Duke Transplant Center

HEART TRANSPLANT PROGRAM

After your transplant

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TAKING CARE OF YOUR NEW HEART

A Guide for Heart Transplant Recipients

Congratulations! We believe you have received one of the most precious gifts one human being can give to another: a new chance at life with a new heart. During your recovery from surgery, you will likely have many questions and a lot to learn about life after transplantation. The purpose of this manual is to provide you with the information necessary to properly care for your transplanted heart. We encourage you to carefully read each section. Write down any questions you may have. A heart transplant coordinator will also review the manual's contents with you and your support person.

The Body's Defense System and Rejection

Your body's defense system — called the immune system — works to protect you against bacteria, viruses, fungi, and other things that are not recognized by the body as "self." White blood cells are part of your immune system. These cells help your immune system recognize, fight, and remove things from your body that may be harmful to you. Because the transplanted heart is not genetically identical to you, your immune system identifies your new heart as being foreign and potentially harmful. Thus, the same protective response that helps you fight off viral and bacterial illness can also cause harm by attacking your transplanted heart.

To prevent your immune system from damaging your transplanted heart, your immune system must be held down (suppressed), but not disabled. Disabling a person's immune system would prevent their body from recognizing or responding to threats from bacteria, viruses, fungi, or cancers. Medications used after transplant will suppress the immune system and are called immune suppressants or anti-rejection medications. There are different classes of medication that work on different parts of the immune response (this is covered in more detail in the section on medications). You will be on more than one medication to suppress your immune system to prevent and/or treat rejection. They are combined in ways intended to maximize each medication's benefits and minimize the medication's side effects. Although the strength of the body's immune response to your new heart typically decreases over time, it never goes away. Therefore, you will take some form of anti-rejection medication for the rest of your life. Despite the use of anti-rejection medications, many patients (50%–80%) are likely to experience at least one episode of rejection in the first few months after cardiac transplant surgery.

The signs and symptoms of rejection are often vague and you may not feel different even though you are having a rejection episode. Early symptoms can include: increased shortness of breath at rest or with activity; weight gain of one to two pounds daily for multiple days; increased or decreased blood pressure; generalized fatigue; inability to rest while lying down; nausea; or low-grade fever. The same symptoms may not indicate rejection, but another health problem. Therefore it is important to notify your transplant team if you are having any of these symptoms. An episode of rejection can often be treated without any damage to your new heart. However, if anti-rejection medications are stopped, rejection can occur quickly and can result in a permanent decline in heart function and death.

Heart Biopsies and Follow-up in Transplant Clinic

It is important to have regular follow-up with your heart transplant team so possible problems can be found and treated early. Heart biopsies are done to look for evidence of rejection in your new heart. A pathologist will look at the tissue samples under a microscope looking for signs that your immune system is active and for any damage to the heart tissue. Since you may have rejection without symptoms, heart biopsies are done at regular intervals during the first few years after transplant, the time when a rejection episode is most likely to occur. A heart biopsy may also be done if you are having any symptoms of rejection. If you have a rejection episode, you may need more frequent biopsies until the rejection is gone.

Typical Clinic Appointment Schedule

First month after transplant	Weekly for 4 weeks
Second month after transplant	Every other week
Month 3-6 after transplant	Every month
Month 8-12 after transplant	Every other month
Second year after transplant	Every three months
Year three and beyond	Every six months

A heart biopsy can be done in either the outpatient transplant clinic or in the cardiac catheterization lab in Duke University Hospital (DUH). Your first biopsy will be done before you go home after your transplant surgery and will be done in the cardiac catheterization lab. Before you leave the hospital, you will be given dates for your first two months of appointments in the heart transplant clinic. These visits will include blood work and a heart biopsy. They may also include a chest X-ray and an EKG. While the time involved will vary, plan to spend an entire day at DUH completing your appointments. We will try to make each follow-up visit as short as possible.

Please follow these instructions before each clinic visit:

- Do not eat or drink anything after midnight until your heart biopsy is complete. You may take medications prior to the biopsy with a small amount of liquid.
- Do not take your anti-rejection medications until after your blood is drawn. You may bring your morning dose(s) with you and take it (them) with a small amount of fluid after your blood is drawn.
- If you take insulin for blood sugar control, take half of your long-acting evening dose the night before the procedure, and do not take your morning short-acting insulin until after the biopsy unless your morning blood sugar level is more than 180.
- Bring at least one day’s supply of medications with you to each clinic visit. If unexpected delays occur, you will then be able to take your medications without delay.
- Bring your medication list (or have your medications memorized) and expect to discuss them with the coordinator and/or medical staff at each visit.

- Bring your vital sign (and blood sugar) records with you each time you come to the clinic for any reason, and expect to discuss them with the coordinator and/or medical staff at each visit.
- Bring a written list of any questions you have for the doctors and transplant coordinators so that you can refer to it during your clinic visit.
- Let a member of your transplant team know if you need any prescription refills. They can be sent to your pharmacy electronically during your clinic visit.

If you are scheduled for a biopsy in the outpatient clinic, the procedure typically takes 30 minutes. You will be awake during the process. The right side of your neck will be scrubbed with an antiseptic soap, and a numbing medication injected to minimize any discomfort you may feel as an intravenous (IV) catheter is inserted into a neck vein. An instrument called a bioptome (biopsy forceps) is then passed through the catheter in your neck to the right side of your heart. An echocardiogram (ECHO) will be done at the same time the biopsies are taken to allow the doctor to “see” the bioptome in the heart. When the biopsy procedure is done, the catheter will be removed and pressure applied to the site on your neck. This area may be tender or bruised for a few days after the biopsy.

If we are unable to access your heart through a neck vein, you may need to have your heart biopsies done in the cardiac catheterization lab in DUH. Six to eight weeks after transplant will we have you go to the cath lab to evaluate your coronary arteries (this is the first picture we will take of the arteries that supply blood and oxygen to your new heart!). They will do a heart biopsy at the same time. The procedure in the catheterization lab is similar to the procedures you had done prior to transplant

After you leave the clinic or hospital, if you begin bleeding or feel pressure at the biopsy site, notify a member of your transplant team while applying gentle pressure at the site. If you feel short of breath or chest pain after a biopsy procedure you should notify your transplant team right away.

Heart Biopsy Results

Biopsy results are usually available 1-2 days after your biopsy. A transplant coordinator will call you after all study results have been reviewed by a transplant cardiologist. When the coordinator calls, you will be informed of the following items:

- Whether or not you had rejection
- The International Society for Heart & Lung Transplantation (ISHLT) number and letter grade of the biopsy result
- What, if any, treatment is planned
- Adjustments in your medications
- Date(s) to obtain lab work locally, if necessary
- The date of your next clinic visit and what diagnostic testing is ordered

It is in your best interest to write all medication changes in your home record. We also encourage you to make a wallet-sized medication list and carry it with you at all times.

Grading Rejection

The International Society of Heart and Lung Transplant (ISHLT) initially promoted the use of rejection grading scores in an effort to help transplant physicians standardize definitions of what is insignificant and significant rejection. There are two scores assigned to each biopsy result, the original grading system developed in 1990 and a revised grading system developed in 2004.

1990 Grading System

0	No rejection
1A	Focal infiltrate without cell damage
1B	Diffuse but sparse infiltrate without cell damage
2	One focus only of aggressive infiltration and/or cell damage
3A	Multifocal aggressive infiltrates and/or cell damage
3B	Diffuse inflammatory process with multiple areas of cell damage
4	Diffuse aggressive polymorphous infiltrate + edema + hemorrhage + vasculitis with cell damage

2004 Grading System

0R	No rejection
1R	Interstitial and/or perivascular infiltrate with up to one focus of cell damage
2R	Two or more foci of infiltrate with associated cell damage
3R	Diffuse infiltrate with multifocal cell damage ± edema, ± hemorrhage ± vasculitis

Don’t panic if your biopsy result shows rejection. We often don’t treat low levels of “rejection” because they do not appear to impact the performance of the heart or have any long term negative consequences. Remember that rejection can occur at any time and that rejection is treatable.

Rejection and Exercise

During episodes of mild rejection, you can continue with your exercise program as usual. During episodes of moderate rejection, avoid strenuous exercise. If your heart biopsy indicates rejection, ask your doctor or transplant nurse coordinator about how much exercise you can do.

Treating Significant Rejection

Not all rejection is significant enough to require changes in your treatment. Some rejection requires a change in your medication regimen. The most common way to treat rejection is to increase your dosage of medication, including your dose of prednisone for a period of three days. This treatment is called a “prednisone boost.” You may also require intravenous (IV) medication or additional treatment. It may be necessary to admit you to the hospital to undergo treatment for moderate to severe rejection. If you have an episode of rejection a member of your transplant team will discuss the recommended treatment regimen with you.

Remember the most important ways to prevent rejection are:

- Always take all of your medications
- Never change or skip a dose of medication unless told to do so by a member of your transplant team
- Let the transplant team know about medications started by other health care providers since they may interact with the immunosuppressants.

Gene Expression Profiling (Allomap)

Allomap is a blood test that checks for immune system activity by testing for substances produced during rejection. A number scale (0–40) is assigned, and, in general, a score of less than 34 is considered no significant rejection. Intermediate scores (34–36) are associated with a one in five risk of rejection and may require you to undergo a biopsy. Your transplant team will discuss whether or not the Allomap is the right test for you. Results of the test are typically available three to five business days after your blood is taken. Use of the test may not be appropriate for some people since certain medical conditions may reduce the accuracy of the testing.

Heart Catheterization

Another form of rejection in the transplanted heart is development of coronary artery vasculopathy (CAV). This may occur in up to 50% of patients within 10 years of their transplant. Monitoring for CAV combines both invasive and non-invasive testing. The first year you should anticipate a coronary angiogram (left heart catheterization) around the anniversary of your transplant operation. If there is no evidence of coronary artery disease, stress echocardiograms alternating with left heart catheterization will be done every year. Talk to your transplant cardiologist or coordinator if you have questions.

LIFE AFTER HEART TRANSPLANTATION

Six-Week Activity Guidelines

When the transplant surgeon did your heart transplant surgery, he had to cut through your breastbone (sternum). The bone is held together initially with wires. It is very stable, but it lacks strength until it is completely healed. You may feel it clicking occasionally when you move. It will take about six weeks for your sternum to heal enough for routine activity. Until then, avoid activities that put too much stress on the sternum. This includes lifting anything heavier than a gallon of milk, pushing, pulling and twisting activities. Sudden, quick changes may result in injury before you become aware of pain. Avoid activities that you know increase pain along the incision.

Driving

To further reduce stress on your sternum, do not drive your car for the first few weeks at home. Steering a car puts a lot of stress on your sternum, especially if your car does not have power steering. If you have concerns about the amount of strength that has developed since your transplant, ask your doctor when you can start driving again. When you are in the car as either a driver or passenger, be sure to always wear your seat belt.

Visitors

Once you go home, friends and relatives will want to stop in and see how you are doing. This is fine, as long as you don't exhaust yourself. If you feel tired, limit your visitors as necessary. Your guests will understand that you are still recovering and know you need your rest. If your visitors are sick, make sure you or your visitor wears a mask. Better still — ask sick visitors to remain at home.

Rest

Above all else, it is important that you stay well rested. Allow ample time at night and during the day for rest, as necessary. Even if you don't nap during the day, allow time to sit down and relax, without interruptions. Be sure to pace yourself each day and include scheduled rest periods.

Sex

You may resume sexual relations when you feel well enough. Sexual activity will not overstress your new heart. How soon you feel ready will depend on your recovery progress. In the first few weeks after surgery, you may find that pain along your incision may limit your activity. In addition, bearing weight with your arms should be avoided in the first six weeks after transplant.

After transplant, certain medications may interfere with sexual performance. Please speak with a member of your transplant team about your options if this happens to you. If you are sexually active and do not have a steady partner, it is important to protect yourself from sexually transmitted diseases. We recommend you use a condom. Avoid sex if your partner has a yeast infection.

GENERAL MEDICATION GUIDELINES

You will take medications to suppress your immune system every day for the rest of your life. These medications must be taken to prevent rejection of your transplanted heart. Remember, stopping or decreasing the doses of your medications without the approval of your transplant team can result in the loss of your transplanted organ and your life.

Follow these guidelines with all your medications:

- Take all medications as directed. Stay with prescribed schedules and try not to miss any doses.
- The doses of your medications will change periodically. After you are home, the medication changes may be discussed with you over the phone. Be sure to write down the changes on your medication list.
- Always take your medication according to your most-recent medication list. Destroy old lists when you make or are given a new one.
- It is extremely important that you take your medications at the same time each day. You may set your schedule around meals and bedtime. It can be easy to forget whether you took your pills or not. You may find it helpful to set up a system to remind you to do so. The seven-day pill box provided by the transplant pharmacist at the time of your initial discharge from the hospital may help you to remember.
- If you miss a dose, take it as soon as you remember. If you are almost due for your next dose, do not take the missed dose and do not double the next dose. Instead, go back to your regular dosing schedule and notify the transplant coordinator.
- If you are vomiting, having trouble keeping your medications down, or experiencing diarrhea, call the transplant coordinator to discuss what can be done since your anti-rejection medication levels may change.
- Store all medications away from heat and direct light. Do not keep medications in the bathroom cabinet as heat and moisture may cause more rapid deterioration of the drug and decrease the medication's effectiveness.

Financial Considerations

Your personal cost of the transplant may be high, especially during the first year after the transplant operation. Your out-of-pocket costs for transplant medications are determined by your insurance plan coverage. The costs are in addition to the costs paid by your insurance pharmacy plan. Any change in your insurance plan may result in changes in the costs associated with your medications. Please obtain detailed information from any new plan before making a change in coverage to avoid unexpected additional medication costs.

A DUH transplant financial coordinator can help you understand the potential costs of medications to you, but it is your responsibility to ensure there are no lapses in insurance coverage after transplant. If you raised funds before transplant, it is your responsibility to ensure that any funds are available for use in your post-transplant care.

Do's and Don'ts for Filling Prescriptions

Do's

- **Do** inform the transplant office of any new medications prescribed by other physicians **before** you begin taking them.
- **Do** keep track of how many refills you have on each medication. Bring a list of any needed refills to the transplant clinic.
- **Do** keep the name and phone number of your local pharmacy handy.
- **Do** keep the transplant office up-to-date on your allergies.
- **Do** store all your medications in their original containers in a cool, dry place — not the bathroom — and away from direct light and heat.

Don'ts

- **Don't** run out of medication before seeking refills.
- **Don't** wait until a weekend or after 4 pm to call for refills needed that day.
- **Don't** take any new over-the-counter medications or new medications prescribed by other physicians without checking with the transplant office.
- **Don't** depend on your pharmacist to notify you when you need prescription refills.

TRANSPLANT MEDICATIONS

Prograf® (Generic Name: Tacrolimus)

- You will be on Prograf after the transplant to prevent rejection.
- Prograf is one of the main drugs that prevent rejection.
- Prograf is usually taken twice daily at 9 a.m. and 9 p.m.
- Prograf comes in 0.5 mg, 1 mg, and 5 mg capsules.
- While you are in the hospital after the transplant and when you come to clinic after you are discharged, we will do a blood test that can tell us exactly how much Prograf is in your body. This is called a "Prograf level."

Why is a Prograf level important?

- It is important to keep the Prograf level between 5 and 15.
- If the Prograf level is too high, you may have side effects.
- If the Prograf level is too low, you may have rejection.
- The blood test for the Prograf level is always **before** your morning dose.
- On clinic days or whenever the transplant team asks you to get a blood level, you will have to **hold** your morning dose of Prograf until your blood is drawn.
- Your dose may change over time based on your Prograf level, so you may not always be on the same dose.
- A member of the transplant team will let you know if you need to change your dose.

Generic tacrolimus

- Several companies now make a generic form of tacrolimus.
- You might take generic tacrolimus after your transplant.
- It is important to observe the appearance of your tacrolimus capsules, and make sure that you are receiving the same brand every time you get your prescription refilled.

What are the side effects of Prograf?

- Several side effects have been listed for Prograf, but you may not have any side effects at all.
- Some of the more common side effects that patients complain about are:

  Nausea

  Headache

  Tremor in the hands
- Many of the side effects go away after your body gets used to being on Prograf.

- The transplant team will be watching for side effects closely after your transplant.
- Always taking your Prograf as instructed by the transplant team can help prevent side effects.

What if I miss a dose?

- If you miss a dose, take it as soon as you can.
- If it is almost time for your next dose, take only that dose.
- Do not take double or extra doses.
- Contact your transplant coordinator if you miss more than one dose, or if you throw up a dose.

Does Prograf interact badly with any other medications?

- Yes!!!
- Prograf has a lot of drug interactions. That means that there are a lot of drugs that can change your blood level of Prograf.
- Some of the most important drugs that may interact with tacrolimus include: antibiotics, anti-inflammatory drugs (NSAIDS such as ibuprofen and naprosyn), medicines for fungal infections (fluconazole, voriconazole, ketoconazole), seizure medicines (such as phenytoin, carbamazepine), and certain high blood pressure medicines (diltiazem, verapamil).
- Do not take any medications prescribed by doctors outside of the transplant team without checking with your transplant coordinator first.

Should I avoid any food?

- You cannot have grapefruit or grapefruit juice when you take Prograf.
- Grapefruit is broken down by enzymes in your stomach that also breakdown Prograf. When your stomach breaks down grapefruit, Prograf is unable to be broken down. This can result in very high blood levels.

Should I take Prograf on an empty stomach?

- Taking Prograf consistently with or without food at the same time each day is important. This will help you keep a constant amount of Prograf in your body.

What do I need to watch for while I take Prograf?

- The levels of tacrolimus in the blood need to be checked periodically, and you will be visiting the transplant clinic on a regular basis to do so.
- You will have an increased risk of infection while taking tacrolimus. Try to avoid people with infections. Call your transplant coordinator for advice if you get a fever, chills, sore throat or a cough.
- Avoid taking aspirin (besides your regular daily aspirin dose), ibuprofen (Advil), ketoprofen (Orudis), or naproxen (Aleve) products unless instructed to do so by the transplant team.

- Tacrolimus, as with other anti-rejection medicine, may increase your risk for certain types of skin cancer. To decrease your risk, wear protective clothing, including hats, and use sunscreen when exposed to the sun.

Neoral®, Gengraf® (Generic Name: Cyclosporine)

- If you are not on Prograf (tacrolimus) after the transplant, you may be on cyclosporine to prevent rejection. Tacrolimus is very similar to cyclosporine, and you will never be on both at the same time.
- Cyclosporine is one of the main drugs that prevent rejection for people who are not on tacrolimus.
- Cyclosporine is usually taken twice daily at 9 a.m. and 9 p.m.
- Cyclosporine comes in 25 mg and 100 mg capsules
- While you are in the hospital after the transplant and when you come to clinic after you are discharged, the transplant team will do a blood test that can tell us exactly how much cyclosporine is in your body. This is called a "cyclosporine level."

Why is a cyclosporine level important?

- It is important to keep the cyclosporine level between 200 to 300 ng/mL in the first months after the transplant.
- If the cyclosporine level is too high, you may have side effects.
- If the cyclosporine level is too low, you may have rejection.
- The blood test for the cyclosporine level is always before your morning dose.
- On clinic days or whenever the transplant team asks you to get a cyclosporine blood level checked, you will hold your morning dose of cyclosporine until your blood is drawn.
- Your dose may change over time based on your cyclosporine level, so you may not always be on the same dose.
- A member of the transplant team will let you know if you need to change your dose.

Generic cyclosporine

- Several companies make a generic form of cyclosporine.
- You might take generic cyclosporine after your transplant.
- It is important to observe the appearance of your cyclosporine gelcaps, and make sure that you are receiving the same brand every time you get your prescription refilled.

What are the side effects of cyclosporine?

- Several side effects have been listed for cyclosporine but you may not have any side effects at all.
- Some of the more common side effects that patients complain about are:

  Nausea

Headache

Tremor in the hands

- Many of the side effects go away after your body gets used to being on cyclosporine.
- The transplant team will be watching for side effects closely after your transplant.
- Always taking your cyclosporine as instructed by the transplant team can help prevent side effects

What if I miss a dose?

- If you miss a dose, take it as soon as you can.
- If it is almost time for your next dose, take only that dose.
- Do not take double or extra doses.
- Contact your transplant coordinator if you miss more than one dose, or if you throw up a dose.

Does cyclosporine interact badly with any other medications?

- Yes!!!
- Cyclosporine has a lot of drug interactions. That means that there are a lot of drugs that can change your blood level of cyclosporine.
- Some of the most important drugs that may interact with cyclosporine include: antibiotics, anti-inflammatory drugs (NSAIDS such as ibuprofen and naprosyn), medicines for fungal infections (fluconazole, voriconazole, ketoconazole), seizure medicines (such as phenytoin, carbamazepine), and certain high blood pressure medicines (diltiazem, verapamil).
- Do not take any medications prescribed by doctors outside of the transplant team without checking with your transplant coordinator first.

Should I avoid any food?

- You cannot have grapefruit or grapefruit juice when you take cyclosporine.
- Grapefruit is broken down by enzymes in your stomach that also breakdown cyclosporine. When your stomach breaks down grapefruit, cyclosporine is unable to be broken down. This can result in high blood levels of cyclosporine.

Should I take cyclosporine on an empty stomach?

- Taking cyclosporine consistently with or without food at the same time each day is important. This will help you keep a constant amount of cyclosporine in your body.

What do I need to watch for while I take cyclosporine?

- The levels of cyclosporine in the blood need to be checked periodically, and you will be visiting the transplant clinic on a regular basis to do so.

- You will have an increased risk of infection while taking cyclosporine. Try to avoid people with infections. Call your transplant coordinator for advice if you get a fever, chills, sore throat or a cough.
- Avoid taking aspirin (besides your regular daily aspirin dose), ibuprofen (Advil), ketoprofen (Orudis), or naproxen (Aleve) products unless instructed to do so by the transplant team.
- Cyclosporine can cause unusual growth of gum tissue and can make your gums bleed. Practice good oral hygiene, and be careful when brushing and flossing your teeth. See your dentist regularly.
- Cyclosporine can increase your blood pressure. The transplant team will want to monitor your blood pressure, and you may have to take another medicine to keep your blood pressure under control.

Cellcept® (Generic Name: Mycophenolate Mofetil)

- You will be taking Cellcept to prevent rejection.
- You will always take Cellcept, if possible. Cellcept is taken twice daily at 9 a.m. and 9 p.m.
- Cellcept comes in 250 mg and 500 mg tablets. Most patients take around 1500 mg (or 1.5 gram) twice a day.

Generic Cellcept

- Several companies make a generic form of mycophenolate mofetil.
- You might take generic mycophenolate mofetil after your transplant.

What are the side effects of Cellcept?

- Cellcept's most common side effects are upset stomach, particularly diarrhea. Taking Cellcept with food can minimize stomach upset.
- Cellcept can sometimes decrease your blood counts (white blood cells and platelets). The transplant team checks your blood counts when you come to clinic. If your blood counts drop, they may decrease your dose.
- Cellcept can be very harmful to developing babies. If there is a young female in your household who is pregnant or could be, they should not handle or crush Cellcept.

Does Cellcept interact with any other medications?

- Magnesium-aluminum containing antacids (such as Mylanta) can decrease the absorption of Cellcept.
- Certain cholesterol medications, such as cholestipol and cholestyramine, can decrease the levels of Cellcept in the body.

Prednisone

- You will be on prednisone after the transplant to prevent rejection.

- Prednisone is taken once or twice daily with food.
- If you are only taking prednisone once a day, take it in the morning to prevent difficulty sleeping at night.
- If you are taking prednisone twice daily, take the doses with breakfast and dinner.
- Your prednisone dose will gradually decrease over time; refer to your medication schedule for your exact dose each day.

What are the side effects of prednisone?

- Prednisone can increase your blood glucose (sugar).
- Some patients may have to take insulin shots at home and check their sugars with a glucometer after their transplant. Some patients will not have to do this.
- Prednisone can cause osteoporosis (brittle bones). Some patients may already have this before the transplant. If you are taking drugs like Fosamax or Actonel before your transplant, you will continue those drugs once you are discharged from the hospital. All patients will take a calcium supplement to prevent damage to their bones.
- Prednisone can cause weight gain. Weight gain can be prevented by maintaining a healthy diet and exercising on a regular basis.

Valcyte® (Generic Name: Valganciclovir)

- Some patients will have to take a medication to prevent the cytomegalovirus (CMV) after their transplant.
- CMV is a virus that most of us are exposed to at some point in our life. CMV does not make you sick when you are exposed to it before the transplant. It lives dormant in your body for the rest of your life though. After the transplant when your immune system is weak, CMV can flare up and cause problems with your kidneys, liver, stomach and/ or lungs.
- After the transplant, you may take a pill called Valcyte (valganciclovir) to prevent CMV.
- Valcyte is a 450mg tablet. You will take either one or two 450 mg tablets every day at dinner.
- You will take this medication for 3-6 months after your transplant.
- Valcyte should be taken with a full meal, otherwise, your body will not absorb the whole dose.
- While you are on Valcyte, you will need regular blood checks in the transplant clinic to monitor for low blood counts.

Valtrex® (Generic Name: Valacyclovir)

- Some patients will have to take a medication to prevent the herpes simplex virus (HSV) after their transplant.

- HSV is a virus that most of us are exposed to at some point and that lives in your body for the rest of your life. Although some people with HSV infection never know they have the infection, it can cause intermittent genital or mouth ulcers (fever blisters). After the transplant when your immune system is weak, HSV can "wake-up" and cause problems.
- After the transplant, you may take a medication called Valtrex (Valacyclovir) to prevent active HSV infection.
- You will never be on both Valcyte and Valtrex at the same time, since these medications are similar.
- Valtrex comes in 500 mg and 1000 mg (1 gram) caplets. You will take 1000 mg once daily for 12 weeks after your transplant.

Septra SS® (Generic Name: Sulfamethoxazole/Trimethoprim or SMX/TMP)

- Septra SS is taken after transplant to prevent a special kind of pneumonia called pneumocystis jiroveci. This is a pneumonia that transplant patients can get because of their low immune systems.
- You will take Septra for at least 1 year after your transplant.
- You will take one tablet daily.
- If you are allergic to Septra, which is a "sulfa drug," you will take either dapsone or inhaled pentamidine instead.
- Septra has very few side effects. Sometimes patients may have nausea, but this can be minimized by taking Septra with food.
- Septra can cause increased sensitivity to the sun. Wear protective clothing and use sunscreen outdoors.

Pentamidine Inhaled

- Pentamidine is an inhaled antibiotic used to prevent pneumocystis jiroveci pneumonia.
- Patients who are unable to take Septra may need to take inhaled pentamidine.
- Inhaled pentamidine is given once monthly for one year after transplant. It is administered at home with Respirgard II, a jet nebulizer. The treatment takes 30-45 minutes to administer.
- Patients with asthma should administer a bronchodilater (such as albuterol) before pentamidine administration to prevent cough and wheezing.

Nystatin

- Nystatin prevents thrush (yeast) from growing in your mouth and throat.
- You will swish and swallow with 1 teaspoon of Nystatin after each meal and at bedtime.
- After swishing wait about 15 minutes before eating or drinking.
- You will take Nystatin for the first 6 months after your transplant.

Stomach Medications

- After the transplant, all patients take a medication to decrease their stomach acid. These medications prevent stomach and intestinal ulcer.
- Examples include pantoprazole (Protonix®), and omeprazole (Prilosec®).
- Some of you may already be on a stomach medication at home. If so, we will try to continue that one.

Pravachol® (Generic Name: Pravastatin)

- After your transplant, you will take Pravachol (pravastatin).
- Pravastatin reduces cholesterol and also helps to prevent rejection in heart transplant patients.
- Even if you have normal cholesterol, you will take pravastatin to help prevent rejection after the heart transplant.
- If you have high cholesterol, pravastatin will be used to both lower your cholesterol and help prevent rejection. If you had been taking a different medication to lower your cholesterol before transplant, you may be switched from that medicine to pravastatin after transplant.
- Rarely, people will develop muscle aches and pains when they take pravachol. If you develop any unexplained muscle pain, tenderness, or weakness, report it to your transplant coordinator.
- In individual cases, other drugs in this class will be used and tailored to the specific needs of the patient.

Pain Medication

- If you have pain after the transplant, acetaminophen (Tylenol®) is safe to take at recommended doses, not exceeding 3-4 grams/ day (depending on the product).
- You will be given a prescription for oxycodone, a stronger narcotic pain medication. This medication should only be taken if needed, for more severe pain that acetaminophen does not help.
- Remember to avoid NSAIDS (ibuprofen, naproxen, ketoprofen, celexocib).

Medications to Avoid After Transplant

- After your transplant, you should not take ibuprofen (Advil, Motrin), naproxen (Naprosyn), ketoprofen (Orudis), or celecoxib (Celebrex). These are medications that help with inflammatory pain. When combined with Prograf they are bad for your kidneys.

INFECTION RISKS

While your anti-rejection medications allow your body to accept your new heart, they also make you more likely to develop an infection. Your risk of infection is greatest when you are on higher doses of medication, usually for the first six to twelve months post transplant and during an episode of rejection when your medication dose is increased. As your doses of anti-rejection medications are lowered, so is your risk of getting an infection. However, being on anti-rejection drugs – no matter what the dose – makes you high risk for infection.

Preventing infection is mostly common sense. It is likely that you will still catch a cold, the flu or other viral illnesses. It may take you longer to recover because of your anti-rejection medications. It is important to have a local primary care doctor who can see you when you develop an infection. Early detection and treatment is important!

Preventing Infection

Handwashing

Studies show that most infections are spread by your hands. The single most important thing you can do to prevent infection is washing your hands. Handwashing with soap and clean water is preferred but the use of hand sanitizers is OK too. You should wash your hands after contact with another person, before and after meals, before preparing and taking your medications, after cleaning and after using the restroom. Enlist the help of your family and friends in your fight against infection by having everyone wash their hands frequently too.

Dental Care

Your mouth is a potential source of infection because bacteria are normally present there. It is important that you brush your teeth and floss regularly. It is also important that you receive routine dental care to help prevent infections and decrease the amount of gum overgrowth that can happen with some of your anti-rejection medications.

Current American Heart Association (AHA) guidelines do not recommend antibiotics before routine dental check-ups and cleaning just because you had a transplant unless you have an abnormally functioning heart valve. Please call the transplant office to review whether or not you need antibiotics and to make sure there are no interactions between the antibiotics and your other medications. If your dentist has any questions or concerns, call the transplant office.

Wounds

The natural ability of your body to heal wounds will be slowed by immune suppression therapy. Minor cuts and scrapes should be cleaned with soap and water and covered with a clean, dry dressing. You may place an antibiotic ointment over superficial wounds to reduce the risk of more serious infection. If the wound develops swelling, a foul odor, pus, or redness, call your transplant coordinator immediately.

Vaccines

We recommend you get a flu vaccine every fall. You must get the injection and avoid the inhaled vaccine since the inhaled one has live virus and can give you the flu. You can get the vaccine in transplant clinic or at your local doctor's office.

We also recommend you get the Pneumococcal vaccine every five years and the Tetanus/Diphteheria/Pertussis vaccine every 10 years. Please discuss this with your transplant physician or coordinator if you believe you are due for a vaccine.

Water Prevention Guidance after Transplant

Water safety, not just food safety, is also of vital importance in the post-transplant time period. We have three phases of water-based precautions at Duke:

- Phase 1: In-hospital, post-transplant; highly immunosuppressed, freshly healing wounds
- Phase 2: Immediate post-discharge from hospital; incisional staples still in place
- Phase 3: Staples removed and wound well-healed

Phase 1: While in the hospital, expect tight water restrictions. Ice chips, drinking water and showering, for example, will all be strictly limited.

Phase 2: After discharge, but before staples and stitches are removed from your incisions, the wounds remain at risk for water-born infection.

- Use boiled water or sterile water for (a) drinking, (b) oral care (e.g. toothbrushing), (c) tube flushes, and (d) washing wounds.
- Showers and baths are not recommended in this phase; chest tube sites and incisions should be cleaned specifically with boiled or sterile water.
- Of note, bottled water is not recommended during this phase; boiled water or sterile water are the most reliable way of ensuring safety.

Phase 3: Once incisions are healed, showering is allowed.

- Hot tubs, because of the aerosols generated, should be avoided.
- Well water, even if filtered, is not considered safe unless it has been tested, as it is rarely appropriately chlorinated and may contain infectious organisms. If you anticipate using well water post-transplant, it may need to be tested.
- Most water filtration devices will not make water safe. Portable water filters (such as Brita® or Pur® system) as well as refrigerated-dispensed water and ice machines do not meet filtration standards. Portable water systems filter for impurities, but not for bacteria.
- Questions about water use and supply can be directed towards your Transplant team, or the Infectious Diseases service.

Other Infection Prevention Techniques

- Avoid people who are sick. If friends or family have a cold, the flu, or other infections, ask them to not visit until they are feeling better.
- If someone in your family gets sick, avoid close contact. Do not use the same plates, utensils and drinking glasses. No hugging, kissing or holding hands. Make sure everyone washes their hands frequently.
- If you are in an enclosed space (for example: restaurants; church; the mall; or a sporting event) and someone near you is coughing or sneezing, put on a mask and move several feet away
- Avoid construction sites. If you live near an active construction site, keep your windows closed.
- Avoid gardening and working in the soil for the first six months after your transplant. Wear gloves and a mask after six months to prevent exposure to fungus spores in the soil.
- Do not water fresh flowers or live plants for the first six months after transplant. You can have them in your home, but someone else should care for them.
- Never change a litter box! Avoid cat litter boxes because cat feces may contain a parasite called toxoplasmosis that can serious infections.
- Avoid all contact with animal waste. Do not clean bird cages or roosting areas if you are around chickens. Bird feces may have cryptococcosis which can cause a serious infection. You should not have birds as a pet unless you are cleared by your transplant team.
- Avoid live virus vaccines such as polio, measles, mumps, rubella, yellow fever, smallpox and the vaccine for shingles. The live viruses in the vaccine can cause infection. If you are not sure if a vaccine has live virus, contact the transplant office.
- Avoid close contact with children or other adults who have received live virus vaccines for two weeks following the vaccination. If you are not sure if a vaccine contains live virus, ask the pediatrician or call the transplant office.

Signs of Infection

The earliest signs of infection may be fever over 100 degrees, headache, fatigue, muscle aches, nausea, vomiting, diarrhea, loss of appetite or a sore throat. **If you have any signs of an infection you should call the transplant office right away.**

Other Types of Infections

Opportunistic Infections

This type of infection is caused by common bacteria, viruses and fungi that float in the air or live on your skin , dirt and/or water. Since your immune system is suppressed after transplant, these pathogens have the opportunity to take advantage of you and cause infection. Some common types of opportunistic infections include pneumocystis jiroveci pneumonia (PCP) and toxoplasmosis. You will be on medications after transplant to prevent this type of infection.

Re-activation of Latent Infection

During your lifetime, you have been exposed to many different types of organisms that cause infection. Sometimes, the virus or bacteria is still in your body but your immune system kept it from making you sick. After transplant, because your immune system is suppressed, these viruses or bacteria can re-activate and make you sick. Some examples include herpes simplex (causes cold sores or fever blisters) and herpes zoster (causes shingles). Your transplant team will routinely test you for some common types of latent infections such as cytomegalovirus (CMV) so if there is re-activation it can be treated early.

Skin Infections

There are three common skin infections after transplant: herpes, warts and acne. The herpes virus is present in 80% of the population but does not always cause symptoms until the immune system is suppressed. If you develop a herpes infection, it can be treated with pills or creams although it is likely to recur. Warts are caused by human papillomavirus (HPV) and look like small, rough skin-colored lumps. Treatment depends on the size and location. Like herpes, warts are likely to recur. Acne is often caused by taking prednisone. Prednisone causes changes in your skin and increased oil production. When this oil is trapped in your skin follicles, you see acne. It is most common on the trunk of your body but can appear anywhere. The best prevention is good hygiene and the treatment of steroid-induced acne is retinoid or antibiotic creams.

HEALTH MAINTENANCE

There are several ways you can help yourself stay healthy. Maintain a good relationship with your primary care physician, and schedule routine visits for check-ups. Routine health screenings are meant to catch problems early.

Skin Inspections

Thoroughly inspect your skin once a month while bathing. Report any new lesions (sores), new or changing areas of discoloration or moles, new lumps or bumps, or a wound that does not heal. Make an appointment with a dermatologist for an annual skin check.

Colorectal Cancer Screening

All men and women beginning at age 50 should have testing for colorectal cancer. This can be arranged through your local physician or can be done at DUH.

Mammograms

All women starting at age 40, should have a yearly mammogram. This can be done at your local physician's office.

Pelvic Exam/Pap Smear

All women starting at age 21, should have a yearly gynecologic examination, which should include a pelvic exam and Pap smear. This can be done by your primary care physician or gynecologist.

Prostate Exam

All men starting at age 45 should have a yearly blood test for prostate specific antigen (PSA) to screen for prostate enlargement or cancer. This can be done with or without a rectal exam.

Tdap Vaccination (Tetanus, Diphtheria and Acellular Pertussis)

Everyone should be vaccinated every 10 years.

Pneumococcal Vaccine (Pneumovax)

This helps prevent a type of pneumonia called pneumococcus. You should be vaccinated every five years.

Hepatitis Vaccines

There are hepatitis vaccines against both type A (two-shot series) and type B (three-shot series). The hepatitis virus infects your liver and can lead to liver failure. We recommend you are vaccinated against both types of hepatitis virus. Unfortunately, there is not a vaccine against Hepatitis C.

HEALTHY LIFESTYLE HABITS

We want you to live with your new heart for as long as possible. Therefore we encourage you to take steps to improve your overall health and protect your heart. Some bad habits can contribute to cancer and other health problems years later. By avoiding these habits and adopting healthy habits, you can help decrease your risk of developing these health problems.

Sun Exposure

Transplant recipients taking anti-rejection medications are at an increased risk of skin cancer because your anti-rejection medications cause increased sun sensitivity. To minimize your risk, wear protective clothing and a UVA/UVB sunscreen (SPF of 15 or greater) on all exposed skin. Men with thinning of their hair should wear a hat when outside for prolonged periods of time.

Smoking

Before you were placed on the transplant waiting list, the transplant team talked to you about previous tobacco use and told you that you cannot use tobacco products after you received a new heart. Heart transplant recipients who smoke or use tobacco products are damaging the healthy new heart that was donated to them.

People who smoke after transplant:

- Are at increased risk for pneumonia and arteriosclerosis (blockages of the coronary arteries) of their new heart.
- Shorten their life expectancy.
- Double their risk of developing cataracts.
- Increase their risk of cancers in the lung, stomach, pancreas, bladder, throat, esophagus, larynx and mouth.

PLEASE honor your pre-transplant commitment to care for your new heart and **DO NOT SMOKE!**

Alcohol

Alcoholic beverages, such as wine, beer or mixed drinks, can interfere with your anti-rejection medications and may damage both kidneys and liver. You should have no more than one glass of wine, one beer, or one mixed drink per day. Drinking more alcohol than this may change the effectiveness of your transplant medications. If you frequently used alcohol (beer, wine, hard liquor) before transplant, please honor your pre-transplant commitment to not drink excessively again.

Diet

Eat a well-balanced, low-fat diet with plenty of fiber, fruits, and vegetables. Diets high in fatty foods can increase your risk for cancers of the colon, rectum, and breast. Diets high in fresh fruits, vegetables, and whole grains can reduce your cancer risk. Drink at least eight glasses of fluid per day to keep yourself hydrated. Being overweight makes you more prone to bone fractures, back pain, and heart disease. Studies show that the strongest anticancer strategy is avoiding obesity.

Exercise

Exercise can decrease stress and fatigue and increase energy levels and your sense of well-being. Indoor or outdoor activities are limited only by the limits of your physical stamina. Use common sense in all activities. Restrictions apply only when there are extremes in pressure changes, such as flying in unpressurized cabins, skydiving, hang gliding and scuba diving. Your new heart's response to these activities is not normal and may make them hazardous.

Swimming in clean pools, rivers, lakes, and the ocean is an excellent form of exercise after full recovery from your surgery. Relaxing in a clean hot tub for 10 minutes or less is acceptable after your incision has healed.

EXERCISE

How is My New Heart Different?

During your heart transplant, the nerves to your heart were cut (the vagus nerve), and will not grow back. The medical term for this is “denervation.” Before your transplant, your heart rate was controlled by your nervous system. In your transplanted heart, your hormones (adrenaline) will make your new heart beat faster. Your hormones act a little slower than your nervous system so you will have a different response to exercise. Your heart functions perfectly well despite this difference and does not limit what you are able to do.

Your resting heart rate will be faster, usually between 90-110 beats per minute. When you exercise, your heart rate will not increase as quickly as it did before your heart transplant. Instead, your heart will slowly speed up over a period of 5 to 10 minutes while adrenaline enters your bloodstream, reaches your heart cells and causes them to pump faster. Your heart rate during vigorous exercise will be slightly lower than that of other people. After exercise, it will also take longer for your heart rate to return to resting levels. This means you should take five minutes to warm up before exercising and five to 10 minutes to cool down.

The denervation of your new heart also means that you will no longer feel chest pain related to your heart. The nerve connections that conducted pain are gone. Any chest pain you feel during activity is probably caused by the healing of your chest after surgery.

Why Exercise?

Exercise strengthens your heart and tones and conditions muscles in your body. It reduces stress and tension. Exercise helps reduce high blood pressure, high cholesterol, triglyceride levels, and helps control blood sugar levels. Exercise helps combat the effects of prednisone, which can cause muscle weakness. Exercise will help you feel better, look better, and have more energy for other activities.

You may get tired and short of breath when you exercise. Don’t confuse muscle weakness and shortness of breath with your pre-transplant symptoms of heart failure. Most likely, you are just weak and out of shape from long periods of limited activity before your transplant. As you exercise, your strength and endurance will improve and the fatigue and shortness of breath will diminish. Before you leave the hospital after your transplant, a physical therapist will give you an exercise program to start during your recovery period.

What Type of Exercise?

Your exercise program should be one that uses large muscle groups for 30 to 45 minutes without stopping. To facilitate this, we recommend participation in a formal cardiac rehabilitation program beginning 6 weeks after transplant. Walking, biking, swimming, low-impact aerobics, cross country skiing, and jogging are exercises that will condition your heart and muscles. For the first six weeks, walking and/or stationary biking are most suitable until you heal from your surgery. If you swim for exercise, swim in chlorinated pools.

How Long, How Often, How Much?

Following surgery, you need to walk or use a stationary bike for short periods daily. As your endurance improves, you will be able to exercise longer. Physical activity sessions can be spread out over the day and can be done initially 10 minutes at a time. Your goal will be to exercise every day for 30 to 45 minutes without stopping. Strolling around the block and chatting with neighbors is fun, but it is not exercise for your new heart. Walking briskly, swinging your arms, and using some effort is fun and good for your heart! This will keep your heart rate high during exercise and make your heart stronger.

What about Stretching?

Warming up muscles before exercise and cooling them down and stretching after exercise will reduce the likelihood of injury to muscles and tendons. Stretching will also improve your flexibility over time and can also reduce pain. Stretches should be slow and gentle. Avoid bouncing since this causes very small tears in muscles.

What about Warm-Up and Cool Down Exercises?

Warm-up exercises increase your circulation and body temperature. The exercises should be low or low-to- moderate intensity and can include stretching. This will gradually raise your heart rate over five to 10 minutes and avoid injuring muscles. Walking is an excellent warm-up exercise.

Cool down exercises are done at the completion of your workout. Slow walking and biking are ideal cool-down exercises. Cooling down is important to avoid pooling of blood in your limbs that can cause light headedness. It also allows time for your muscles to cool down and helps prevent muscle cramping and soreness.

Where?

When you exercise outdoors try to find safe areas, such as tracks, parks, or sidewalks. You can exercise indoors during adverse weather conditions if you want, but you can safely exercise in hot or cold weather as long as you dress appropriately. Walking in the shopping malls, gymnasiums, or stationary biking are other ways to keep in shape during inclement weather. If you exercise outside, don’t forget to wear sunscreen to protect your skin. (Prednisone increases your sensitivity to the sun.)

Checking Your Pulse (Heart Rate)

Before you exercise and immediately after you exercise, check your pulse. You will become familiar with your heart’s response to exercise.

- Relax.
- Turn one hand palm up.
- Use index and middle finger of opposite hand to find the pulse (don’t use your thumb!). It should be best felt on your wrist just below the base of your thumb.
- Press lightly, and hold your two fingers over areas shown in the diagram.
- Count the number of beats you feel in 10 seconds.

Pulse check conversion chart

10- second heart rate	Calculated one minute heart rate	10-second heart rate	Calculated one minute heart rate
9	54	19	114
10	60	20	120
11	66	21	126
12	72	22	132
13	78	23	138
14	84	24	144
15	90	25	150
26	96	26	156
27	102	27	162
18	108	28	168

MONITORING VITAL SIGNS

Measurements of your body's functions, such as blood pressure, heart rate (pulse), temperature, and fluid status (weight), are vital signs. To help us monitor your progress and adjust your medications, we ask that you record your vital signs and weight each day. Recording vital signs is an important way you can help the transplant team help you do well after your heart transplant. Remember to bring a log of your vital signs with you to transplant clinic.

Blood Pressure (BP)

You will need to get a blood pressure cuff that you can easily use to monitor your own blood pressure. BP cuffs that require a stethoscope for listening to blood pressures are very difficult to use when checking your own blood pressures. Instead, use a semi-automatic blood pressure cuff that runs on batteries or electricity. With a semi-automatic cuff, you can easily put the cuff on your arm and pump it up. The machine then causes the cuff to deflate on its own and displays the BP reading. There are many good brands of semi-automatic BP cuffs available for $35–$95. Cuffs can be purchased in many pharmacies (drug stores), hospital supply stores, or at discount stores with pharmacy services. Store personnel can help you make an appropriate selection.

Become familiar with your usual blood pressure and pulse rate. Blood pressure readings have two parts. The top number is called the systolic blood pressure; the bottom number is called the diastolic blood pressure.

Always check your vital signs at rest. In most instances, we do not need to know how your pressure changes with exercise. Sit and rest for at least five minutes before checking your vital signs.

When to Call

Blood Pressure

In the period immediately before your transplant, your blood pressure was probably low because your heart was too weak to contract effectively. However, many people develop high blood pressure (hypertension) after heart transplantation. Since a single blood pressure reading taken during a clinic visit may be falsely high, we will depend on your home records to adjust your medications.

This is a **high** BP reading: 160/100 (or higher)

If you have more than three high readings (see above) in one week, call the transplant office at 1-800-249-5864, or 919-613-7777 between 8 am and 4 pm, and ask to talk to a coordinator.

This is a **very high** BP reading: 180/120 (or higher)

If you get a very high reading, check your blood pressure cuff to make sure it is working correctly. Relax a few minutes and then recheck your pressure. If it remains high, page the cardiac transplant coordinator on call at 919-684-8111.

Heart Rate (Pulse)

Automatic blood pressure cuffs also display your heart rate or pulse. Your pulse is the number of heart beats per minute and will naturally increase with activity and exercise. Again, we are interested in knowing your heart rate at rest. Page the transplant coordinator on call for very low (less than 60) or very high (greater than 120) heart rate when at rest. See the section on checking your pulse.

Temperature

Your temperature is generally lowest in the morning and highest in the evening. If you have recurring temperatures greater or equal to 100°F or a single temperature greater than 101°F, you should call the coordinator who is on call to discuss this and any other symptoms you may have.

Weight

Please weigh yourself daily in the morning. If you gain one pound per day for three days or five pounds in a week, call the transplant office.

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WEIGHT	AM							
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NAME			MONTH			YEAR		
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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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NUTRITION AFTER HEART TRANSPLANT

Diet is a very important part of your life after transplantation. The drugs used to prevent rejection have several side effects that require good diet control.

The immunosuppressive drugs:

- Cause the body to hold salt and water.
- Cause the body to lose potassium.
- May increase hunger and cause weight gain due to overeating.
- May increase the amount of sugar, cholesterol, and fats in the blood.
- May speed up the thickening and narrowing process of the blood vessels of the heart.

Take care of your transplanted heart by eating a healthy diet and following these nutrition guidelines, even if you did not have weight problems or thickening of the heart's blood vessels pre-transplant.

Post-Surgery to Two Months after Transplant

Immediately after transplant your nutritional needs will be increased due to the stress of surgery and need for wound healing. You may not feel hungry or foods may taste different while you are taking large amounts of medicine. You still need to eat, even with a decreased appetite.

- Eat three balanced meals a day and one to two snacks as needed.
- Increase protein intake. Choose high protein foods such as peanut butter, fish, lean cuts of meat, seafood, nuts, seeds, beans, low-fat or non-fat pasteurized dairy products (yogurt, milk, cheese), and eggs, egg substitutes or egg whites.
- Limit the amount of fat eaten. Choose only low-fat or non-fat dairy products.
- Limit the amount of sugar eaten. Avoid cakes, cookies, sugary beverages, juices and other sweets that are high in calories, sugar and fat.
- Avoid high sodium foods and adding salt to food.
- Follow food safety guidelines for post transplant.
- Follow food-drug interaction guidelines for post transplant.

Long-Term Nutrition after Transplant

The immunosuppressive drugs you will need to take to prevent organ rejection may cause diabetes, decreased bone mass, high fat in the blood, high blood pressure and unwanted weight gain. Eating a healthy diet can help minimize the side effects of these medications and is a very important aspect of everyday care after transplant.

Get Enough Protein Daily

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. Include a high protein food at all meals. Good sources of protein include lean meat, fish, chicken, tofu, beans, nuts, peanut butter, and low-fat dairy products

Maintain a Low Waist Circumference

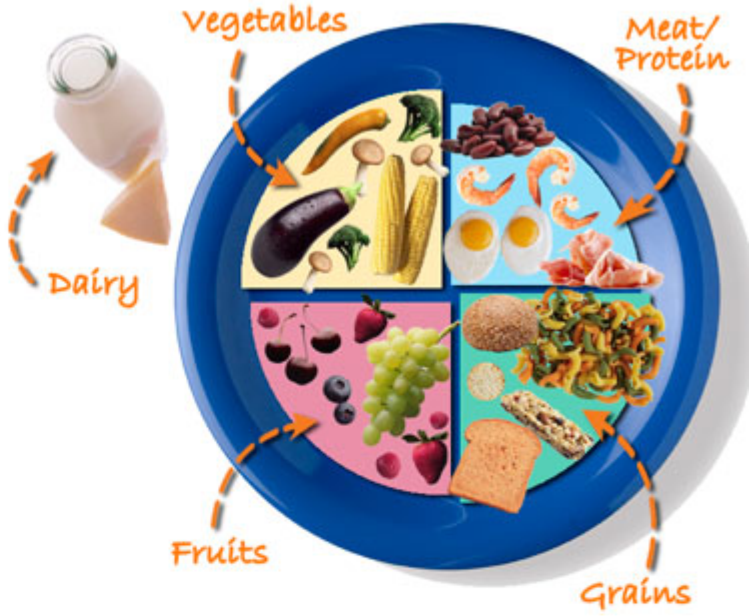
Regardless of your body weight, men and women who are very large around the middle are at much greater risk of premature death than those with thinner waists.

- Aim for a waist circumference (distance around the waist) under 40 inches for men, and under 35 inches for women.
- A large waist size increases the risk of developing heart disease, high blood pressure, type 2 diabetes, certain types of cancers, acid reflux and death.

Reach and Maintain Your Desired Body Weight

Reaching and maintaining your desired body weight is very important in your overall health. If you are already at your desired body weight, a good diet including moderate serving sizes and limited added fats and sugars will help you to maintain it.

- Regular exercise of 30-60 minutes/day, 5-7 days/ week is very important in controlling your weight, and overall health.
- Practice portion control. Half of your plate should consist of fruits and vegetables, one fourth should be lean protein and one fourth should be grains (whole grains preferably).



Reduce Concentrated Sweets and Sugars

Prednisone, one of the medications you will take after your transplant, is often associated with an increase in the level of sugar in your blood. It is recommended that you decrease the amount of concentrated sweets and sugars in your diet and control the amount of carbohydrates you eat.

- Carbohydrates are found in sugar, fruit, breads, crackers, cereals, pasta, rice, grains, milk and yogurt, starchy vegetables such as potatoes, corn, beans and peas. You don't need to completely eliminate these foods, but you should control the amount you eat at each meal/snack. Aim for about 30-75 grams of carbohydrate per meal (make most as whole grains/whole wheat).
- Use nutrition labels to learn about the carbohydrate content of foods. Make sure you compare the serving size you are eating to the serving size on the label.
- Limit intake of "simple sugar" from soda, candies, desserts and fruit juice.

Modify Fat and Cholesterol

Reducing the overall amount of saturated fats, trans fats and cholesterol in your diet is recommended in order to maintain a healthy blood cholesterol level. Blood cholesterol levels can be lowered if polyunsaturated and monounsaturated fats, such as olive and canola oil, are substituted for saturated fat (butter) in your diet.

- Cholesterol and saturated fats are found in animal foods. It is therefore wise to decrease your intake of foods such as high-fat red meats, high-fat dairy products, and egg yolks (eat no more than 4 egg yolks per week)
- Avoid trans fats (partially hydrogenated oils) which are found in many processed foods.
- Choose healthy fats from fatty fish (such as salmon, mackerel, sardines and tuna), walnuts, Flaxseed, Chia seed, canola and olive oil. Eat 1-2 servings of fatty fish per week.
- Choose foods that are baked, grilled, steamed, broiled, or boiled rather than deep fried.
- Read food labels and choose foods that contain:

  less than 5 g total fat per serving

  0 – 3 grams saturated and trans fat per serving

  less than 300 mg sodium per serving

  5 g or more of fiber per serving

Restrict Sodium (Salt) Intake

Dietary sodium (salt) can cause you to retain fluid and contributes to swelling and high blood pressure. Read nutrition labels to be aware of the sodium content of foods. Choose foods that contain less than 300 mg sodium per serving. When possible, choose fresh or frozen (frozen beans or vegetables without sauces) instead of canned. Limit your total sodium intake to 2000-3000 mg per day.

Avoid these foods that are high in sodium:

- Cured, smoked and canned meats
- Most cheeses (Swiss cheese is lowest in sodium) especially processed cheese
- Canned soups, vegetables and sauces
- Fast food and pre-packaged convenience foods like frozen meals, pizzas and instant noodles
- Chips, crackers and foods with additional sauces

Increase the Amount of Calcium in Your Diet

Osteoporosis (low bone mass) is a common consequence of long-term steroid use. Dairy products or dairy alternatives such as soy are the main sources of calcium and should be included in your diet to help keep bones strong. Aim for 1200-1500 mg/day of calcium + vitamin D from your diet and/or a calcium supplement.

Prevent Food-Drug Interactions

Avoid the following due to their interaction with a group of immunosuppression medications (calcineurin inhibitors):

Foods, Herbs, and Sodas to Avoid

These interact with immunosuppression medications.

Fruits	**Herbal Products**	**Sodas**
Grapefruit or grape fruit juice	St. John's Wort	Fresca
Pomelo	Camomile	Sun Drop
Serville orange	Dandelion	Sunny Delight
Star fruit	Guggul	Squirt
	Goldenseal	
	Peppermint	

Follow Food Safety Guidelines

Keep food safe from bacteria by implementing the following:

- Keep your hands and surfaces clean. Wash them often.
- Separate raw meat, poultry, seafood and eggs from other foods.
- Buy only pasteurized milk, soft cheeses made with pasteurized milk, and pasteurized juices.
- Check “Sell-By” date and “Use-By” date. Do not use expired products.
- Cook foods to the proper temperatures. See USDA-recommended safe minimum internal temperature in the USDA handout Food Safety for Transplant Recipients:

http://www.fda.gov/downloads/Food/FoodborneIllnessContaminants/UCM312793.pdf

- Keep cold foods chilled. Refrigerate them promptly.
- Thaw food in the refrigerator. Never thaw at room temperature.
- Keep your refrigerator temperature less than or equal to 40°F. Keep freezer less than or equal to 0°F.

Food Safety Tips		
Food Groups	**Recommended Foods**	**Foods Not Recommended**
Vegetables	Thoroughly washed fresh vegetables	Unwashed fresh vegetables
Fruits	Thoroughly washed fresh fruits	Unwashed fresh fruits Unpasteurized juices including apple cider
Milk and Milk Products	Pasteurized milk Hard cheese, processed and pasteurized cheeses (cheddar, mozzarella, cream cheese)	Unpasteurized milk Soft cheeses made from unpasteurized milk (brie, feta, camembert, blue cheese, Queso fresco)
Eggs	Fully cooked eggs with firm yolk and whites If recipe calls for raw eggs, purchase pasteurized, refrigerated liquid eggs or pasteurized eggs such as Safest Choice™ Pasteurized eggs can be found at Harris Teeter, Kroger and Lowes Foods. Look for the red circle P stamped on the shell. Buy shell eggs from the refrigerated section of grocery store	Soft-boiled or "over-easy" eggs, as the yolks are not fully cooked Foods that contain unpasteurized raw eggs
Other	Cooked sprouts Pasteurized honey Commercially packaged and shelf-stable salsa (in the jar, in the dry section of grocery store) Nuts that are found in baked goods, or shelf-stable roasted nuts that are commercially processed	Raw alfalfa and bean sprouts Unpasteurized honey Fresh salsa in the refrigerator section of grocery store Nuts that are bought in their shell Outdated or expired foods Spoiled or decayed food, fruits, or vegetables

Which Foods Are Good and Good For Me?

FOOD GROUP	FOODS TO CHOOSE	FOODS TO DECREASE
Dairy Products	Skim milk, ½% to 1% low-fat milk nonfat dried milk; buttermilk (from skim milk), low- fat yogurt; low-fat cottage, farmer's, mozzarella cheese, (cheeses made with 5 gm of fat or less per serving), frozen low-fat yogurt sherbet, sorbet, ice milk.	2% low-fat milk, whole milk buttermilk (from whole milk); condensed milk; evaporated milk; cream; half/half; natural cheeses (blue, Colby, cheddar, Swiss, Camembert)
Meat, Poultry, Fish & Alternative Protein Sources	Lean cuts of beef, pork, lamb, wild game. Fresh/frozen fish, scallops, clams, crab. If watching cholesterol, limit shrimp and lobster intake to 3 oz/week. Canned tuna or salmon packed in water. Fresh or frozen chicken or turkey (without the skin). Extra lean ground meat. Beans. Tofu.	Heavily marbled or fatty meats, bacon, sausage, ham, duck, goose. Virginia-cured style. Bologna, salami, pastrami, pepperoni, corned beef, hot dogs (made from turkey, chicken, beef), organ meats (heart, kidney, liver, brains, chitterlings). Fried chicken or fried fish.
Eggs	Egg whites, cholesterol free eggs. 2 egg whites can be substituted for 1 whole egg in whole egg used in most recipes	Egg yolks – 4 or fewer per week including cooking.
Fruits	Fresh, frozen, canned in light syrup. Dried fruit. Fruit juices.	Coconut – high in saturated fat.
Vegetables	Fresh, frozen, canned with low salt (no added meat/meat fat). Starchy vegetables, peas, corn, lima beans. Potatoes should be considered a bread. No-added salt tomatoes, tomato sauce, paste, vegetable juice.	Vegetables prepared in butter, cream, cheese sauces, gravies. Fried vegetables prepared with fat back, bacon grease. Olives, pickles, relishes.
Nuts/Seeds	All seeds. Nuts and nut butters (1-3 Tbsp. per day)	Coconut. Cashew and macadamia nuts.
Beverages	Tea, coffee, diet soft drinks, cocoa made with skim or 1% low-fat milk. Water. Fruit juices.	Cocoa made with whole milk. Soft drinks. Alcoholic beverages. High-caffeine beverages.
Soups	Low-fat soups, such as vegetable broth, nonfat bouillon, chicken noodle, tomato-based seafood chowders, minestrone, onion, split	Cream soups, soups made with whole milk, cream or cheese.

	pea, tomato, vegetarian vegetable. Mix with water, skim or low fat (1 1/2 % or 1%) milk.	
Breads & Cereals & Grains **Breads & Cereals & Grains (con't)**	Whole grain, raisin, rye, white, French, Italian, pumpernickel bread. English muffins, bagels (if made without eggs), rolls (hamburger/hot dog buns). Melba toast, bread sticks, graham crackers, Zwieback, low-fat, low-salt crackers. Homemade biscuits, muffins, corn bread. Waffles and pancakes made with "approved" liquid: Vegetable oil, milk, egg products. Hot/cold cereals, except those that contain coconut or coconut oil. Pasta (if made with eggs). Angel food cake.	Commercially made biscuits, muffins, corn bread, pancakes, waffles, coffee cakes, pies, doughnuts, sweet rolls, croissants. Commercial mixes containing dried eggs and whole milk. Cereals containing coconut. Cheese crackers, butter type crackers. Egg noodles. Macaroni and cheese package mixes. (Any commercially prepared item that contains more than 500 mg of sodium per serving.)
Fats & Oils No more than 5 servings per day 1 serving = 1 tsp. oil or 1 tsp. margarine or 1 tsp. mayonnaise	Liquid vegetable oil, such as safflower, sunflower, corn, soybean, cottonseed, sesame, canola (Puritan), peanut, olive. Soft margarine, mayonnaise, salad dressings made from one of the above oils.	Butter, lard, bacon drippings, ham hock, salt, pork, fat back, meat fat, or gravies. Solid shortening. Salad dressings made from blue cheese or sour cream. Coconut oil, palm oil, palm kernel.
Snacks	Unbuttered popcorn (air-popped or popped in unsaturated oils), pretzels, rice cakes, breadsticks, low-fat yogurt, vegetable sticks, fresh fruit.	Snacks containing cheese, buttered popcorn, microwave popcorn containing palm or coconut oil, potato chips, and deep-fried snack foods, granola and granola bars, yogurt-covered snacks.
Desserts & Sweets	Ice milk, frozen low-fat yogurt, sherbet, angel food cake, fruit juice bars, desserts and cookies made with "allowed" ingredients: Sugar, honey, jams, jelly, preserves, syrups, carob, cocoa powder. Sugar substitutes and products made with sugar replacements. Puddings made from	Cream pies and any dessert containing butter, chocolate or coconut, ice cream, whipped toppings (Cool Whip/Dream Whip), whipped cream, chocolate candy.

	skim milk.	
Miscellaneous	Vinegar, spices, herbs, Tabasco sauce, catsup, mustard, soy sauce, Worcestershire sauce, lemon juice, pepper, barbecue sauce, vanilla and other flavorings or essences	

Eating Out

Most people make better food choices when eating at home. We recognize that many individuals have a lifestyle that makes it difficult to eat many home-prepared meals. Some non-home prepared meals are purchased at take-out sections of supermarkets or restaurants. Other options include food delivery, and, of course, eating out. There are better and worse choices that can be made if it is not possible to eat food prepared in the home. Also, the following Web sites provide important dietary information for nutrient and calorie management as well as making good eating choices:

http://www.choosemyplate.gov/

http://www.healthydiningfinder.com/

http://www.eatright.org

http://www.restaurant.org/Home

http://www.heart.org

Successful Restaurant Eating

Most people have a lifestyle that includes some eating away from home. Many people find it easy to cut back on the fat in their diet while eating at home, but difficult when dining away from home. Here are some strategies for controlling fat in your diet while dining out.

- Decrease frequency of dining out.
- Avoid fried foods.
- Be assertive. When in doubt, ask how the food is prepared. You're the customer and should have the final say in what you eat. Many restaurants often appreciate your interest and are willing to make small changes in preparation methods.
- Have sauces and salad dressings served on the side. This way, you can control the portion size of these high-fat ingredients.
- Remember, there is nothing wrong with removing the skin from poultry or cutting the fat off a steak or chop. If you ask for this to be done before cooking, you'll save even more fat and calories.
- Choose foods that are poached, steamed, broiled, or roasted. Avoid dishes with the words: creamed, pan-fried, sautéed, buttery, cheesy, or crispy in their description.

- Ask what's in the salad. Many restaurants add cheese, bacon, or butter-fried croutons. Avoid them. In addition, ask for the dressing to be served on the side. If you like creamy dressings, mix them with a little vinegar to make a strong taste go a long way without adding the fat. Many restaurants now have low-fat or nonfat salad dressings.
- When in doubt, eat half as much and leave half the fat and calories behind.
- When dining with friends, enlist their support. Remove high-fat freebies, such as chips, from the table and focus on the company and conversation. Ask for fresh vegetables with salsa for a low-fat hors d'oeuvre.
- In fast food restaurants, don't rely on the fish and chicken as being low-fat choices if they are deep-fried in saturated vegetable fat. Choose a broiled hamburger without cheese, roast beef sandwich without mayonnaise, salad with low-fat salad dressing, or a grilled chicken sandwich.
- Submarine shops and delicatessens can be a good location for low-fat choices. In most cases, your sandwich is made to order. Choose turkey or lean beef with lettuce and tomato, instead of salami or pastrami. Come prepared with your own supply of low-fat condiments. Low-fat salad dressing fits nicely in a drug store traveling shampoo container.

CONTACTING THE HEART TRANSPLANT TEAM

The members of the Heart Transplant Team want to help you achieve the best outcome possible after your heart transplant. You are an important part of that successful outcome. Please provide updated information about changes in address, telephone numbers, medical providers, pharmacies and lab providers. Request that your local medical provider send summaries of your office visits to the Heart Transplant Program, and let us know where to send summaries of your follow-up clinic visits with us. Do not hesitate to ask team members questions you may have.

All post-heart transplant communication should come through the Heart Transplant Office. Office hours are Monday–Friday, 8 am–4:30 pm. Calls are generally returned within one business day unless you state your question is urgent, and requires a response that day. After hours, a recorded message will remind you how to page a coordinator for urgent questions. You may also leave a voice message at any time of the day or night if your question is not urgent. If your call is not returned by the next business day, please call again since record of the call may have been accidentally lost.

Requests for personal medical records should be made to the DUH Medical Records Office directly. The contact phone number is 919-684-6831. Please note there is a copying fee for the records.

Requests for medication refills must be made before you run out of medication! Remember if the medication is to be refilled through a mail order pharmacy it can take up to two weeks to get your medication. Don't run short! Call early!

Communication

The Heart Transplant Office address and phone numbers are:

Duke University Medical Center
Heart Transplant Office
Box 102347
Durham, NC 27710

Phone: 800-249-5864
Phone: 919-613-7777

For Fed-Ex or UPS delivery, address please contact our office.

After Hours Communication

For **urgent** questions or needs after business hours, you may page the heart transplant coordinator by calling 1-919-684-8111 (Duke Operator). Ask for the heart transplant coordinator on call.

HEART TRANSPLANT PROGRAM STAFF MEMBERS

Secretary

La Quinta Thornton

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William Mason

Nurse Clinician

Amy Miller, RN

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NOTES AND QUESTIONS