, tacrolimus, or sirolimus), you must follow these directions to optimize your anti-rejection regimen.

Determining How Much Immunosuppressant is Right for You

It is important to determine the amount of antirejection medication in your blood stream so that your dose can be adjusted to your individual needs. This blood should be drawn in the morning before you take your first dose. Each time you come for a Liver Transplant Clinic visit or have labs at home, we will be drawing blood for a cyclosporine, tacrolimus, or sirolimus level. On these days, bring your morning dose of cyclosporine, tacrolimus, or sirolimus with you so that you can take it as soon as the blood sample has been drawn. You may take all other medicines prior to coming to clinic.

You will receive a letter to take to your local doctor and your lab explaining the procedure for drawing and mailing the blood for the cyclosporine and tacrolimus. Sirolimus levels may be processed by commercial labs.

Grapefruit and grapefruit juice increase the concentrations (or levels) of cyclosporine, tacrolimus, and sirolimus. Therefore, if you want to eat grapefruits or drink grapefruit juice, you should do so consistently. To drink or eat it some days and not others will cause your levels to vary too much, being too high some days and too low other days.

Prednisone

Prednisone is another medication that helps to prevent rejection by suppressing the body's immune system. Because of prednisone's actions within the body, it belongs to a class of medications, known as steroids. After transplant, you will start taking a fairly high dose of prednisone, but this dose will be tapered (decreased) rapidly to a lower dose to avoid as many side effects as possible. Patients with certain liver diseases will take a small dose of prednisone for the rest of their life.

Prednisone Side Effects

Not every patient experiences all of these side effects, but they do occur frequently enough that we want you to be aware of them. Most of the time, the side effects are dose-related. In other words, as your dose is decreased the side effects should become less troublesome. Side effects of prednisone include:

- **Increased appetite**: It is very important that you watch your calories and maintain your ideal weight. Increased appetite does not have to mean increased weight!
- **High blood sugar:** Prednisone (like the other antirejection medications listed before) may increase your blood sugar level. We will check your blood glucose with your routine labs. If your blood glucose is high, you may need to avoid concentrated sweets or take insulin injections to control your blood sugar.
- **High blood pressure**: Prednisone, like the other antirejection medications listed before, may increase your blood pressure. It is important to have your blood pressure monitored regularly.
- **High cholesterol**: Prednisone, like the other antirejection medications listed before, may increase your cholesterol level. It is important to have your cholesterol level checked regularly.
- **Change in appearance:** You may notice a rounded face, larger abdomen, and thin skin. You may bruise easily.
- **Increased sweating**: This often occurs at night.
- **Acne on the face, back, and chest**: Wash your skin two to three times a day, and keep the area as clean and dry as possible. If acne becomes problematic, an antiseptic wash followed by application of 10 percent benzoyl peroxide ointment is usually helpful.
- **Muscle weakness (particularly in the legs):** Exercise! Walking is one of the best ways to strengthen leg muscles.
- **Eye problems**: Inform the Transplant Team of any blurring or other changes in vision. We will examine your eyes for cataracts.
- **Bone/joint problems**: Steroids may cause loss of bone mass. We would like you to tell us if you have persistent bone or joint pains; you may need X-rays or referral to a specialist.

- **Delayed wound healing:** Surgical incisions do not heal as quickly when taking prednisone. Inform the Transplant Team if you notice increased drainage or redness around your wound.
- **Emotional changes:** You may notice an increase in restlessness or moodiness while on high doses of prednisone.

Cellcept (Mycophenolate Mofetil)

Mycophenolate is an antirejection medication that comes in a pill form. It works by decreasing the T-cells in the body that cause rejection.

The side effects of mycophenolate are similar to sirolimus with a decrease in WBCs and RBCs and platelets as well as upset stomach. Taking mycophenolate with a meal may help with upset stomach. A minority of patients taking mycophenolate may experience loose bowel movements.

ANTIBIOTICS OR ANTI-INFECTION MEDICATIONS

Septra DS (Bactrim DS, TMP–SMZ, or TMP–SMX)

Septra is a combination of two different antibiotic compounds (trimethoprim and sulfamethoxazole) which is used to help prevent a specific bacterial infection, known as pneumocystis carinii pneumonia (PCP). This bacteria, PCP, causes pneumonia in patients who are taking antirejection medications.

If you are allergic to sulfa, you should not take this medication.

Septra is started within one week after transplant. You will take one Septra DS (double-strength) tablet three days a week (for example— Monday, Wednesday, and Friday). We will stop this medicine after 90 days.

Septra Side Effects

Patients may experience nausea/vomiting, diarrhea, loss of appetite, dizziness, and headache. Septra increases your skin's sensitivity to sunlight (sun exposure). Therefore, when you go out in the sun, you are more likely to get a BAD sun burn in a shorter period of time. You must be aggressive in protecting yourself from the harmful sun rays by wearing hats, and clothing that is appropriate for covering your skin while outdoors. This is very important, because transplant patients have an increased risk of developing skin cancer after transplant.

Mycelex Troche (Clotrimazole)

Clotrimazole is a medication used to prevent fungus infections in the mouth and throat (fungus infection also known as thrush). This troche (lozenge) should be taken four times a day, after meals and at bedtime. Slowly, let the lozenge dissolve in your mouth. Do not rinse your mouth or eat or drink anything for at least 15 minutes after dissolving this medicine in your mouth. If you wear dentures, they should be removed prior to taking this medication. No side effects have been reported to occur with clotrimazole. Expect to take this medication for approximately three months after transplant.

Cytovene (Ganciclovir) or Valcyte (valganciclovir)

Ganciclovir is an antiviral medication that treats infections and prevents infections caused by the cytomegalovirus (CMV) virus. It can be given through IV or by mouth.

When given intravenously, usually once or twice daily, ganciclovir is usually administered in the hospital. However, after the initial doses, it may be received (via IV) at home with the assistance of a home health care agency. A usual IV course of ganciclovir treatment is 14–21 days.

Ganciclovir is available in pill form (called Cytovene), and some patients will need to take these pills for three months after the transplant to prevent infection with CMV. Taking ganciclovir by mouth often means taking as many as 12 pills of ganciclovir a day.

Ganciclovir Side Effects

Side effects may include abdominal pain, diarrhea, fever, headache, and tingling in the hands and/or feet. WBC need to be monitored at least every two weeks while ganciclovir is being given.

Because ganciclovir is a large pill and a patient may have to take as many as 12 pills a day, Valcyte (valganciclovir) was developed as a medication, based on ganciclovir, to treat and prevent CMV infection. Valganciclovir is taken by mouth, and the dose typically requires patients to take no more than four capsules a day, (significantly fewer than the 12 capsules of ganciclovir).

Antacid Medication or Anti-Ulcer Medication

Axid, Zantac (ranitidine), Pepcid (famotidine), Prilosec (omeprazole), Protonix (pantoprazole)

These medicines are used to decrease the amount of acid in your stomach. You are at risk for developing an ulcer because you are taking prednisone. You will take one of these medicines after transplant to reduce the risk of ulcer.

Medications available in the hospital include:

- Axid, 150 mg tablets, two times a day.
- Pepcid, 20 mg tablets, two times a day.
- Protonix, 40 mg tablet, one time a day.

Side effects of these medications include abdominal pain, nausea, and headache.

Magnesium Supplement

Magnesium oxide

Cyclosporine or tacrolimus can cause your kidneys to lose the ability to maintain constant levels of magnesium in your body. Diuretics (water pills) may cause you to lose magnesium through your kidneys as well. If magnesium stores in your body decrease too low, you will be at risk to experience heart rhythm changes and possibly, seizures. These are serious problems, and we want to prevent these risks by having you take magnesium oxide (a magnesium supplement).

Magnesium oxide is taken by mouth usually two to three times each day. The main side effect of this medication is diarrhea.

It is very important that you NOT take your magnesium supplement (magnesium oxide) with your antirejection or antibiotic medications. Magnesium is a salt that can bind your medications and have them go through your stomach without being absorbed into the blood stream.

Antihypertensives or Blood Pressure Medication

Many liver transplant patients develop high blood pressure (hypertension) after transplant. This is usually caused by prednisone, Prograf, and/or cyclosporine. If you have high blood pressure, we will have you take an antihypertensive medication. There are a lot of different types of antihypertensive medications. Some examples of commonly prescribed antihypertensive medications for our transplant patients include diltiazem (Cardizem), verapamil (Calan), nifedipine (Procardia), metoprolol (Toprol), and many, many more.

Because there are so many antihypertensive medications to choose from, we recommend discussing the blood pressure medication with your coordinator or transplant pharmacist when one is prescribed for you at that time.

Diuretic or "Water Pill"

Lasix (Furosemide)

Furosemide is one type of diuretic. It is also called a “fluid pill” or a “water pill.” It is used to treat extra fluid in your abdomen or swelling in your legs. It tells your kidneys to pump out more urine or “water,” and you will then get rid of extra fluid in your abdomen and legs.

The dose of furosemide is adjusted to each patient's needs for fluid loss. When you are first discharged from the hospital, a certain dosage will be prescribed for you, but we will need your assistance in making sure that the dosage is correct.

You will be asked to weigh yourself daily. A gain or loss of two or more pounds overnight indicates a change in body fluid, rather than true weight gain. If your weight increases by two or more pounds overnight, or if you have swelling in your lower legs and feet in the late afternoon, you are retaining fluid. If your weight decreases by two or more pounds overnight, if you notice dizziness when standing, or if you are constantly thirsty, then you are eliminating too much fluid. Please notify the transplant coordinator if you experience any of these symptoms.

Other Medications

Actigall (Ursodiol)

Some patients will be placed on Actigall after transplant to help decrease the bilirubin in their blood. Too much bilirubin in your blood can make you itch. Bilirubin can also clog the drainage system for the liver waste products and cause an infection in your liver.

Actigall can decrease the bilirubin and decrease the opportunity to have problems. There are no major side effects with this medication.

Colace or Bowel Stimulants

While you are taking pain medication and returning to your typical activity and diet, you may experience constipation. Prescription pain medication also contributes to constipation. You should drink at least 6 glasses of water each day. Taking a stool softener, such as Colace, along with a bowel stimulant, like Sennekot, will help keep you from being constipated. These may be prescribed while in the hospital. Please continue to take these while you are taking pain medication.

CARING FOR YOURSELF

When you leave the hospital after your transplant, you will go to a local hotel if you live more than one hour away. This is to be sure you will be able to return to the hospital promptly if you experience problems. Caring for yourself requires the support of your family, good common sense and following these instructions. The Resource Directory in this folder includes information about lodging.

Daily Care and Activity

Activity after discharge should be focused on increasing activity each day while incorporating some rest periods. Walking is an excellent activity.

- No driving, no lifting greater than 5 lbs.
- Do not return to work until cleared by the surgeon (usually eight-12 weeks).
- Use pain medications prior to starting am shower/care activity and prior to bedtime to reduce pain. While taking pain medicine, drink plenty of fluid. Use a stool softener, like Colace.
- Continue a low-salt diet, if still on diuretics. No other limitations if weight is stable. If overweight, a low-fat, high-fiber diet is recommended.

Problems to Report to the On Call Transplant Nurse Coordinator

- Fever greater than 100.5 F, chills, nausea, vomiting (more than once), watery diarrhea
- Inability to take medicines
- New pain that is sudden or sharp
- Drainage from wounds that is cloudy, has an odd smell or is very bloody. Pink-yellow fluid is OK.
- Severe headaches not relieved with Tylenol or pain medicines.
- You are admitted to the hospital at home for any reason.

Contacting the On Call Liver Transplant Nurse Coordinator

- Transplant nurse coordinators are available 24 hours a day, seven days a week.
- If the call can wait until normal business hours; call the transplant office at 919.613.7777, option 3.
- The office is open 8 am–4:30 pm. If a coordinator is not available when you call, leave a message, and your call will be returned. We ask that you call the office for things like prescription refills, non-urgent questions, or anything that can wait for a response.
- If it is the evening, night time, or the weekend, and the call is urgent (like you are having the symptoms we just talked about), call 919.684.8111, and ask for the liver transplant nurse on call. Do not ask for the surgery intern on call or the attending physician.

- Stay on the line while the operator places the page. The call will be returned immediately, and the operator will connect you with the coordinator. Please recognize that the nurses are not at the hospital during nonbusiness hours. We are available for urgent needs. We want to attend to your needs in the most efficient manner possible.

Wound Care

- Staples from surgery will be in place for three weeks as steroids reduce tissue healing time.
- You may shower with staples and tubes in place. Cleanse sites with antibacterial soap. Pat dry, and be careful not to pull. Do not use powder or lotion around incision.

Clinic Visits after Discharge

We keep a close watch on you especially during the first month after your surgery. You will stay in a local hotel or friend's home for two weeks if you must travel more than 1 hour to get home.

Do not take your rejection medicine before clinic. This includes Prograf (tacrolimus), Neoral (cyclosporine), and Rapamune (sirolimus). You may take all other medicines.

- Bring a list of your medicines to each clinic visit.
- Bring a record of your home monitoring (temperature, weight, etc.)

We will see you in clinic two to three times each week for labs and/or doctor’s visits. Frequency will depend upon your individual progress and concerns.

When you are released to go home, you should plan to see your local GI doctor and family doctor when Duke visits are reduced to every two to three months.

When you return home, you will be provided with doctor orders to take to your local doctor or a to local lab to have blood work done and the results faxed to our office. Labs are imperative during the first year when your risk of infection and rejection are the highest.

You should contact your local doctor for non-transplant issues or acute needs when your visits to our office are every two to three months.

Develop a Support System

Your family will be your biggest support system after your liver transplant. There may also be others who you will have to help you, such as friends or neighbors. They are welcome at any time to come to clinic with you to learn more about the transplant, and how to care for you.

Another very good resource is The Liver Connection support group. Patients and their families who are waiting for liver transplant or who have had a liver transplant are invited to attend the support group. It is a safe place to share thoughts, feelings and experiences about liver disease and transplant. There are also educational presentations related to transplant. This group meets every Monday from 9 am–10 am in the conference room across from Clinic 2C. For more information, contact the liver transplant social worker.

MANAGING AND AVOIDING COMPLICATIONS

Rejection

It is very common for liver transplant patients to experience a rejection episode. Rejection of your transplanted liver may occur at any time following your surgery. Rejection episodes most commonly occur during the first few months of a transplant. Try not to become too alarmed if you are told that you are experiencing rejection. Episodes of rejection are expected, and other than taking your immunosuppressive medications correctly, there is nothing you can do to prevent them from happening.

Rejection can usually be reversed if it is detected early. For this reason, it is important for you to be able to recognize signs and symptoms of rejection. These include:

- Fever (greater than 100.5° F)
- Jaundice (yellowing of eyes and skin)
- Fatigue

Elevated Liver Function Tests

We will biopsy your transplanted liver whenever your liver function tests are elevated. A biopsy may be performed in the hospital or as an outpatient. Treatment of rejection usually consists of three daily doses of intravenous methylprednisolone. This drug is also known as Solu-Medrol and is an intravenous form of prednisone. You may be admitted to the hospital to receive the Solu-Medrol. In some cases, we arrange for a home care company or your local doctor to give you your Solu-Medrol at home. One of the major side-effects of Solu-Medrol is increased blood sugar. You may need extra monitoring if you are diabetic.

If rejection is extremely severe, or if it persists after the above treatment, a second antirejection medicine may be used. Your normal immunosuppression medicines may be adjusted or changed also during a rejection episode.

Infection

Your immune system is the part of your body that is responsible for fighting infection. When this system is weakened by the immunosuppressive drugs to prevent rejection of the transplanted liver, you become more susceptible to infections. Your susceptibility to infection is directly related to the amount of immunosuppression that you are receiving at any given time.

The highest level of immunosuppression is immediately after the transplant operation. One of the best methods to prevent infection is good handwashing. Everyone who comes into your room will be required to wash their hands thoroughly to prevent transfer of bacteria, viruses, and other microorganisms to you.

Preventing Infection

- Handwashing, handwashing and handwashing are the keys to preventing infection, especially during the first year.

- Take your temperature two times a day for the first month after transplant. Consider early morning and late afternoon.
- Many people will want to visit when you return home. Be sure to ask people to visit at a later time if they have been sick or if members of their family have been sick recently. Avoid large crowds.
- If you have well water, ask your well company to treat the water for people who have suppressed immune systems.

Symptoms of Infection

If you experience any of the following symptoms of infection, you should notify your transplant doctor or coordinator immediately. As always, if there is ever a question, please call and ask!

- Temperature greater than 100°F or 38°C.
- Productive cough, change in color of sputum, or shortness of breath.
- Sores, blisters, or lumps.
- Chills or shaking episodes.
- Flu-like symptoms or severe cold symptoms.
- Drainage or swelling from a cut or wound.
- Nausea, vomiting, or diarrhea that is severe and prolonged, lasting more than 24 hours.
- Increase in fatigue and decrease in exercise tolerance.
- Burning on urination, or very frequent urination.
- Weight gain or loss of more than 5 lbs. in a week.

Common Sense Precautions

Infection in a transplant patient can be quite serious, even life-threatening. It is therefore very important that you take some precautions to prevent infection whenever you can.

Especially during the first three months following your transplant, we urge you to practice frequent hand washing. We do not recommend wearing a mask, but we do encourage you to avoid crowded spaces with coughing and sneezing people. This is most important in flu season. If you wash your hands frequently and avoid close contact with potentially sick people you will escape most common germs. We recommend that you and your family get a flu shot every year early in the fall.

It is important that you avoid large crowds, where someone with a contagious illness could be present. This does not mean that you must always stay at home; it just means using common sense. For example, plan to eat out when restaurants are not crowded, for an early lunch or dinner. Matinee showings of movies are rarely crowded, but later shows often are.

It is also important to avoid a crowd in your own home. If you are staying in a small apartment after transplant, do not invite guests and family members to come out and see you right away. It is best not to have a large number of house guests at any one time for at least two months after your transplant. For those people who do visit, please be sure they have not had recent infections, colds or exposures to childhood illnesses like the measles.

Around the house

Light housekeeping will not harm you and is a very good way to get back into shape. It is important, however, to observe the following precautions:

- Do not lift more than 5 lbs. for the first six weeks after your surgery.
- Avoid inhaling strong fumes from some cleaning products, such as ammonia or bleach.
- Wear gardening gloves if you enjoy gardening or working with plants and flowers since many infectious organisms live in the soil.

Pet Care

If you have always enjoyed having a pet or pets in the house, there is no reason for that to change. Here, too, you should take care to avoid contact with infection-causing organisms. You should not change cat litter boxes nor clean the droppings from bird cages. Cat and bird feces may carry infections that could be harmful to you.

First Aid and Hygiene

The natural ability of your body to heal wounds will be slower because of the immunosuppressive medication.

- Clean any cut or injury and keep a clean, dry dressing on the wound.
- If healing is prolonged or if you experience pain, swelling, redness, or other signs of infection, see your health care provider.
- Be aware of unusual rashes, blisters, or other lesions on your skin. Report these to your doctor if they persist.
- Good care of your teeth and gums is also very important, since your mouth has many germs. Visit your dentist every six months to avoid tooth and gum disease.
- Contact your dentist prior to your appointment to obtain an antibiotic before having any dental work done for the first six months after your transplant. He may prescribe this routine medicine as long as you do not have an allergy to the medicine. If it has been more than 6 months after your transplant, you do not need an antibiotic.
- Notify your physician if you notice sores, ulcers, or white patches in your mouth.

Nutrition and Exercise after Transplant

After liver transplant, it is important to follow a nutrition and exercise plan that promotes a healthy lifestyle. Nutrition and exercise are vital components to a successful liver transplant. Some of the medications you are taking can cause an increase in your appetite, high blood pressure, high cholesterol, high blood sugar, osteoporosis, and fluid retention. Nutrition and regular exercise can help prevent these side effects.

The basic diet and exercise principles to follow are outlined below. Following these guidelines is one way you can prevent medication side effects from occurring:

Limit sodium

- Too much sodium, or salt, in your diet can contribute to high blood pressure and fluid retention. Your antirejection medicines can also contribute to these side effects. Reducing the amount of sodium in your diet will help prevent these problems. Limit your sodium intake to less than 3000 mg per day. This is especially true if you are still taking fluid medication after transplant.
- Never add salt to food. Keep the salt shaker off of the table.
- Do not cook with salt. Do not use salt-containing seasonings. Use herbs and spices in cooking to replace salt.
- Avoid foods with visible salt like crackers, chips, pretzels, salted nuts, salted popcorn, and salted french fries.
- Limit highly processed foods. Canned, processed, and preserved foods contain high amounts of sodium. Watch out for processed meats and cheeses, canned soups, frozen dinners, and pickles.
- Limit dinner and side dish mixes that come with sauce or seasoning packages, like Hamburger Helper, Rice-a-Roni, and au gratin potato mixes.
- Limit high-sodium sauces, like soy sauce, canned spaghetti sauce, and packaged sauce, gravy and seasoning mixes.
- Do not use potassium chloride salt substitutes, like Lite Salt, No Salt, and Salt Sense.
- You should also avoid low-sodium foods that contain potassium chloride (low-sodium bouillon, low-sodium baking powder).

Reach and Maintain Your Ideal Weight

Your dietitian will help you determine your ideal body weight. Being overweight increases your risk for developing heart disease, diabetes, high blood pressure, and complications from surgery. Being underweight also has its risks. Your dietitian will help you develop a plan to either lose or gain weight as needed. Following a healthy nutrition and exercise plan will help you reach and maintain an ideal body weight.

Reduce Concentrated Sweets and Sugars

Steroids (i.e., prednisone) and other antirejection medications can increase the level of sugar in your blood. High blood sugars can cause many health problems. Therefore, it is recommended that you decrease the amount of sweets and sugars in your diet to limit this effect.

Steroids can also increase your appetite. Limiting your concentrated sweets intake will help you prevent excess weight gain. Examples include cakes, cookies, pies, ice cream, donuts, and regular soda. Healthier dessert choices include angel food cake, graham crackers, sugar-free Jell-O or pudding, and vanilla wafers.

Get Enough Protein Daily

A diet high in protein is needed to help your body heal from surgery and to help strengthen body muscles and organ tissues. Steroids can have a negative effect on muscles and break down muscle protein. A high-protein diet can help overcome this effect. Good sources of protein include lean meat, fish, chicken, and low-fat dairy products. Include a high-protein food at all meals. Also, include protein in snacks, like peanut butter, cheese, and milk.

Modify Fat and Cholesterol

Some of your antirejection medicines can increase your cholesterol level. High cholesterol levels cause fatty deposits to build up in the walls of the blood vessels and are associated with heart disease and blood vessel disease. Reducing the amount of saturated fat and cholesterol in the diet can lower cholesterol levels. Cholesterol levels can also be lowered if polyunsaturated fats are substituted for saturated fats and cholesterol in your diet. Even if your cholesterol level is normal, it is recommended that you decrease the fat and cholesterol content of your diet. Excess amounts of fat in the diet can also contribute to undesirable weight gain. Follow these guidelines:

Choose high protein foods, which are lower in fat, such as skim or 1% milk, low-fat cheese, lean cuts of red meats (center-cut loin chops, chuck or round, and flank steak), chicken and turkey without the skin, and fish. Avoid organ meats, like liver, brain, and kidney.

- Trim all visible fat and skin from meats.
- Limit fried foods. Bake, broil, roast, grill, or boil more frequently than frying.
- Try using low-cholesterol egg products or egg whites.
- When choosing fats to cook with or to add to food, use fats from vegetable sources (corn oil, safflower oil, canola oil, and margarine). Avoid fats from animal origin (butter, lard, and bacon fat).

Get Enough Calcium in Your Diet

The long-term use of steroids can cause thinning of the bones, or osteoporosis. Getting enough calcium in your diet and participating in weight-bearing exercise will help prevent fractures and maintain bone density. Milk products are the best source of calcium. Many juices, cereals, and breads are fortified with calcium. A calcium supplement may be necessary if you are unable to regularly include enough calcium in your diet. Your doctor and dietitian will determine your need for a calcium supplement.

Exercise Regularly

Exercise is one of the single most important contributions you can make to your successful transplant and a longer, healthier life. Inactivity after your transplant will make you very weak and increase the chances of medical problems. Activity is expected after your transplant while you are still in the hospital. We encourage walking in the hallways when you are transferred from the ICU. Exercise, however, is not just expected right after transplant. Regular exercise should continue through your life. Regular exercise helps you maintain an ideal body weight, prevent high blood pressure and high blood cholesterol, reduce stress, and prevent osteoporosis. During the first few months after your transplant, low-impact exercise, such as walking, is recommended.

As time passes, you may increase your activity as tolerated to more strenuous activities. Choose an activity that you enjoy. You will likely continue to exercise if you enjoy what you are doing. It is recommended that you exercise at least 3 times a week for a minimum of 30 minutes. Always check with your physician before beginning a new exercise program.

MONITORING AND FOLLOW-UP

Lab Studies

Periodically, you will need to have a blood count and blood chemistries drawn. You will also need to have Prograf or other drug levels checked. These drug levels cannot usually be completed in local doctor offices or hospitals. These lab studies are generally done at least monthly, and more often if necessary. Your transplant coordinator will give you specific instructions on when to obtain blood work. Please remember that whenever blood is to be drawn, it should be drawn first thing in the morning, before you take your morning dose of Prograf, cyclosporine, or Rapamune.

The Liver Transplant Team members are available to your local doctor 24 hours a day if he or she needs our help especially if you have been hospitalized. If your doctor wants to start you on any medications, we would like you to let us know so that we can keep your records up to date. We will also continue to follow you at regular intervals in the Duke Liver Transplant Clinic.

Self-Monitoring

You will be asked to measure your temperature, weight, and often your blood pressure or blood sugar once you are home. You will be asked to record these and bring them to clinic visits.

Temperature

Your temperature should be taken at the same time each day and whenever you feel feverish. If your temperature is above 100°F or 38°C, call your transplant physician. Fever may indicate that you have an infection or rejection episode. Do not take any medications that can lower your temperature, such as aspirin or Tylenol, unless instructed to do so by your transplant physician.

Weight

Weigh yourself at the same time each day, preferably in the morning. Weigh yourself with the same type of clothing on and on the same scale each day. A weight gain of two pounds a day for two days is significant and should be reported to the transplant physician.

Blood Pressure

Your blood pressure may need to be measured and recorded daily. Your nurse will teach you how to measure your blood pressure if you do not know how, or do not have a family member who can do it for you. You may need to purchase a blood pressure cuff if you do not already have one. We generally recommend the digital read-out type cuffs because they are more convenient. Please call your transplant coordinator for blood pressure higher than 160/100 or lower than 90/60.

Blood Sugar

If you are taking insulin, you will be taught how to monitor your blood sugars using a glucometer. There are several commercial varieties of this machine. You should call your transplant coordinator for blood sugars over 300 or less than 70.

Biopsies

After your liver transplant, almost all patients require at least one liver biopsy. We will need to do a liver biopsy if your liver tests become elevated, and we suspect liver rejection or infection. If you are admitted to the hospital when this occurs, then we will do the liver biopsy in your room. If you are an outpatient, we usually do the liver biopsies in our outpatient biopsy area on the third floor of the main hospital.

Many patients have had biopsies before their transplant and know that we do these by placing a needle through the skin into the liver. We always inject the skin with a drug like Novocain to minimize any pain during the biopsy. We remove a tiny piece of liver about one inch long and about as thick as a piece of string and then examine the liver under the microscope to help us make a diagnosis.

There is very rarely any damage done to the liver, and the tiny piece of liver removed does not affect the liver's ability to function. While there is some pain during the biopsy, patients tell us that the pain from the liver biopsy after the transplant is like having an IV put in the arm. They also tell us that the pain is much less than biopsies done before the transplant.

If we do the biopsy while you are an outpatient, we will need for you to stay for three hours after the biopsy to observe you for any problems. You will need to stay in a local hotel if you live more 50 miles away in case you experience complications after your biopsy. You will need somebody to stay with you in case you need to go to the emergency department. The results are not available immediately, but you will be told as soon as possible. Overall, liver biopsies after your transplant are not particularly painful or unpleasant.

RESUMING LIFE AFTER TRANSPLANT

Clinic Visits

You will be seen quite frequently in the Liver Transplant Clinic during the first months after your discharge from the hospital. As time passes and your condition improves, we will see you less frequently

At each Clinic visit you will have blood drawn before seeing your doctor. A Prograf, cyclosporine, or Rapamune blood level will be drawn each time you come to the clinic. Do not take your Prograf, cyclosporine, or Rapamune until after the blood has been drawn.

In addition, please remember to:

- Bring a list of your medicines including dose and how often you take it.
- Bring a days' supply of all your medications with you, in case you are delayed.
- Bring your home records with you to each clinic visit.
- Organize your questions for your doctor.
- Review our prescriptions so you may ask for new prescriptions if needed.

NOTE: We will only provide refills for those medicines prescribed by our team. Medicines prescribed by your local doctor should be refilled by that office.

Preventive Medicine

When you have completed the outpatient phase following your surgery and are ready to return home, some of your care will be taken over by our local doctor. Your relationship with your local doctor is important because he or she will monitor your general health for prevention and acute needs. Additionally, the liver transplant doctors are not available every day in Clinic. We will send a letter to your doctor describing your transplant experience and your current condition, and instructing him or her in obtaining lab studies.

All of the members of our team feel very strongly that you should continue to follow the common health prevention recommendations that apply to all patients. Your local doctor can arrange these studies based on your history, your family history and the American Cancer Society guidelines.

- Women over 40 should have a yearly mammogram and Pap smear.
- Everyone over 50 should have regular colon cancer screening.
- Men over 45 should have a yearly prostate exam and blood test for prostate cancer.
- Wear a hat and sunscreen on exposed skin areas whenever going into the sun.

In addition to these common recommendations, some liver transplant patients have special health maintenance needs. Patients who had previously identified benign polyps (benign growths which can grow into tumors if not removed) found in their colon before transplant will need a colonoscopy after transplant to make sure that no new polyps have formed. Patients with a condition called ulcerative colitis will require a colonoscopy every year after transplant to make sure that they are not at risk to develop colon tumors.

Second, being on powerful immunosuppressive drugs may increase your risk for cancer — especially skin cancer. However, you should know that this risk is very small, and in our experience with liver transplantation, we have had very few problems related to cancer from immunosuppressive drugs. Your primary care doctor should routinely check your skin for abnormalities.

We also routinely check all patients who are six months or more out from their transplant for high blood cholesterol. Prograf, cyclosporine, Rapamune, and prednisone can elevate cholesterol. Therefore, if we discover that your cholesterol is elevated, we will recommend dietary changes or in some cases advise that you start taking a drug to help lower your cholesterol.

Medical Condition Alert Bracelet

We strongly recommend that each liver transplant patient wear an identifying tag on either a bracelet or necklace after transplant. The following information should be included:

- Your name
- Liver transplant recipient
- Immunosuppressed
- 919.684.8111

Other serious conditions you may have such as diabetes or epilepsy should also be included on the tag.

Going Back to Work

It is our goal to make it possible for patients who have been employed to return to work after the transplant. Most patients can go back to work about three months after their transplant. Depending on the type of work you do and your financial situation, you may need to return to work as soon as possible.

It may be best to start back to work part-time and eventually move toward full-time work. We will assist you in dealing with your employer and insurance company by providing them with any information they require to help you get back to work again.

Sexual Activity

Sexual activity may be resumed after your incision heals, which is usually about six weeks after surgery. You should be careful at first to minimize the weight or strain that is put on your incision. Pain is the best indicator that too much weight is being put on the incision. Also, be especially careful of any tubes or drains you have in place.

In today’s world, sex is sometimes a life-and-death matter, and everyone who is sexually active should take precautions to make sex as safe as possible. This is especially true for you, as the immunosuppressive medications that you are taking make you more susceptible to sexually transmitted diseases, as well as other infections.

The use of latex condom is essential to safe sex. Using a condom does not guarantee that you will not get a sexually transmitted disease, but it is our best preventive measure. Some diseases that can be acquired sexually are hepatitis, CMV (cytomegalovirus), HIV, herpes, and candida (yeast infection).

If you are certain that your partner is monogamous, use of a condom may not be necessary. But since something as simple as a woman's common vaginal infection could cause serious infection in a male transplant patient, complete, candid communication with your partner is essential.

In such a situation, even faithful partners should use a condom or abstain from sexual intercourse.

Single people must insist on using a condom when a relationship becomes sexual. This is not always an easy or comfortable thing to do. But you have come too far to make what could be a very dangerous mistake.

Finally, do not forget about birth control. Although many women have had babies following their liver transplant, pregnancy could be hazardous. During the first year following your transplant, pregnancy would be strongly discouraged. Your transplant coordinator and doctor are available to discuss these matters with you if you so desire, so please don't be afraid to ask about your concerns.

CONCLUSION

Please remember that is will always be important for you to practice good health habits and to take good care of yourself. A balanced life, one that includes good nutrition, rest, exercise, work, and play will do wonders for your health. Please take your medication correctly, keep up with your daily records, and come for your scheduled transplant clinic visits.

Remember that we are only a phone call away at any time. **The transplant coordinator on call can be reached 24 hours a day by calling 919.684.8111 and asking for the liver transplant nurse on call.**

It is hard to believe now, but in several months you will not think about your transplant every day. All that you've been through, and all the work you've done to make your liver transplant a success, is toward the ultimate goal to give you a fresh chance to enjoy life.

HEALTH MAINTENANCE RECORDS

Please use the following sheets included in this material to track your health data as directed by your coordinator.

NAME			MONTH			YEAR		
DAY	TIME	1	2	3	4	5	6	7
WEIGHT	AM							
BLOOD	AM							
TEMPERATURE	AM							
BLOOD	PM							
PULSE	PM							
DAY	TIME	8	9	10	11	12	13	14
WEIGHT	AM							
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PULSE	PM							
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NAME			MONTH			YEAR		
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NAME	MONTH	YEAR

DATE	BREAKFAST		LUNCH		DINNER		BEDTIME	
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NAME	MONTH	YEAR

DATE	BREAKFAST		LUNCH		DINNER		BEDTIME	
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Exercise Log – Time Spent Walking, Swimming, or Biking, etc.						
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NOTES AND QUESTIONS