

PRE-OP LUNG TRANSPLANT PATIENT GUIDE



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INTRODUCTION

Thank you for choosing UK HealthCare as your medical provider. We are passionate about improving the quality of life for those with end-stage lung disease.

The purpose of this guide is to provide you and your family with a better understanding of the transplant process and prepare you for the journey ahead.

In the coming days and weeks, you will meet members of our team and learn the benefits and risks of lung transplant. Our goal is to provide all the information you need to decide if a lung transplant is the right choice for you.



USING THIS GUIDE

We want you and your family to understand the transplant process. The more you know, the better prepared you will be. We designed this guide to help you get ready. Please read it to learn what to expect and what steps you can take.

You will read about evaluation, surgery and life after transplant. If you become a transplant candidate, we will give you a more detailed manual that will explain your medicines, clinic visits and tests you will have after transplant.

The education process begins here and never ends. As you read, write down the questions you have in the back of this guide. When you have a question, don't be afraid to ask. We are happy to go over the details until you feel comfortable. We know that you

will receive a lot of information, so if you need help, we are here 24 hours a day, 365 days a year.

We are excited about the chance that you will join our UK HealthCare transplant family. Once you become a candidate, you will be part of our transplant team, along with your doctors, nurses and other health care providers.

We also encourage you and your caregivers to attend the transplant support group. There are more details about the group later in this guide.

We promise to work as hard as we can to make this a smooth process. You can help by keeping all your appointments and asking questions.



YOUR TRANSPLANT TEAM

Transplant coordinators

The coordinator is a registered nurse. This nurse will be your main contact person. Throughout the process, the coordinator will work with you and the transplant team. Before transplant, the coordinator will teach you and your family what to expect. If you are a transplant candidate, the coordinator will add you to the transplant list. After transplant, you will have a new coordinator, who will teach you how to care for yourself going forward.

Transplant surgeon

This doctor will perform your transplant. The surgeon will help decide if a transplant is right for you. The surgeon will meet with you before your transplant and meet with your family afterwards. While you are in the hospital, the surgeon will help manage your care.

Transplant pulmonologist

The pulmonologist has special training in treating lung disease. This doctor will help decide if transplant is the best treatment for you. The pulmonologist will help care for you during your hospital stay. After transplant, the pulmonologist will manage your care. You will see the pulmonologist at all your Transplant Clinic visits.

Advanced practice providers

Advanced practice providers, such as nurse practitioners and physician assistants, work with the other transplant doctors to care for you during your hospital stay.

Social worker

A social worker will be here to help you throughout the transplant process. You will meet the social worker during your evaluation. The social worker will see what social, mental and financial needs you may have. Your mental health plays a significant role in the transplant process. If you feel stressed or afraid, the social worker may be able to help, or they

can refer you to a transplant psychiatrist for help. After transplant, the social worker will help you find resources and support.

Financial coordinator

After referral, the financial coordinator will check your insurance benefits and will let you know if there are steps you need to take. The coordinator will tell you what you should expect to pay out-of-pocket. If you have problems with your insurance or with hospital billing, the coordinator will help. If you have a change in your insurance during the process, you must let the coordinator know.

Transplant pharmacist

The transplant pharmacist will make sure you are on the right medicines and that they work well together. The pharmacist will meet with you before and after transplant to discuss your medicines.

Transplant dietitian

Eating right is key to a successful transplant. The dietitian will make sure the foods you eat have the vitamins and minerals you will need. During your evaluation, the dietitian will check your weight, lab results and eating habits. The dietitian will create an eating plan of care just for you, which will help you get the most out of your transplant. In the hospital after transplant, the dietitian will make sure you get the nutrition you need and will teach you how to eat healthy before you go home.

HEALTH PROBLEMS THAT LEAD TO LUNG TRANSPLANT

Each year, more than 2,000 people receive lung transplants. Some common health problems that lead to transplant include:

- Alpha-one-antitrypsin deficiency
- Bronchiectasis
- Cystic fibrosis
- Emphysema due to tobacco smoking
- Eosinophilic granuloma
- Lymphangioleiomyomatosis
- Pulmonary fibrosis
- Pulmonary hypertension
- Sarcoidosis

What are the available lung transplant options?

Single-lung or double-lung

We can transplant one or both lungs. This decision will be based on a thorough review of your past medical history.

Heart-lung

Some patients need to have their lungs and heart replaced. This is often because they have damage to these organs that cannot be fixed.

Pediatric lung

Some children need a lung transplant. This may be caused by:

- Cystic fibrosis with end-stage lung disease
- Pulmonary fibrosis
- Pulmonary hypertension

THE LUNG TRANSPLANT PROCESS

A lung transplant is not just a surgery. It's a process with several steps, including evaluation, a waiting period, a hospital stay for surgery and follow-up care afterward. It is important for you and your family to understand each step in the process.

Getting started

The process starts when your doctor refers you to us. We will then schedule a visit for you at the Transplant Clinic. You will meet with the coordinator and at least one transplant doctor. After this initial visit, the team will meet to decide if you should have an evaluation.

The evaluation process

To be a candidate for lung transplant, you must have a transplant evaluation. You will undergo many tests and exams. These will help us make sure transplant is the best treatment for you. They will also tell us if transplant could make your other health problems worse.

You will need to come to UK HealthCare for three days of outpatient testing, which includes tests, consults and labs. We typically expect patients to stay in town for those three days of evaluation testing, so you will need to arrange for oxygen if you require it. Your transplant coordinator will give you a list of tests that will be scheduled here at UK HealthCare during your stay, with the exception of general health maintenance exams, such as a colonoscopy for individuals older than 50 years of age; and for women, a Pap smear and mammogram.

You will need to get these with the help of your other doctors.

Here are some of the tests you will have during your three-day stay:

- Arterial lower extremity duplex
- Barium swallow
- Bone mineral density scan
- Cerebrovascular duplex
- Chest X-ray
- CT of abdomen and pelvis
- CT of chest
- Diaphragm fluoroscopy (sniff test)
- Echocardiogram (echo)
- Electrocardiogram (EKG)
- Hearth catheterization
- Mandible panorex
- Pulmonary function test
- Ventilation perfusion scan

During the evaluation, you will meet the pharmacist, social worker and dietitian on your transplant team. They will ask you for information and tell you more about transplant. To help you remember some of the people involved in your care, a list of transplant team members is provided with this guide. We also encourage you to add names of people you meet that are not on the list.



LUNG TRANSPLANT CANDIDACY

Conditions to be a candidate

You must meet these conditions to be considered for lung transplant:

- Transplant is an effective treatment for your condition.
- You have severe and progressive lung disease and medical treatment no longer helps.
- You accept the risks of transplant and medical treatment after.
- Your body can handle the transplant and medical treatment after.
- You do not smoke or use any type of nicotine and you do not abuse alcohol or drugs.

If you meet these conditions, the team may still find that you are not a candidate. This may happen if transplant or transplant medicines will make your other health problems worse.

How we decide

We have a weekly meeting that consists of the following hospital personnel: doctors, surgeons, nurse coordinators, nurse practitioners, financial

coordinators, social workers, dietitians, pharmacists, laboratory staff and physical therapists. At this weekly meeting, we will discuss your need for lung transplant, review your evaluation testing and discuss your options.

We will also talk about any problems that could make transplant too risky. We may need to run more tests before we can decide. If so, we will arrange for these tests as quickly as we can.

How you will find out

Once we decide your plan of care, the transplant coordinator will call you. Here are the possible results:

- You are a candidate. The transplant coordinator will explain the listing process. You will get a letter to confirm you are on the list.
- You are not a candidate. The coordinator will explain why and tell you your options.
- You need more tests. The coordinator will order those tests. Based on the results, the team will make a decision.

WAITING LIST

We place transplant candidates on a national waiting list. The United Network for Organ Sharing (UNOS) keeps this list. It is a fair and organized process for transplant patients. For more information, go to unos.org. There is a list for each transplant center, and each center decides who to accept as candidates. It may be helpful to be on the list at more than one transplant center.

Matching donors and recipients

Donor lungs are assigned based on Lung Allocation Scores. For each donor, there will be a list of potential recipients. If the donor is local, Kentucky Organ Donor Affiliates (KODA) will make the list. There is a system that makes sure all transplant centers follow the same rules. A patient's listing is based on waiting time and how well the patient and donor match.

Waiting list status

Active: If you are on the active waiting list, your transplant team can get a call with a new organ for you at any time. Your coordinator will tell you about average wait times.

Inactive: If you are inactive on the waiting list, you are still listed for transplant and gaining waiting time. But the transplant team will not get any organ offers for you. There are many reasons you may be inactive. The most common reasons are:

- You are too far from the transplant center.
- You are using tobacco or drugs your doctor did not order.
- You need to lose weight for surgery.
- When your status changes, your transplant coordinator will let you know.

Being on the waiting list may be the toughest part of the process. It is normal to wonder if you will get your new lung in time. Follow these steps to manage your time on the waiting list:

Stay healthy at home

- Talk about your feelings with family and friends.
- Eat healthy meals.
- Exercise as much as you can.
- Take all medicines as ordered.

Keep in touch with the transplant team

- Talk with the transplant team about your health. Tell the team about new medicines, hospital stays or if you feel worse.
- Always be near a phone.
- Tell your coordinator if you will be traveling more than five hours from the transplant center, as you may be inactivated from the waiting list until you return from your trip.
- Go to all Transplant Clinic appointments.
- The transplant coordinator, social worker and other team members are here to help. Call us any time during the waiting period.
- Meet with the transplant psychiatrist or another psychiatrist. Discuss ways to manage anxiety or depression while waiting.

Prepare financially

- Organize fundraisers to help pay for the transplant.
- If you can, save money for costs after transplant.

Plan for your hospital stay

- Keep a packed suitcase ready the day of your surgery.
- Think about what clothes and items you would like to have in the hospital. You may want to pack books, magazines or a music player.
- Plan the route you will use when coming to the hospital.
- Know where your family plans to stay when they visit the hospital.



PREPARING FOR YOUR TRANSPLANT

As soon as there is a lung for you, the transplant coordinator will call you. Once you get this call, come to the hospital as soon as you can. After we call you, do not eat or drink anything. When you get to the hospital, go straight to the registration desk. A person at the desk will tell us you are here.

Getting ready for surgery

Before surgery, members of your team will check on you, including your nurse, anesthesiologist and surgeon. For your safety, we will do many tests and procedures before surgery, including:

- Chest X-ray, electrocardiogram (EKG) and urinalysis.
- Blood samples from a vein and artery in your arm.
- Place an IV in your arm or hand.
- Vital signs: blood pressure, pulse and temperature.

We will ask you to sign a consent form. It explains the possible risks involved. When you sign it, you give the medical team permission to do the transplant. Your family can stay with you for most of the time before surgery. Once you go to the operating room (OR), we will take your family to a waiting room.

In the OR

In the OR, doctors and nurses will prepare you for surgery. The anesthesiologist will give you medicines to help you relax and sleep. The start time will depend on when we get the lung from the donor team. The donor team is a group of doctors and specialists who travel to get the lung.

The donor team keeps us informed about the progress. Once the donor team decides that the new lung is right for you, they will tell our team. The donor team will also tell us if the lung will not work for you. In that case, we will have to cancel your transplant at this time.

player. Plan the route you will use when you come to the hospital. Know where your family plans to stay when they visit the hospital. The more prepared you are, the less stress you will have.

Right after surgery

If the lung is a match for you, you will have the transplant. After that, you will recover in the Cardiothoracic and Vascular Intensive Care Unit (CTV-ICU).

STAYING IN THE HOSPITAL

The CTV-ICU phase

After surgery, you will be placed in a private room in the Cardiothoracic and Vascular Intensive Care Unit, or CTV-ICU. Here, your lung transplant team will follow you very closely during this critical initial healing period. The nurses and doctors will be checking your vital signs every hour, and you will have frequent labs drawn and a chest X-ray done every day. This type of close monitoring is essential for your team to see how you are progressing and healing.

The acute care phase

As you heal, we will move you to a private room on a less acute floor, where you will be attached to fewer monitoring machines. During this phase of your hospital stay, we will expect you to participate in more physical therapy and education in preparation for your discharge.

You should limit the number of visitors that come to your hospital room to reduce your risk for infections. If your loved ones are sick, please ask them to refrain from visiting you in the hospital at this time. Make sure to wash your hands frequently and wear a mask when you leave your hospital room.

There will be many things for you and your family to do and learn. We will try to educate you as much as we can prior to your discharge. You will learn about your medications, how to take your vitals and any new equipment that you will be using when you leave the hospital.

Many members of your transplant team will be involved in your care at this time. You will meet with doctors, nurses, respiratory therapists, physical therapists, dietitians and social workers. Do not be afraid to ask us any questions. Please speak up if you do not understand something.

Immunosuppressant therapy

Your body will want to treat your new lung as foreign, and your immune system will try to attack it. This could cause your body to reject the lung. To avoid this, you will need to take special medicines to suppress your immune system.

You will need to take some of these medicines each day for the rest of your life. Because these medicines suppress your immune system, they make it easier for you to get infections. We recommend that you stay away from people who are ill and practice thorough hand washing.



GOING HOME

You will need to learn to care for yourself at home. We will teach you what to do and make sure you can do it on your own.

Taking medicines

The pharmacist and coordinator will teach you about your medicines, including:

- When to take them.
- How much to take.
- Potential side effects.

During your last few days in the hospital, you should be ready to take all of your medicines on your own.

Exercising

Physical therapists will help you exercise while in the hospital. As you get ready to go home, a therapist will review your daily exercise program. The therapist will make sure you exercise the right way and set you up for outpatient physical therapy locally, once you are discharged.

Eating right

Before going home, you will meet with the transplant dietitian who will teach you the basics of eating right and how to choose the right foods. You and your family can ask any questions you have about nutrition.

Taking vital signs

Your transplant coordinator will teach you how to check and record your vital signs. These include your temperature, pulse, blood pressure and peak flow.

Other needs

- The coordinator will help you arrange clinic visits and order prescriptions from the pharmacy.
- For a couple weeks after transplant, you must stay within 30 minutes of Lexington. The social worker and coordinator can help arrange local housing if needed.
- If you have other needs after you go home, a member of the transplant team is only a phone call away.

POSSIBLE COMPLICATIONS

Rejection

This means your immune system is attacking your new lung, which happens because your body knows it is foreign. Rejection should be expected. We can treat it with medication if caught early. This is why it is important to record your vitals and peak flow, as this information will help us catch rejection as early as possible.

To test for rejection, a doctor will do a bronchoscopy and take a biopsy. For the biopsy, we take a small piece of the lung tissue – about the size of a breadcrumb – and examine it under a microscope. You may also need other tests, such as chest X-rays, breathing tests, and sputum and blood samples.

For a few months after transplant, you will have regular biopsies. The coordinator will tell you the results and make any adjustments to your medicine or other changes.

Let your transplant nurse coordinator know if you experience coughing, shortness of breath, or temperature 100 degrees or greater after your transplant. These may be signs of rejection, and your transplant team needs to be notified as soon as possible.

Infection

You will be at greater risk for infection after transplant because the drugs you take to prevent rejection make it easier to get infection. The tests for infection include X-rays, sputum and blood tests, and urine tests.

To prevent infection in the hospital:

- Wash your hands.
- Stay in a private room.
- Limit your visitors.

- Wear a mask outside your hospital room and when being transported to another part of the hospital.
- We will check your temperature, blood oxygen and blood.

To prevent infection at home:

- Wash your hands.
- Avoid construction sites.
- Avoid gardening or any contact with soil.
- Do not change litter boxes or birdcages.
- Avoid crowds, crowded rooms and sick people.
- Check with your transplant team before getting flu shots or vaccines.
- Talk with your transplant team before having any dental work performed – including cleaning. You must have antibiotics before these procedures.
- Wear a mask when you are in the hospital or clinic.
- Check your heart rate, breathing, and blood pressure.
- Watch for coughing, sputum production, scratchy throat and changes in the color of your sputum.
- Check your temperature every day. Call if your temperature is above 99.5 degrees.

Call the nurse coordinator right away if you have any concerns, as it is important to learn about infection early. Once we are sure you are not having rejection, we can treat the infection with medicine.

Tumors and cancers

When taking immunosuppressants, you will have a greater risk for tumors and cancers. Your body's immune system naturally fights tumors and cancer cells, but the medicines you take after transplant may keep your body from doing this.



Skin cancer

This is the most common cancer in transplant patients. To prevent skin cancer, you should:

- Use sunscreen when out in the sun.
- Wear a broad-brimmed hat, long sleeves and pants to protect your skin.
- See a dermatologist every year. Have any suspicious growths removed.

Lymphoma

This is another type of cancer more common in transplant patients and occurs in approximately 3 percent of patients. Symptoms include fever, feeling tired, weight loss, poor appetite and sweating. If you feel these symptoms, please let us know immediately, so that we may run tests to see whether you have this type of cancer. As soon as we have confirmation of lymphoma, we will work closely with our oncologists to provide you with the best treatment plan.

Transplant patients should get regular health maintenance screenings as needed. These include mammograms, Pap smears, prostate exams and colonoscopies. You should see your primary care physician to schedule these.

MEDICATIONS

You will need to take medicines daily for the rest of your life. Here are some common medicines patients need after transplant.

Immunosuppressants

These medicines help prevent your body from rejecting the lung.

Steroids

You may take a steroid called Prednisone. You will be weaned to a low dose if there is no rejection.

Anti-infection

Transplant patients have a high risk of infection. Taking immunosuppressants causes this. You will need to take medicines that fight infections.

Anti-ulcer

These will help protect your stomach and bowels. Some of the other medicines you take can cause ulcers and an upset stomach.

TAKING CARE OF YOURSELF AT HOME

Taking medicines

- Talk to your transplant team before you start taking any new medicines.
- Talk to the team before you change the time or dose of any medicines.
- Do not run out of any of medicines. If you get your medicines from the Kentucky Clinic Pharmacy, please allow two to three days for delivery. You need to order medicines yourself. The Kentucky Clinic Pharmacy phone number is 859-323-5855.
- Never take aspirin or medicine that contains aspirin or ibuprofen – unless your transplant doctor orders it. These medicines irritate your stomach and can harm your kidneys. Many pain cold medicines have aspirin in them. Ask the pharmacist if you have questions. Use acetaminophen (Tylenol) only.

Exercise

- Follow an exercise plan.
- Walk at least two times a day.
- Stop if you are short of breath, feel dizzy or have pain.
- You may ride a bike or swim if you wish.
- Avoid lifting anything heavier than 10 pounds until your doctor says it is OK. For about eight weeks after surgery, you should lift up to five pounds to make your arms stronger. After that, you may increase the weight.
- Check your heart rate before and after you exercise for the first few weeks at home.

Ask the pharmacist if you have questions. Use acetaminophen (Tylenol) only.

Tracking important numbers

- Each morning and evening, check your heart rate, blood pressure and temperature. Call if your temperature is above 99.5 degrees.
- Check peak flow once a day.

Smoking

You must not smoke. Smoking can damage the lungs. This makes it easier for you to get a lung infection. Try to stay away from places where people smoke. If family members smoke, they must smoke outside your home. Lung infections can lead to death in someone taking immunosuppressive drugs.

Alcohol

You may drink an alcoholic beverage in moderation (one drink). Excessive alcohol with immunosuppressive drugs can cause liver damage.

Pets

- Avoid all birds and amphibious lizards.
- If you have cats, do not change the litter box.
- Dogs are OK.

SEXUALITY**Female patients:**

- You must have a Pap smear and a breast exam every year. Have a mammogram as recommended by your gynecologist.
- Any doctor may do these tests, but all reports must be sent to the transplant office.
- You must use some form of birth control. You should not get pregnant.

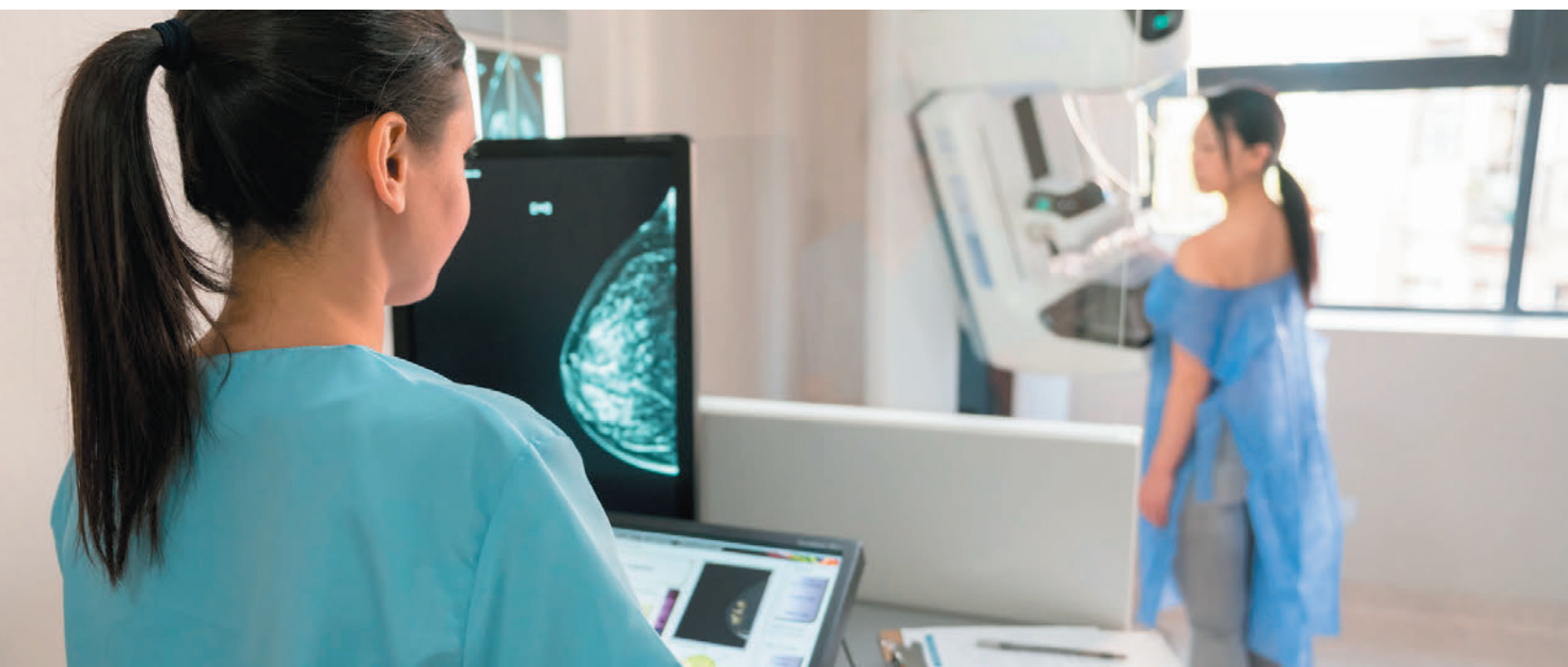
Male patients:

If you notice a change in your sexual ability, discuss it with us.

Cold sores

Herpes simplex virus causes cold sores. These sores look like tiny water blisters on the lip or face. Always tell us if you get a cold sore.

Diseases like chicken pox, measles, or mumps Tell us if you are exposed to any communicable disease you have not had before.



Shingles (herpes zoster)

Shingles appear as a rash or small water blisters. They are usually on the chest, back or hips, but they may be on other areas. The rash may or may not be painful. Your primary care physician may treat your shingles, but tell the transplant office, too. You may use any topical treatment or pain medicine.

Regular clinic visits

At first, you will see a doctor once a week and have labs drawn twice a week. This is a very important time in your healing. We will check labs, chest X-rays and pulmonary function tests. We will also see you as needed if you have any changes that might mean infection or rejection.

**DIET AND NUTRITION****Before transplant**

It is important that you start eating healthy, as it will help you heal better after transplant. Healing well means less time in the hospital and better quality of life. A registered dietitian will meet with you before transplant and will work closely with you to help you eat healthy during that period.

After transplant

Eating healthy will be one of your most important jobs after transplant, too. You should do all you can to have a healthy body weight. Weighing too much is bad for your new organ. Consuming too much salt, cholesterol and triglycerides can also cause problems. Your dietitian will work with you to design an eating plan you can follow. You will also learn how to eat heart-healthy foods at home. Eating heart-healthy foods is important to your health after transplant.

Gaining too much weight after transplant is bad for your health. It can cause your cholesterol, triglycerides, blood sugar, and blood pressure to go up. To avoid weight gain, you should cut back on simple sugars and concentrated sweets. This means you should limit table sugar, brown sugar, corn syrup, honey, sodas, rich desserts and candy. You should use fresh fruit as dessert most of the time, and save heavy desserts for special occasions. Your dietitian can help you learn to eat balanced meals.

Fats

You will need to change the kinds of fat you eat. Here are three ways to do this:

- Eat foods with a little less cholesterol.
- Eat less saturated fat.
- Use polyunsaturated and monounsaturated fats instead.

These changes are very important. Too much saturated fat is related to high cholesterol, which causes problems in your arteries. Also, some of the medicines you will take may cause higher cholesterol and weight gain, so you will have a greater risk of artery disease after transplant. The best way to fight it is to eat less fat and follow a heart-healthy diet.

Blood sugar

Some of the medicines you will take may cause high blood sugar. If your blood sugar is not under control, it can damage your new organ. This can lead to rejection, so it is very important you control your blood sugar. Right after transplant, you may need insulin through an IV. After a few days, you will get insulin shots as needed. If need insulin shots at home, a nurse will teach you how to:

- Use a glucometer.
- Draw up insulin in a syringe and give yourself a shot.
- Decide how much insulin you need.
- Care for yourself if your blood sugar is too low.

The nurse will watch you do these things before you go home so that you can keep your blood sugar under control. You should also:

- Eat a heart-healthy diet.
- Cut back on sweets and carbs.
- Exercise often.





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Section 1557 of the Affordable Care Act
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Si usted habla español, tiene a su disposición servicios de asistencia con el idioma sin costo alguno.

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