

Being Evaluated for Liver Transplant

A Guide for Patients and Their Families



VANDERBILT  UNIVERSITY
MEDICAL CENTER

Vanderbilt Transplant Center

Vanderbilt Transplant Center in Nashville, Tennessee, is one of the South's main providers of solid organ and stem cell transplantation. We offer programs in heart, kidney, liver, lung, pancreas, and bone marrow transplantation, and our outcomes are among the best in the country. Our specialists strive to return every patient to a full and active life. Our mission is to provide patients with end-stage organ failure the opportunity to lead extraordinary lives. We thank you for trusting us with your care.

As we treat you, we promise to:

- include you as the most important member of your health care team
- personalize your care with a focus on your values and needs
- work with you to coordinate your care
- respect your right to privacy
- communicate clearly and regularly
- serve you and your family with kindness and respect.

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Overview of the Transplant Process

Your liver doctor (hepatologist) has suggested that you be evaluated for a liver transplant. For you to decide if you want to consent to this evaluation, you need to understand both the risks and benefits of the evaluation, as well as transplant surgery itself. Learning about what you are agreeing to is a process called “informed consent.”

This booklet will help you learn what happens when a person gets a liver transplant. This process includes getting approved for a new liver, waiting for a new liver, and all the other things you can expect before and after surgery.

Why do I need a new liver?

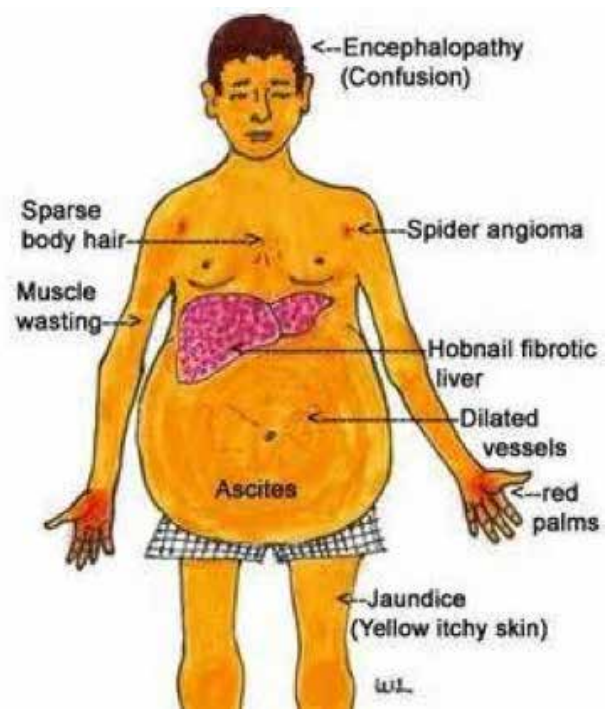
A person who needs a new liver has liver problems that cannot be fixed any other way. The most common reasons for a liver being so damaged that it needs to be replaced are:

- viruses or other liver diseases, such as hepatitis B or hepatitis C
- a tumor that cannot be surgically removed without removing the entire liver
- prior alcohol abuse
- fatty liver disease.

What are the signs of liver problems?

Some signs and symptoms of liver problems are:

- yellowing of the skin and the whites of the eyes, a condition called jaundice
- feeling tired or weak
- loss of appetite or feeling sick to your stomach
- weight loss
- muscle loss
- itching
- bruising or bleeding easily
- bleeding in the stomach, throwing up blood, or black stools
- having a swollen belly
- becoming forgetful or confused.



What are the steps of a transplant?

A liver transplant has four major steps:

1. Evaluation and education
2. Waiting for a liver
3. Surgery
4. Lifelong care and follow-up.

Step 1. Evaluation and education

This first step includes the many tests done to see if you are healthy enough for a new liver. Having all these tests does not guarantee that you'll get a new liver.

You will also learn a lot about the transplant process, which will help you decide if transplant is the right thing for you.

During the evaluation and education phase, you will learn about:

- the risks and benefits of transplant
- alternative treatments to transplant
- the evaluations and tests that are required to see if you are eligible for transplant
- the results of all the tests you will have done
- how the waitlist works
- how transplant recipients are chosen

- any psychosocial or financial issues that may affect your ability to get a transplant
- the strict medical regimen that transplant recipients must follow for the rest of their lives
- current results and outcomes at the Vanderbilt University transplant program
- organ donor risk factors
- your right to refuse a transplant at any time, up until surgery.

Step 2. Waiting for a liver

If tests show that you are healthy enough to get a new liver, and you meet all other requirements, you will be put on a waitlist for a donor liver.

Where donor livers come from

Most livers come from donors who have complete brain damage that cannot be fixed. This damage may have been caused by stroke, tumor, or a really bad head injury. Sometimes livers come from people who die when their heart stops beating.

Step 3. Surgery

As soon as you agree to have surgery, even before a liver is found, your surgeon will talk to you about the surgery and its risks. At this time, you will be asked to sign a consent form for the surgery. At all times, your health and safety are our main concern.

When a liver becomes available, you will have surgery. Note: there are times when patients are called in for a transplant, but for whatever reason, it is discovered that the donor liver is not suitable for transplant and surgery is cancelled. Although this is disappointing for patients and their families, your health is our main concern.

Step 4. Lifelong care and follow-up

Having a transplant is just the first step in a lifelong process. For the rest of your life after transplant, you will be required to follow a strict medical plan, which includes follow-up appointments and medicines you will have to take every day.

What are my treatment options besides having a transplant?

You are being evaluated for a liver transplant because you have end-stage liver failure. This means that having a transplant is your only option for a possible cure. You have the right to decline a transplant. If you decide you do not want a transplant, your doctor will continue to manage your liver disease. We can also arrange for you to have a consult with palliative care to help you plan your goals of care.



Can I get a new liver, even with a history of alcohol or tobacco abuse or illegal drug use?

Yes. You may still be able to get a new liver, but you must do the following to stay on the waitlist:

- You should not use alcohol or illegal drugs for 6 months before your evaluation. You may be tested for alcohol and illegal drugs at random during this time. All these tests must show no alcohol or illegal drug use.
- You must be tobacco free before you can get on the transplant list. Quit now!
- You will have to complete a tobacco, alcohol, or illegal drug rehab program, if your evaluations shows it is needed.
- You may be required to be in an ongoing support rehab program such as AA, NA, etc. In this case, we would require written proof that you are in such a program.

Staying eligible for transplant

To remain eligible for transplant, there are some behaviors you must commit to.

To qualify for a transplant:

- no alcohol
- no tobacco
- no illegal drugs.

It is expected that you will not use drugs, drink, or smoke for the rest of your life after transplant.

The first time you come to our office, we will test you to see if you have any alcohol, drugs, or nicotine in your system. If these tests show that you have been using alcohol, drugs, or tobacco:

- we will re-test you randomly at return visits
- you may be expected to do stop-smoking counseling or another treatment program.

If your tests show repeated use of alcohol, tobacco, or illegal drugs, you will be placed "on hold" for transplant until you talk to your Vanderbilt doctor about your substance use.

What kind of support will I need through the transplant process?

A successful transplant requires that you have people in your life who are able to give you the support and help you will need. You cannot go through this process alone. You will need 2 caregivers to qualify for a liver transplant.

Your two caregivers

To get on the transplant waitlist at Vanderbilt, you are required to have:

- a primary caregiver
- and a secondary caregiver.

These two people must agree to help you manage your health care before and after your transplant. There are no exceptions to this caregiver requirement. If you cannot meet this requirement, you will not be listed for transplant at Vanderbilt.

The tasks and roles of your caregivers will be explained in depth during the evaluation. Come prepared with questions and concerns.

Your primary caregiver:

- is your main caregiver
- will go to all your appointments with you
- will learn about your disease and all the medicines you will need to take—both before and after transplant
- will learn how to navigate the healthcare system to help you go through all the steps of transplantation
- will learn about your treatment, and make sure you are following your treatment exactly the way you are supposed to—both before and after transplant.

Your secondary caregiver:

- will provide relief for your primary caregiver if it becomes necessary at any time
- must be prepared and ready to replace your primary caregiver if your primary caregiver becomes unable to care for you for any reason.



Caregiver time commitment

Your caregiver(s) must understand that caring for you is a significant and major time commitment—both before, but especially after, your transplant.

The role of your caregiver(s) before transplant:

- Your caregiver(s) will need to go to the psychosocial evaluations with you
- Your caregiver(s) will learn everything they'll need to do for you before and after surgery, including at the hospital and in the long-term
- Your caregiver(s) will help care for you if you need it. Your doctor will work closely with you and your support system to determine if you need care before your surgery.

The role of your caregiver(s) after transplant:

- Your caregiver(s) will be trained on how to care for you after transplant. One of your caregivers will need to be with you at all times during the 30-day recovery period.
- You must have caregiver supervision 24 hours a day, 7 days a week for a minimum of 30 days after your transplant. **There are no exceptions to this requirement.**

At the hospital, your caregiver(s) will:

- be present with you when we give you your medicine, once you are out of the ICU (intensive care unit)
- learn about all your medicines and what they are for, including their side effects
- learn how to care for your transplant incision as you heal.

By the time you leave the hospital, your caregiver(s) will:

- know all about the medicines you'll take and the side effects associated with them
- be able to help you take your medicines exactly how you are supposed to
- be able to help you keep track of the medicines you take by writing down in a daily diary the times you take them and the doses you take
- be ready to go with you to your lab appointments, clinic appointments, and other visits to discuss your condition with the doctor and report any issues you are having
- have learned about (and be able to help you watch for) signs and symptoms of organ rejection, medicine side effects, or any other medical issues
- will know how to check your blood sugars and give you insulin injections, if you need them.
- be ready to help you with your personal care activities, such as bathing or shaving.

For 1 month after you leave the hospital:

- 1 of your caregivers is required to stay with you 24 hours a day, 7 days a week
- you and your caregivers will be required to live within 1 hour traveling distance from Vanderbilt Medical Center.



Can I change my mind about having a transplant?

Yes. At any time during the evaluation process, while you are on the waitlist, or just before surgery, you can change your mind about having a transplant.

If you do change your mind ...

If you decide that you will not have a transplant, your treatment for liver disease will continue. Understand, however, that without transplant, your health is likely to get worse and how long you will live will likely be shorter.

What happens if my transplant fails?

If your transplant fails, you may be eligible for another transplant in the future. This will depend on:

- the reason your transplanted liver failed
- the state of your health.



Transplant Evaluation

What happens during the evaluation stage?

Getting a new liver is serious, risky surgery. You will have many tests to find out if you are healthy enough for a new liver. All of these tests will determine if you are medically, surgically, emotionally, and mentally able to go through a transplant. How much social support you have and your financial situation will also be considered.

During evaluation, you will meet members of the liver transplant team, including your:

- nurse practitioner
- transplant coordinator
- social worker
- transplant doctor
- transplant surgeon
- nutritionist
- pharmacist
- psychiatric nurse practitioner.

Your transplant coordinator

Your transplant coordinator will be your partner through the entire transplant process. This person will be available starting from the evaluation stage. You may contact your coordinator any time you have questions or concerns.

What kinds of medical tests will I need?

Not every person will need all of the tests described in this section, or even the same tests. The tests you have are based on your own situation.

- Every test will be carefully explained in detail in advance.
- If a test has any risks, we will explain these to you before we start the test. We will also require you to sign a consent form that outlines the risks in detail.

Will I need to see different doctors during my evaluation?

During the evaluation stage, you might need to see other doctors in addition to the doctors on the transplant team if you have other medical problems. For example, many patients need to be seen by a lung doctor (pulmonologist) for lung problems or a heart doctor (cardiologist) for heart problems.



Medical tests and consultations

You will have tests and office visits that help us learn about your overall health:

- a review of your health history
- urine tests
- blood tests
 - We will find your blood type (so you can be matched with a liver).
 - We will check your blood to see if you are immune to or have certain viruses, including HIV (human immunodeficiency virus).
- an EKG (electrocardiogram), a test that measures electrical activity of the heart
- a chest x-ray
- tests to see how well your liver works:
 - an ultrasound of your liver and blood vessels, using sound waves to see how well blood is flowing to your liver
 - a CT scan or MRI of your liver and belly to look at the blood vessels and to see if you have a tumor and what size it is.
- a test called an upper endoscopy to check the health of the blood vessels in your stomach
- a colonoscopy to look for colon polyps and bleeding
- lung tests to show how well you are breathing
- a bone density scan to check for any bone loss
- a cardiac stress test to see how well your heart works under stress.

People you will meet and talk with during these consultations, include:

- one of the transplant surgeons
- your transplant coordinator
- a social worker
- a nutritionist.

If you're a male older than 50

If you're a man older than 50, you will need to have a recent prostate screening test (called a PSA).

If you're female

If you're female, we will need the results of your last pap smear and mammogram, if they were done in the past year. You can have the results faxed to us if necessary.

If you haven't had a pap smear or mammogram in the past year, you'll need to have these tests done by your own personal provider.

Dental evaluation

Dental diseases can cause infection or other problems after transplant. See your dentist to be sure any problems you have are fixed before surgery. You'll need to get a written statement from your dentist showing that any needed work has been done. You'll give this document to your transplant coordinator.

Nutrition evaluation

You'll meet with a nutritionist, who will decide if you are eating as healthy as you should be. The goal is for you to be as strong as possible for surgery. The nutritionist will help you make any diet changes you need to make.

Risk evaluation

There are many risks associated with getting a new liver. We'll talk about all of this with you in great detail. In addition to the medical risks, getting a new liver has risks that are psychological, emotional, social, and financial.

Meeting with your social worker

A social worker will meet with you for what is called a psychosocial evaluation. At least 1 of your designated caregivers (support persons) is required to be at this meeting. **If you come without your support person(s), the meeting will be cancelled and rescheduled.**

At this meeting, your social worker will:

- do an in-depth evaluation of your life and social circumstances, including discussions about your:
 - employment
 - financial situation
 - substance abuse history (if you have one)
 - mental health history
 - legal history.
- decide if you are able to understand and agree to the risks, benefits, and expected results of a liver transplant
- discuss the reasons you have decided to pursue a liver transplant
- decide if you and your family are able to hold up under the emotional, financial, and physical stress of this type of surgery
- determine if you will have the amount of social support you'll need through the transplant process.

What happens after the evaluations are finished?

If the evaluations show you are a good candidate for transplant, you will be put on the Vanderbilt Transplant Center Waitlist for a donor liver. We must be able to reach you at all times while you are waiting for your liver. Avoid traveling to areas that may not have cell phone reception. Always let us know if you plan to travel.

Waiting for a Donor

Where do new livers come from?

Most livers come from donors who have complete brain damage that cannot be fixed. This damage may have been caused by a stroke, a tumor, or a very bad head injury.

Sometimes donors can be people who died when their hearts stop beating.

People who die when their hearts stop beating are called "DCD donors." DCD stands for "donation after cardiac death." The number of donors who die this way is actually very small.

If you get a liver from a DCD donor, you may have a slightly higher risk of complication after transplant, including developing bile duct problems. Your surgeon will discuss this with you at the time of your transplant.

How are donor livers chosen?

Good liver function is the most important consideration when a donor liver becomes available. Donor livers are not matched by sex, color, race, or culture. Organ donation is voluntary. Donation often helps families deal with grief.

If a liver becomes available, your surgeon will talk with you about the risks and benefits of accepting that liver. The choice to accept the liver is entirely up to you. If you decide not to take the donated organ, you will not lose your place on the transplant waitlist.

How does the transplant waitlist work?

Your transplant coordinator will explain to you in detail how this waitlist works and how it is decided who gets a liver. There are three issues that are key to being offered a donated liver:

- blood type
- body size and weight
- a score called a MELD score used for adults who are waiting for donor livers.
 - The MELD is a numeral scale.
 - The range of the scale is 6 to 40. The sicker you are, the higher your MELD number, with 40 being the sickest.
 - The MELD score determines how badly a patient needs a liver transplant in the next 3 months. The score is calculated using the results of lab tests.

How long does it take to get a new liver?

There is no way to know how long you will wait for a liver. It can take a very long time. It is possible for a patient to die while waiting.

Is there anything I can do to help support my liver and health while I am on the waitlist?

Follow and do everything your health team says you should do. This includes everything from taking your medicines to eating a healthy diet.

Can I get on the waitlist at other transplant hospitals?

Yes; you have a right to do this. Your transplant coordinator will talk to you about how to get on the waitlist at more than one transplant hospital. You'll also learn how to transfer your listed wait time from one transplant center to another if needed.

How is it decided who is highest on the waitlist?

Your place on the liver transplant waitlist is based on your medical needs (your MELD score). The sickest patients are highest on the waiting list. A patient's status on the list can change as their health and medical needs change.



Do I need to stay close to Vanderbilt while I wait for a new liver?

- It is best if you are within a 6-hour drive from Nashville while waiting for your liver. This is because the donor liver must be transplanted within a 6-hour window to have optimal function.
- If you do live more than a 6-hour drive away, you can still get on the waitlist, but you must arrange air transportation to Vanderbilt at the time the donor liver becomes available.
 - It is your responsibility to pay for these air transportation costs.
 - The transplant coordinator or social worker will give you the contact information for several air ambulance companies.
 - When you choose the companies you will use, give the names and contact phone numbers to your transplant coordinator.

We have program coverage at all times

A transplant surgeon, transplant doctor, and transplant coordinator are available 24 hours a day, 365 days a year to assist with patient management. Back-up coverage is available for each of these people as well. If you ever need help or assistance at any time, a surgeon or doctor can always be on site at Vanderbilt within 60 minutes.

What happens when I get the call for transplant?

While you wait for transplant, you should have your cell phone with you at all times. When your liver become available, we have only 1 hour to reach you or your support person. If we cannot reach you or your support person within 1 hour, we have to move on to the next person on the list. Once you get the call, go directly to the hospital. If it is normal business hours, check into the “Admitting” office located in the main lobby of the main hospital. If it is after hours, go to the ER and tell the staff that you have been called in for a liver transplant.

Important reminders:

- Have a bag packed and ready to go at all times.
- Do not eat or drink anything once you get the call to come to the hospital for your transplant.
- Bring all of your home medicines with you to the hospital, as well as a list of your current medicines.
- Remember that there is always a chance that the transplant may be cancelled.

What if Vanderbilt is unable to do my transplant?

If Vanderbilt is unable to do transplants for any reason, such as a natural disaster, we will let you know as soon as possible. If necessary, we will also refer you to another center for transplant care.

At the Hospital

What happens when I get to the hospital for surgery?

As soon as you get to the hospital, you will be prepared for surgery. When the transplant surgeon and your new liver arrive, you will be taken to surgery.

What happens during surgery?

In the operating room:

- You'll get medicine (called anesthesia) that will make you sleep.
- You'll be asleep and not feel any pain during the procedure.
- When you're asleep, the surgery begins.
 - The transplant surgeon will make an incision in your belly.
 - Through this incision your gallbladder and diseased liver will be removed.
 - The donated liver will be placed into your belly and your incision will be closed.

How long will my surgery last?

Liver transplant surgery usually takes 4 to 8 hours.

What happens after surgery?

After surgery, we will take you to the ICU (intensive care unit), where we will watch over you as you wake up and begin to recover. You will have various machines connected to you after surgery:

- Breathing machine (ventilator) with a breathing tube. One end of the tube is connected to the breathing machine. The other end goes into your mouth and down your throat. The machine helps you breathe until you can do so on your own. You may have your breathing tube in for up to 24 hours after surgery.
- IV tubes. These tubes go under the skin into your veins. They are used to give you medicine. These may be in your hands, arms, or neck.
- Urinary catheter. This tube carries your urine from your bladder into a container. It will be removed when you are able to go to the bathroom on your own.
- Biliary drains. You will have 2 to 3 tubes that carry fluid from your belly into a container. We will remove these one at a time over the first few days after your transplant.

When you are ready, we will move you to a regular hospital room.

How will I feel after surgery?

Pain

After surgery you can expect to feel pain. This may include:

- gas pains
- sore throat
- soreness
- backaches
- incision pain.

Confusion

You may be confused for a short time after surgery because of the medicines you are taking.

What will my recovery in the hospital be like?

- When you are allowed to eat, you will start clear liquids and then move to solid foods.
- The nurses will expect you to take part in your care—such as brushing your teeth, bathing, and combing your hair
- We will expect you to walk. Walking helps your body get back into shape and heal faster.
- Coughing and deep breathing exercises will help prevent pneumonia. The nurses will show you how to do these exercises.
- We will teach you about your new liver, your new medicines, your appointment schedule, and how to prevent infection.

Am I allowed to have visitors in the hospital?

Yes. You will be able to have visitors and we encourage you to do so. But remember that you are at high risk of getting an infection. So anyone who has a cold, flu, or other infection, should not come to see you.

How long will I be in the hospital?

Liver transplant patients are usually in the hospital for 4 to 10 days. However, this may change depending on how sick you were before your transplant and if you had any trouble during surgery. You will be able to leave the hospital when your doctor is confident that it is safe for you to leave.

Leaving the hospital

Your support person will need to give you a ride home from the hospital. You will not be allowed to leave on your own.

After You Leave the Hospital

When you leave the hospital, you will still be recovering. Because of this, you will need to stay in the Nashville area for at least 4 to 6 weeks after surgery. Your support person will need to be with you during this time.

Depending on your circumstances, your recovery time may be even longer. Your transplant surgeon and nurse will tell you when you can go home.

Short-term care

Your short-term care will include:

- appointments with your doctor to check on your new liver
- blood work and other tests to see how your liver is doing.

Long-term follow up with the transplant team

Though every effort will be made to transition your regular medical care to your primary doctor, you will be followed in the transplant clinic for the rest of your life.

Follow up typically involves:

- frequent lab work
- a clinic visit once a year.

If you develop any complications, the transplant team may need to see you more often.



Risks and Possible Complications of Transplant

What are the risks associated with a liver transplant?

A liver transplant is complex and the risks are high, including the risk of death. Your doctor cannot know exactly how your body will respond to a transplant until it happens.

The overall success rate, defined as living for at least one year after a liver transplant is about 92 percent. However, we never really know how the condition that caused your original liver problems will affect your transplant. The success of a liver transplant will also be affected by:

- how sick you are before your surgery
- how well you follow the rigorous treatment plan prescribed by the transplant team.

This section of the book will tell you about the risks associated with a liver transplant.

Risk of interrupted surgery

Sometimes a surgery is cancelled. This can happen if the surgical team decides a patient has become too much of a high risk. It can also happen if the donor liver does not seem healthy enough to use.

If your surgery is cancelled:

- you will return home and continue to wait for a new liver
- you will not lose your place on the waiting list.

Risk of rejection, failure, and re-transplant

The chance that your body will reject your new liver is always possible. The risk is highest the first year after your transplant. The good news is that rejection is usually treatable. Treatment may be provided at home or may require that you go to the hospital.

Your body will never develop a tolerance to the new liver. This means you will need to take medicines to keep your immune system from attacking your liver. To prevent organ rejection, you will have to take medicine for the rest of your life.

There is also the risk that your new liver will not work. If this happens, you may need to be listed for re-transplant.

Risk of complications from your lifelong, anti-rejection medicines

Anti-rejection medicines are critical to preventing organ rejection. You will take them for the rest of your life after transplant. However, these medicines do have potential complications, including:

- increased risk of cancer
- high blood sugar levels
- damage to other organs, including your kidneys
- high blood pressure
- increased risk of infection
- increased risk of bone disease.

Risk of pain, bleeding, or injury

Transplant surgery can cause pain, bleeding, or damage to other organs in the belly.

Risk of sickness or infection

This surgery can cause sickness and infection, including:

- wound infections
- feeling sick to your stomach
- fevers
- pneumonia
- infections of the bladder
- infections to organs in the chest.

Risk of blood clots and vessel problems

This surgery may cause you to have blood clots in your legs. This is dangerous since clots can travel to your lungs and make it hard for you to breathe.

To prevent blood clots from forming, you may be given special devices, such as plastic boots that inflate and deflate around your legs. Such devices help to keep the blood in your legs flowing both during and after your surgery.

There is also the risk of problems developing in the reconstructed arteries and veins in your liver after your transplant. These problems include:

- narrowing of the reconstructed veins or arteries
- the formation of a blockage, often called a thrombosis, in one of the reconstructed veins or arteries.

Risk of nerve damage

Liver transplant surgery can cause nerve damage, which can cause numbness, weakness, paralysis, or pain in your body. Most of the time these symptoms last only a short time and go away on their own. In rare cases they can last for extended periods of time, or even become permanent.

Risk of bile leakage

Bile is a liquid released by the liver. It contains cholesterol, bile salts, and waste products. A common problem after a liver transplant is a bile leak. This risk is caused when the surface of the liver is cut. The risk of having a bile leak after a liver transplant is about 5 to 15 percent.

A leak may be treated with tubes or drains that pass through the skin and into the liver to drain bile from the liver into a bag worn outside the body for a period of time. This can often be done without surgery. Most bile leaks get better without another surgery.

Risk of bile duct narrowing

Bile ducts are the drains that carry bile out of your liver. Sometimes these ducts can narrow after surgery. If this happens, some of the ducts may be fixed by placing a stent (a plastic tube that holds the duct open) in the area where it has narrowed. This can be done through the mouth or through the skin. Narrow bile ducts can usually be fixed without surgery.

Increased cancer risk

You will have an increased risk of getting certain kinds of cancers (skin and some lymph cancers). This risk is caused by the medicines you will take for the rest of your life to keep your body from rejecting your new liver.

Risk of disease or infection from the donor

The risk of catching a transmittable disease or infection from your donor is very rare. All donors are carefully tested for transmittable diseases and infections, including HIV, hepatitis B, and hepatitis C. However, you need to know that no organ transplant is completely free of this risk. If you catch a disease or infection, you could end up with a serious illness. The situation would be complicated by the fact that some of your post-transplant medicines will weaken your immune system.

Elevated risk donor

During the screening process, we may find that a potential donor has a higher than normal risk for having a transmittable disease or infection. This type of donor is often called a "PHS elevated risk donor." If we find that your donor has an elevated risk, we will discuss this with you to help you decide if you wish to accept the organ for transplant.

Please remember that all donors carry the risk of transmittable disease or infections, even though this risk is low.

Risk of death and multi-organ failure

Like any surgery, there is the risk of death. This is especially true with liver transplant surgery given how serious it is. There is also a risk that some of your other organs may fail during the transplant process. Your medical team will treat you for any complications. However, there is still a risk of death.

Anesthesia risks

This surgery will be done under general anesthesia that will make sure you sleep and feel no pain during surgery. Any time general anesthesia is used there are a number of known risks. An anesthesiologist will explain these to you and give you a separate consent form to sign.

The risks of blood transfusion

You may need to receive blood during or after your surgery. Even though all blood is carefully checked for HIV, hepatitis B, hepatitis C, and other diseases, anytime you receive blood, there is the risk of being infected.

Risk of additional complications

Across the country, the risk of having some kind of complication (major or minor) from a liver transplant is greater than 30 percent. Most problems get better. However, sometimes, another surgery or procedure may be needed.

Possible risks and complications in addition to those already mentioned are:

- injury to structures in your belly
- pressure sores on the skin caused by the position your body was in during surgery
- burns caused by the electrical equipment used during surgery
- damage to your arteries and veins
- heart attack
- stroke
- seizures
- permanent scar where your incision was made.

Psychosocial risks

Having a transplant can be very stressful emotionally and psychologically, as well as physically. After transplant, there is the risk you may develop psychosocial health problems, including:

- depression
- post-traumatic stress disorder (PTSD)
- generalized anxiety
- anxiety about having to depend on others
- feelings of guilt.

There are many resources to help you if you have any of these issues. Let us know if you need any help at any time.

Financial risks

Getting a transplant can affect you financially, both now and in the future:

- During the evaluation process you may find out that you have some health problems that you didn't know about.
 - You may have to spend money to treat these problems.
 - Some of these problems could also affect your ability to get health or life insurance, depending on what they are.
- Getting a liver transplant may affect your ability to get life or health insurance in the future. Insurance companies may identify you as having a pre-existing condition and refuse payment for medical care, treatments or procedures.

Common Medicines for Transplant Recipients

As a transplant recipient, you will need to take various medicines for the rest of your life. You will get medicines to help your body accept your new organ. These are known as “immunosuppressive drugs” or “anti-rejection medicines.”

After transplant, patients usually go home taking 2 or 3 types of anti-rejection medicines. This is in addition to their other medicines. Anti-rejection medicines help your body accept the transplanted organ by lowering your body’s natural reaction, which is to attack foreign tissue. At first, you will take large doses of these medicines. The amount you take will gradually be lowered as your body accepts the new organ.

It is important that you ALWAYS take your medicines exactly as directed.

- You need to know the names of these drugs, how much you are taking, and what the pills look like.
- Your nurse will help you and your support person learn all about your medicines so you can take them yourself in the hospital and at home.
- Failure to take these drugs or skipping doses can cause your body to reject your new organ.
- It will be necessary for you to take all your medicines on a strict schedule.

Common medicines

The two most common anti-rejection medicines for transplant patients are:

- Tacrolimus (Prograf)
- Mycophenolate (Cellcept).

These medicines are very good at lowering the risk of rejection, but they also have a number of potential side effects including:

- lower ability to fight infection
- increased risk of certain cancers
- increased risk of birth defects
- nausea or diarrhea
- high blood sugars.

There are additional side effects as well. We will talk with you about them.

After transplant, you will have to take anti-rejection medicine for the rest of your life. Once you are transplanted, we will give you more detailed information about the specific medicines you will be on and instructions on how to take them.

Prednisone

After transplant, you will be sent home with daily prednisone. However, at our center, most transplant patients do not have to take prednisone long-term. You will decrease the amount of this medicine over several weeks after transplant.

Your Life after Transplant

Prevent infection

The medicines you will take for the rest of your life will make you more prone to getting infections. The good news is that with good habits, you can stay healthy.

Some of these things you will need to do for the rest of your life. Other restrictions may be lifted in time. Your transplant doctor or nurse will tell you when some of these restrictions may be lifted.

Tips to prevent infection:

- Stay away from people who are obviously sick with the flu or a cold.
- Try to avoid children with chicken pox or strep throat.
- Wash your hands with soap and water before you eat and after you go to the bathroom.
- Shower or bathe regularly. Wash your incision as you would any other part of your body. Do not use lotions or powders on your incision.
- Clean cuts and scrapes right away with soap and water; then apply an antiseptic and a bandage.
- Do not, under any circumstances, change the litter in the cat box or birdcage without wearing gloves. This could cause a serious infection. Avoid cat scratches.
- Talk to your doctor about getting the injected flu and pneumonia vaccines. Neither vaccine contains live viruses. Both vaccines are safe for you to have.
- Do not get any vaccine that contains live virus, such as the shingles, smallpox, polio, or nasal influenza vaccine.
- Talk to your doctor if someone in your house is going to get a live virus vaccine, such as the oral polio vaccine, and you have not already been vaccinated for that virus.
- Do not smoke. And do not expose yourself to second-hand smoke.

If you want to have a child

Women

If you decide to become pregnant after your transplant, it is very important to discuss this with your transplant doctor or nurse in advance. Some of the medicines you will be on may not be safe for you to take during pregnancy.

Avoid pregnancy:

- for 1 to 2 years after your transplant
- at all times if you are taking the medicine mycophenolate.

Men

Although men may father children at any time, talk to your doctor before trying to conceive to be sure the medicines you are taking, such as mycophenolate, will not affect the baby.



Medicare and Financial Considerations

If I have Medicare, can I have my transplant at Vanderbilt?

Vanderbilt Transplant Center is currently Medicare-approved. However, the center is audited every 3 to 5 years for continued approval. If Vanderbilt ever lost its Medicare approval, Medicare would no longer pay for transplants at Vanderbilt. We will keep you informed about our status. If we become deficient in any Medicare requirements at any time, we will let you know right away.

Paying for your medicines

Without your proper medicines, your body will reject your new organ. You will need to be able to pay for your medicines or have enough prescription drug coverage at the time of your transplant. Without adequate drug coverage, your estimated costs for your medicines are as much as \$5,000 a month (\$60,000 a year). Some of these medicines you will take for the rest of your life.

Because the cost of your medicines is so high, it is important that you always have drug coverage. Also, you should let us know right away if you ever have any changes to your drug coverage.

If Medicare pays for your medicines

If Vanderbilt Transplant Center ever loses Medicare-approved status, your ability to have your immunosuppressive drugs paid for may be affected. Our financial counselor will talk with you about these details so you can make the best decision for you.

Fundraising

If you anticipate that you will have any major costs that may not be covered by your insurance (including prescription co-pays, travel, and lodging), we encourage you to consider doing some fundraising. Call the numbers below and to begin the process of fundraising as soon as possible.

These organizations have been able to make quite a difference in the lives of many of our patients. They are often able to help patients before, during, and even years after their transplants.

Two organizations that help transplant patients raise money:

- National Foundation for Transplants
Transplants.org
(800) 489-3863
- Help Hope Live (was the National Transplant Assistance Fund)
HelpHopeLive.org
(800) 642-8399

Your financial coordinators

Your financial coordinators will keep everyone at Vanderbilt informed about your current insurance coverage, will get all the necessary authorizations and approvals required from your insurance throughout the process, and will help you in any way possible with your insurance questions and concerns. We know this can be a lot of information to process all at one time. Please don't hesitate to call us any time you have questions or concerns.

Notify your financial coordinators immediately if:

- you begin or end the coverage you have through COBRA
- you obtain any new insurance
- any of your current insurance policies change or end
- there are any changes in your Medicare Part D coverage.

Learn more:

- Medicare
Medicare.gov
- Centers For Medicare and Medicaid Services (CMS)
CMS.gov
- Social Security Administration
SSA.gov

Resources and Patient Tools

United Network for Organ Sharing

You may get more information about transplantation from the United Network for Organ Sharing (UNOS).

- The UNOS website: **UNOS.org**.
- The UNOS toll-free patient phone line: 1-888-894-6361. This phone line:
 - is to help transplant candidates, recipients, donor, and family members understand the way organs are matched with patients who need them
 - can be used to find data, information, and statistics about transplants
 - can be used to talk about any problems you have at your transplant center or with the overall transplant system.

National and local transplant data

During your evaluation meeting, your transplant coordinator will provide you with copies of the current data about national and Vanderbilt-based transplants. This information will help you learn about the number of transplants performed both nationally and at Vanderbilt, including the results of the transplants.

Information sharing

As you go through the transplant process, members of your transplant team may access and share your medical information as permitted by law and Vanderbilt University Medical Center policies.

If you do end up getting a new liver, information about you, which will include your identity, will be shared with the United Network for Organ Sharing (UNOS). This information may also be sent to other transplant-related agencies or companies as permitted or required by law.

Information sharing is an important part of overall transplant program success, both nationally and locally. As a person who gets a transplant, it is expected that you agree to postoperative and long-term follow-up tests with the knowledge that this information will also be shared.

Learn more:

American Association for the study of Liver Disease
AASLD.org

American Liver Foundation
LiverFoundation.org

Coalition of Donation
ShareYourLife.org

National Foundation for Transplant
Transplants.org

National Transplant Assistance Fund
TransplantFund.org

United Network of Organ Sharing
UNOS.org

Vanderbilt Liver Transplant Program
VanderbiltHealth.com/transplant



