

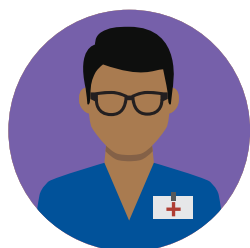
Your Liver Transplant at Duke



DukeHealth

Your Liver Transplant Team

Duke's Liver Transplant Program uses a team approach to care for you. We work together to give you the best possible care during the transplant process.



Transplant Coordinator is a nurse who will teach you about your liver disease and how to take care of yourself before and after liver transplant. The nurse coordinator is your best way to access assistance regarding new problems, questions, or results.



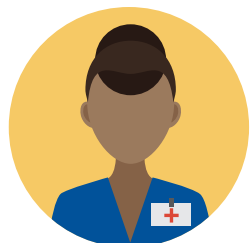
Transplant Surgeon is a doctor with special training to perform transplant surgery. Your surgeon will meet with you to talk about the liver transplant operation. They will review your surgical history and discuss the risks and benefits of the liver transplant. After the liver transplant surgery, they will visit you in the hospital and, for a short time, see you in clinic afterwards.



Hepatologist is a doctor with special training in managing liver disease and liver transplant. This doctor will review your medical history and decide what testing needs to be done for evaluation. They will provide ongoing medical care after your transplant.



You and Your Caregivers



Nurse Practitioners and Physician Assistants are providers with advanced training that help the transplant surgeons and hepatologists while you are in the hospital and clinic.



Medical Psychologist may talk with you about the stress or anxiety that can come with the transplant process. They can help you adjust to life after a liver transplant.



Social Worker is here to support you and your loved ones through the transplant process. They will make sure you have the support you may need. They offer help with places to stay locally around the time of transplant.

Welcome to the Duke Liver Transplant Program

If you have liver failure, liver transplant surgery may be in your future. At Duke, we are experts in liver transplant. We work with you to help you live a long life after your liver transplant. Our team of specialists work with you to manage your health during and long after your liver transplant surgery.

We understand that the road to transplant can be scary for you and your loved ones. The transplant team will be with you every step of the way. We want you to ask questions and be informed. Our goal is to provide excellent care. In order to do this, we include you and your loved ones as important members of the team. We view each patient as a unique person and will work with you to get you the best care possible.

This book will answer many of your questions about liver transplant. If you are unable to find the answer to a question you have in this booklet, please let a team member know and we will work to find the answers.

Additional Team Members

Financial Coordinator

Your financial coordinator works with you and your insurance plan. They will let you know what is and is not covered by your insurance. They may also advise you about fundraising methods if needed to pay for expenses not covered by your insurance.

Transplant Dietitian

Your dietitian is a nutritional expert who will recommend foods to improve your overall health before and after transplant.

Transplant Pharmacist

Your pharmacist will explain your medicines to you, their purpose, and how they interact with each other. They will make sure the medicines you are on are best for you.

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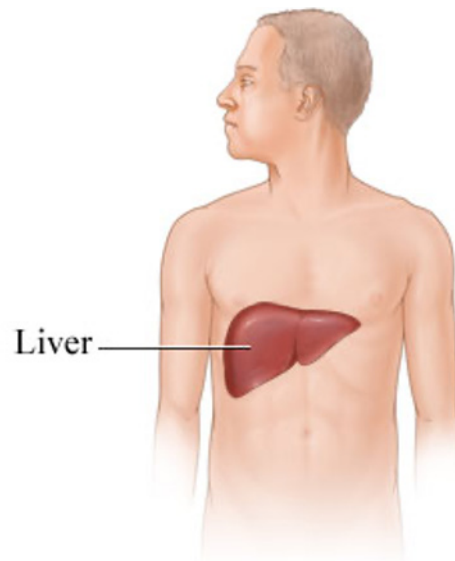
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About Liver Transplant

This section will help you to understand what the liver does and why transplant might be the best treatment option for your liver.

What Does the Liver Do?

Your liver is located just behind your ribs on the right side of your upper abdomen. A normal, healthy liver is tucked under the ribcage to help protect it. Your liver has many different jobs. It filters all of the blood from the intestines and helps break down nutrients. It helps to get rid of toxins and to keep the nutrients your body needs. Your liver also helps your blood clot and helps your body fight infection.



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What is Liver Failure?

Liver failure happens when your liver has too much scar tissue to repair itself. Scarring of the liver is called cirrhosis. Cirrhosis can happen for many different reasons and will cause the liver to not work properly. When the liver does not work the way it should, you may have:

- Fatigue (feeling very tired most of the time)
- Jaundice (your skin or eyes have a yellow color)
- Hepatic Encephalopathy (confusion, slow thinking, or irritability)
- Itching
- Edema (swelling in the legs and feet)
- Ascites (fluid in your abdomen)
- Low platelet count (you bleed easier)

What Are My Treatment Options?

When your liver has become so scarred that it cannot repair itself, you have end-stage liver disease (ESLD). With ESLD, your treatment options are limited. People who have ESLD must have a transplant to get better. Not everyone who needs a transplant can get one. The reasons will be discussed later.

How Long Will My Transplanted Liver Last?

There is no way to tell exactly how long your liver will last. In the United States, 3 out of every 4 people who have a liver transplant are still living 5 years after the transplant. The better you take care of your liver, the longer it will last. Many things can impact how long your transplanted liver will last, such as the cause of your liver disease. Ways you can help your transplanted liver last longer are:

- Taking your medicines as prescribed
- Keeping your visits with your transplant team, including getting your blood drawn
- Having a healthy lifestyle, including diet and exercise

Liver Transplant and the Immune System

The immune system monitors everything in your body. It keeps track of what does and does not belong and fights things that try to make you sick. All cells have unique proteins on them called antigens. Antigens are like labels. They help the immune system identify “friend” or “enemy.” When the immune system finds an antigen it does not recognize, it labels it “enemy.” This label tells the other immune cells (antibodies) to attack that cell so it does not make you sick.

After getting a liver transplant, your immune system does not recognize the new liver as “friend.” It will try to label it as “enemy” and have antibodies attack it. This will cause rejection of the new liver. We put you on medicines after the transplant to help prevent your body from labeling your liver as an “enemy.” These medicines are called immunosuppressants. You will be on them for the rest of your life.

What is a Living Donor Transplant?

Most people get a liver transplant from a deceased donor. This means that the liver comes from someone who has died. Some patients may be able to get a living donor transplant. In living donor transplant, the liver comes from someone who is a living person. This person is called a donor. You are called the recipient. You will get a piece of the donor's liver and a piece will be left in the donor. Both pieces of the liver will grow back to full size in about 6 weeks. A living donor can be a loved one, friend, or sometimes a stranger.

Living donors complete an evaluation to make sure they can safely donate a piece of their liver. They will have tests and meet with providers to make sure they are healthy enough to donate. They must be 18 years of age or older. Ask your surgeon if you would be able to get a living donor transplant.

Once you are on the liver transplant waitlist, the living donor team will help your donor through this process. Anyone interested in being a living donor should call the Duke Living Donor Transplant Center at 919-613-7777 to speak with the program specialist.

After approval of both the donor and recipient, your living donor transplant surgery is scheduled. The benefits to a living donor transplant include:

- Less time spent waiting for a new liver
- Surgery can be planned
- Getting transplanted before you get sicker

Steps to Liver Transplant Surgery

This section of the book will guide you through the steps of the transplant process leading up to transplant surgery.



Evaluation > The UNOS waitlist > Getting the call

Evaluation

Your transplant team will need to gather a lot of information to decide if a liver transplant is the best treatment for you. You and your loved ones will meet with members of the transplant team for a complete medical, psychosocial, and financial evaluation. You will also have many tests based on your individual needs.

What can you do to prepare?

Make sure you are up to date on your preventative health care screenings. These can include:

- Colonoscopy if you are over 50
- PAP if you are a woman
- Mammogram if you are a woman over 40

What to Bring

In order to develop a transplant plan that is right for you, you may have to visit Duke a few times and have many appointments in one day. It is important that you arrive on time to make sure you get the time you need at each visit. Remember to bring these items to each visit:

- Insurance card
- Photo ID
- Insurance card
- Immunization record
- List of current medicines
- List of any questions you may have
- Snacks and water

Imaging Studies

Every person is unique inside and out. Your transplant team will use imaging studies to help them learn your differences and find out if transplant is a safe option for you. Your imaging is ordered based on your diagnosis and medical history. These tests may include:

- X-ray or CT to study the chest
- MRI of the liver
- CT of the abdomen to look at the veins and arteries
- EKG and echocardiogram to study the heart
- Lung function testing

Infection Screening

Your transplant team will also want to learn about your immune system. After transplant surgery, you will take medicines that weaken your immune system. These medicines prevent the immune system from attacking your new liver. They also make it harder for your immune system to fight infections. It is important that you do not have any active infection when being transplanted.

Your body is not able to fight off the infection because of the medicines and you can become very sick. Your transplant team will screen you for some infections while you are in evaluation. Some of the infections that the team looks for are:

- CMV (Cytomegalovirus)
- HIV (Human Immunodeficiency Virus)
- TB (Tuberculosis)
- Hepatitis
- Syphilis

Dental Exam

You will need dental clearance before having transplant surgery. If you do not have a dentist, you will need to see one before you can be placed on the liver transplant waitlist. Your dentist will need to sign a form saying that you do not have any infection in your mouth that could make you sick. It is common to need to have teeth pulled prior to transplant. If your dentist would like to do this, please have them contact your transplant coordinator at 919-613-7777.

Selection Guidelines

Depending on your unique medical history, you may need to visit with other specialists. You may also need more tests or blood work done.

In addition to your test results, the team also uses the below guidelines to decide if you are a good transplant candidate:

Good transplant candidate	Transplant may not be right for you at this time
You have a reason for transplant including metabolic disease, tumors, or end-stage liver disease. You cannot be treated with other medicines or another surgery.	History of cancer within the last 2 years, unless approved by the transplant team and other specialists
You have expressed interest in transplant.	Body mass index (BMI) more than 40
You are able to pay for expenses that your insurance does not cover. These can include medicines, housing, procedures, and testing after transplant.	Weakness or frailty
You have a stable and reliable social support system. This includes dependable transportation and someone to come with you to every transplant appointment.	Active substance abuse
You can travel to Duke University Hospital in less than 6 hours.	Continued non-compliance with medicines or medical recommendations
You are able to live within 1 hour of Duke for up to 3 months after your transplant surgery.	Severe restrictive or obstructive lung disease
You must not drink, use tobacco products, or use illegal drugs. If you have a history of substance abuse, you must have counseling.	Active infection
	Medical or psychosocial risk factor(s) that make transplant surgery unsafe

The Decision

After the team has all of your information from the evaluation, the Selection Committee will meet to discuss if transplant would be the best option for you.

The committee can make one of the decisions below:



Suitable candidate

The committee thinks liver transplant is a good option for you and would like to move forward with the transplant process.



Further workup needed

The committee thinks there is more to learn about you before they can decide if liver transplant is the best option for you. They will need you to see more specialists or have more tests before making a decision.



Not a suitable candidate

The committee does not think that liver transplant is the best option for you at this time.

The transplant coordinator will share the committee's decision with you.

If the committee decides you are a suitable candidate, your financial coordinator will work with your health insurance to get approval for the liver transplant surgery. Once approved, you will need to get blood drawn and then you will be placed on the UNOS national waiting list for liver transplantation.

The UNOS Waiting List

What is UNOS?

UNOS stands for the United Network for Organ Sharing. It is the organization that manages deceased donor organs for transplant. Once approved for transplant, you are placed on their waiting list while they search for the best liver match for you.

You can be either **active** or **inactive** on the waitlist. An **inactive** status means that you are not receiving organ offers, but will continue to gain wait time.

Active	Inactive
You can receive an organ offer at any time	<ul style="list-style-type: none">▪ Active illness or infection▪ Unclear caregiving plan▪ Traveling for an extended amount of time▪ Need to lose weight or get stronger

You can be removed from the waitlist if:

- Your health improves and you no longer need a transplant
- You become too sick
- Do not have caregiving plan that is approved by the committee

While you are on the waitlist, it is very important that you notify your coordinator with any of these changes:

- Medicines
- New or worsening symptoms
- Any illness needing medical care
- If you are seen in an emergency room or admitted to a hospital

While You Wait for Your Transplant

UNOS wait times are based on many things, including blood type, the size of the donor's liver, your size and MELD (Model for End-Stage Liver Disease) score. Your MELD score is based on the 4 blood tests:

- Kidney function (creatinine)
- Liver function (bilirubin)
- Clotting time (INR)
- Sodium level

These 4 lab results are put into a calculation and that gives us a number score between 6 and 40. A higher score means that your need for a liver transplant is greater. Your position on the waiting list changes based on your MELD score. The higher your MELD score, the higher you are on the liver transplant waitlist.

Model for End-Stage Liver Disease (MELD) Score



6

Lower score = Lower need

40

Higher score = Higher need

Your MELD score is based on the lab results from the four blood tests listed above.

You must have blood drawn to update your MELD score. How often you need blood drawn will depend on your MELD score. Your transplant coordinator will inform you of your score and when to have blood drawn again. You will also need to continue to see the liver transplant team. This includes clinic visits, blood tests, imaging, and visits with other specialists.

UNOS Multiple Listing

You do have the option to be listed at multiple transplant centers. You must have a complete transplant work-up and insurance approval at each center. Waiting time can vary from one transplant center to another depending on the number of active candidates on the list at that center.

Staying Healthy for Transplant

The healthier you are before surgery, the quicker your recovery will be. Here are some things you can do while waiting for your transplant to keep you as healthy as possible.

Exercise

The best thing you can do for yourself is walking. Ideally, we would like to have you walking at least 30 minutes each day. If you cannot do that, start slowly and work up to it. Start with 5 minutes a few times each day and slowly build every day.

Use the camera on your iPhone or QR Code reader on your Android phone to access a short video.

How to Do Chair Push Ups (video)

Chair push-ups can strengthen your arm muscles.



How to Do the Long Arc Quad Exercises (video)

Strengthen your thigh muscles with the long-arc quad exercise.



Diet: Limit Your Sodium (Salt)

Eating too much sodium will make your body hold on to fluid. This can make your swelling worse. The goal is to get less than 2000 mg of sodium a day.

You can limit the amount of sodium you eat by:

- Not using your saltshaker. Instead, use herbs and seasonings that do not contain salt.
- Limiting the number of times you eat out at fast food and restaurants. Instead, cook meals at home where you can control the amount of salt you use.

Reading food labels:

- Look for foods with less than 140 mg of sodium per serving
- Avoid foods with 140 to 300 mg of sodium per serving
- Do not eat foods with more than 300 mg of sodium per serving

Avoiding high sodium foods:

- Deli meat and cured meat
- Pizza
- Pre-prepared poultry like chicken and turkey
- Canned foods
- Soups
- Prepared frozen meals



Healthy Eating:
Eating Heart-
Healthy Foods

Nutrition Facts	
6 servings per container	
Serving size	1 cup (230g)
Amount per serving	
Calories	250
% Daily Value*	
Total Fat 12g	14%
Saturated Fat 2g	10%
Trans Fat 0g	
Cholesterol 8mg	3%
Sodium 210mg	9%
Total Carbohydrate 34g	12%
Dietary Fiber 7g	25%
Total Sugars 5g	
Includes 4g Added Sugars	8%
Protein 11g	
Vitamin D 4mcg	20%
Calcium 210mg	16%
Iron 4mg	22%
Potassium 380mg	8%
<small>*The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.</small>	

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Diet: Increase Your Protein

Your transplant dietician will give you a goal of how many grams a day of protein you should eat.

Foods high in protein include:

- Meat (chicken, beef, pork, fish)
- Dairy (Milk, yogurt, cheese)
- Nuts
- Beans and lentils
- Eggs
- Tofu

Getting the Call

When you have matched with a potential donor, the on-call liver transplant coordinator will call you. It is very important that we are able to reach you quickly. If we cannot reach you within 30 minutes, the offer will go to the next person on the list. We will also tell you if you are the 1st (primary) or 2nd (backup) recipient in line for the liver. If a primary recipient is unable to receive the liver, it will go to the back-up recipient.

During the call, the transplant coordinator will ask you a few questions to see how you are feeling. It is very important for you to report all symptoms. If you have a fever, cold, or active infection, you will not be able to receive a transplant until you are feeling better. We want to make sure that any infection is treated before you have your transplant. Your body cannot fight an infection well after transplant because of the medicines you will be taking.

Admission to the Hospital

Before your transplant, you will be admitted to the hospital. The transplant coordinator will give you instructions on where to go when you arrive at Duke.

You should bring these things with you:

- An overnight bag
- Insurance cards
- Current medicine list



Once you arrive at Duke, the transplant team will perform several tests. These will help make sure you are healthy enough for the transplant. These include:

- Blood tests
- EKG
- Chest x-ray
- Urine test

There are times when the donated organ is not a good fit. If this happens, you will be notified and sent home. This is called a “dry run.”

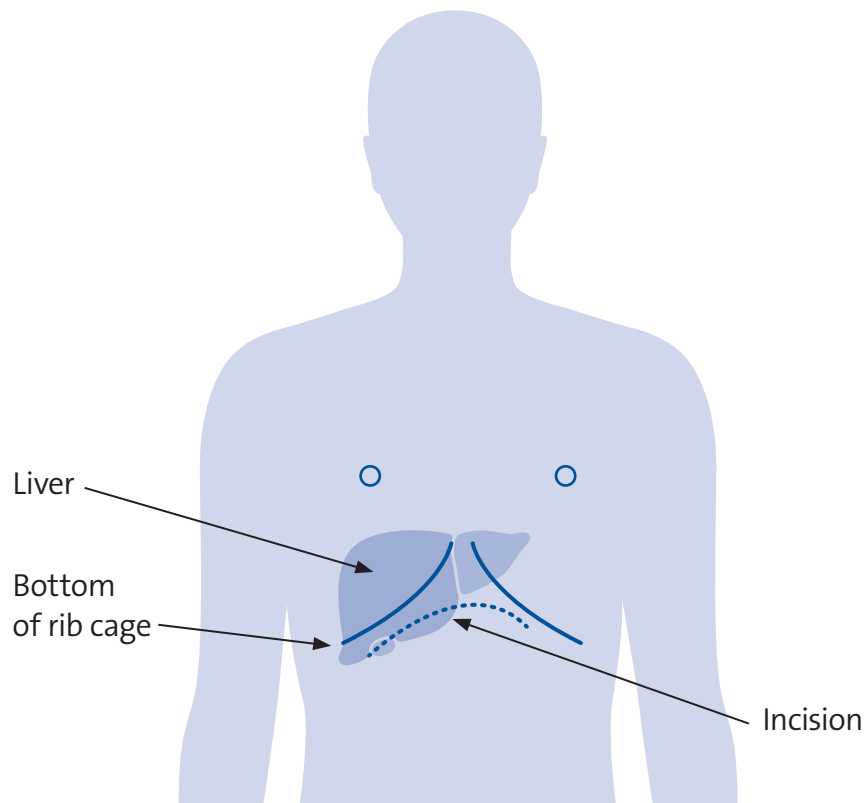
You will continue to be active on the waitlist and able to get offers. Our goal is to help you get a liver that will work for a long time!

If the organ is healthy and a good fit, the transplant team will prepare you for transplant surgery.

Liver Transplant Surgery

This section will help you know what to expect during your transplant surgery and hospital stay.

Liver transplant surgery will last 6 to 10 hours. The surgeon makes a cut across your abdomen. It will be just under your ribcage and lets the surgeon see all of the veins, arteries, and bile tubes. The surgeon will take your liver out and replace it with the donor one. If you still have your gallbladder, it will be removed. The gallbladder is also removed from the donor liver.



What Happens After Surgery

Post-Op Recovery Unit

After your surgery, you will either go to the intensive care unit (ICU) or the surgical step-down unit to recover. The average length of stay is 7 to 10 days. If you were very sick before your transplant, you may need to stay in the hospital longer.

Your blood pressure and heart rate will be checked every 4 to 6 hours.

You will be connected to tubes and machines to help monitor your recovery. These include:

- Machines called IV pumps used to give you medicines and fluids
- You will have small stickers on your chest so that we can observe your heart and breathing rate. We will often measure your comfort level and vital signs, including heart rate, blood pressure, breathing rate, temperature, and oxygen level.
- You will have a tube inserted in your bladder to drain urine called a urinary catheter. It helps measure the amount of urine you make. This tube is usually removed a few days after surgery. You will have an IV in your neck called a central line. This is used to give you fluids and medicine. The central line will be removed before you leave the ICU.
- You will have an arterial line in your wrist to help watch your blood pressure. The arterial line will be removed before you leave the ICU.

You will have drains in your abdomen to help remove extra fluid from the surgical site. The nurse will empty these drains. Most patients have the drains removed before leaving the hospital. Some patients are sent home with the drains. If needed, you will be taught how to take care of the drains.

You will have labs drawn often to make sure your liver is working. As you get better, we will not draw labs as often.

We will check your blood sugar 3 to 4 times a day even if you don't have a history of high blood sugar. One of your transplant medicines, prednisone, can increase your blood sugar levels.

What Happens After Surgery

Managing your pain

- We will use multiple types of pain control to help you be comfortable.
- It is normal to have some moderate pain after surgery, especially with coughing and moving.

Our nurses will ask you to rate your pain on a 1 to 10 scale. Review the pain scale below before surgery so you know how to respond. You will also be asked what your “pain goal” is. Most patients think an acceptable pain goal is 3 or 4.



The pain scale

0 = No pain.

1 = Pain is very mild, barely noticeable. Most of the time you don't think about it.

2 = Minor pain. It's annoying. You may have sharp pain now and then.

3 = Noticeable pain. It may distract you, but you can get used to it.

4 = Moderate pain. If you are involved in an activity, you're able to ignore the pain for a while. But it is still distracting.

5 = Moderately strong pain. You can't ignore it for more than a few minutes. But with effort you can still work or do some social activities.

6 = Moderately stronger pain. You avoid some of your normal daily activities. You have trouble concentrating.

7 = Strong pain. It keeps you from doing normal activities.

8 = Very strong pain. It's hard to do anything at all.

9 = Pain that is very hard to bear. You can't carry on a conversation.

10 = Worst pain possible.





Breathing Exercises

- To keep your lungs healthy, you will need to cough and breathe deeply.
- Take 10 breaths in the hospital-provided breathing device (Incentive Spirometer) every hour when you're awake.
- Breathing exercises keep your lungs clear and prevent infection.



How to Use
an Incentive
Spirometer
(video)



Bowel Function

- After surgery, your bowel function can take time to return.
- Some pain medicines can also cause constipation. You will be given stool softeners and other medicines to help you pass gas and have regular bowel movements.



Eating and drinking

- As soon as it's safe, you'll be able to drink and eat.
- We will start with giving you a small amount of fluids to be sure you are swallowing safely.
- Once you start to pass gas, you can have more solid food.



Getting you moving!

- We will help you out of bed to sit in a recliner to complete daily tasks, such as eating meals and grooming. Most people start this within 24 hours of surgery.
- You will walk in the hallway 3-4 times a day to help with your pain and bowel function.
- The staff will place inflatable sleeves on your legs to help circulation and to prevent blood clots.



How to Get
Moving While
in the Hospital
(video)

After Transplant and Recovery

While you are in the hospital, members of the transplant team will visit you every day. It is important that your caregivers be present to hear what the team has to say and ask any questions you or your caregiver may have.

- Your transplant coordinator will teach you about what to expect after transplant and review your medicines.
- Your transplant pharmacist will meet to discuss medicines and make sure you can fill your pillbox before you leave the hospital.
- Your social worker will visit to offer help with local housing and any non-medical issues that may arise.
- Your dietician will explain the best foods to eat to keep you healthy.
- The physician assistants and nurse practitioners will be available any time, day or night, to treat you and answer questions that you have.



When you are well enough to be discharged from the hospital your caregiver will need to pick up your medicines from the Duke pharmacy. Be prepared to pay any co-pays that your insurance requires at this time.

If you live more than an hour away from Duke, you will need to stay locally for about 30 days after you get discharged from the hospital. Your social worker will provide you with a list of local hotels, apartments and other lodging that may work for you. The surgeon will tell you when it is safe to go home.

After leaving the hospital, you will follow up in the clinic 2 times a week for the first few weeks. As you heal, your appointments will be more spaced out.

Resources

Duke University Health System	DukeHealth.org
Duke MyChart	DukeMyChart.org/home
Medical records requests	919-684-6831
HonorBridge (formerly Carolina Donor Services)	Honorbridge.org
National Foundation for Transplant	NFT.org
United Network for Organ Sharing (UNOS)	UNOS.org
Medicaid	Dma.NCdhs.gov
Medicare	Medicare.gov
Other Transplant Information	TransplantHealth.com TransWeb.org MyTransplantLife.com AstellasCares.com/transplant Secure.MedactionPlan.com/mymedschedule TransplantLiving.org

How To Contact Us

Duke Liver Transplant Clinic

40 Duke Medicine Circle

Clinic 2B/2C

Durham, NC 27710

Liver Transplant Office number: **919-613-7777**

Fax number: **919-681-7930**

Email: livertra@dm.duke.edu

Who to Call:

Transplant Coordinator: **919-613-7777**

Monday-Friday from 8 a.m. - 4:30 p.m.

After Hours Emergencies:

Call Duke Operator at **919-684-8111** and ask for the Liver Transplant Coordinator on-call.

Transplant Appointment Center: **1-800-249-5864**

Go to the Emergency Room or Call 911 If:

- You suddenly have trouble breathing or start having chest pain.
- You start having severe pain in your abdomen, chest, or legs.
- You have a change in your level of consciousness or a loss of vision.

DUHS Patient Education Governance Council approved January 2021. Flesh Kincaid 7.0

Liver Transplant Surgery

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