

PRE-OP LIVER TRANSPLANT PATIENT GUIDE





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WELCOME

Welcome to the UK Transplant Center. We understand the challenges of undergoing a liver transplant and will do our best to help you return to good health.

This booklet explains the liver transplant process and what you can expect leading up

to your transplant surgery. We hope it makes your time with us more comfortable.

We want you to take an active role in the transplant process. If you still have questions after reading this guide, please ask. Our doctors, nurses, and other staff members are happy to help.

WHAT IS A LIVER TRANSPLANT?

A liver transplant is a surgical procedure where you receive a healthy liver from a donor. At the UK Transplant Center, livers for transplants come from people who have just died, or deceased donors. The new liver takes over the work of the failing liver.

Deceased donors are donors who have been declared brain-dead. This is an irreversible condition. People become deceased donors two ways:

- They sign up on the organ donor registry while still living.
- Their families decide their loved ones would want to be donors.

While on the transplant list, you will be matched with a deceased donor. This is based on blood type, size, and how urgently you need a transplant.

HOW THE LIVER WORKS

The liver is the largest solid organ in the body and is located underneath your ribs on the

upper right side of your abdomen. It's shaped like a half-moon and its size varies based on your age, sex, and your body type. Your liver does several jobs to keep you healthy:

- Makes bile to help your intestines digest food.
- Produces proteins that help blood clot.
- Cleans toxins and filters bacteria from your blood.
- Breaks down medications.

A liver can be damaged by viruses, alcohol use, obesity, or by disease. If the damage is serious enough, it can cause scarring. This condition is called cirrhosis, and it can stop the liver from doing its job. Symptoms of serious liver damage can include:

- Yellowed skin and eyeballs (jaundice).
- Mental confusion and fatigue.
- Abdominal pain and swelling.
- Itching.
- Easy bleeding or bruising.

ROLES OF THE TRANSPLANT TEAM

Surgeons

The surgeons will perform your transplant. They work with the rest of the team to decide if a transplant is the best option for you. A surgeon will meet with you before your transplant and will update your family after surgery. The surgeons will manage your care as you heal in the hospital.

Transplant hepatologists

The hepatologists are liver specialists who will also help decide if a transplant is your best option. After the transplant, they will manage your care. A transplant hepatologist will see you at your clinic visits.

Advanced practice providers

These include nurse practitioners and physician assistants. One of them may assess you at a routine or follow-up clinic visit. They play an active role in deciding if you are a transplant candidate. During your hospital stay, they will be part of your care team.

Transplant coordinator

The coordinator is a registered nurse who works with the transplant team and who is your main contact. Before the transplant, your coordinator will teach you and your family about the process. The coordinator will schedule your evaluation. If you are a

transplant candidate, the coordinator will place you on the United Network for Organ Sharing Network. After the transplant, the coordinator will teach you and your main support person about transplant care.

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 big role in the transplant process. If you feel stressed or afraid, the social worker may be able to help. Transplant patients often need psychiatric counseling. After the transplant, the social worker will help you find resources and support.

Financial coordinator

After referral, the financial coordinator will check your insurance benefits. This coordinator will let you know if there are steps you need to take before your procedure and 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.

Pharmacist

The transplant pharmacist will make sure you are on the correct medicines and that they work well together. Your pharmacist will teach you about your medicines and will meet with you before and after transplant.

Dietitian

Eating right will help you have a successful transplant. Your dietitian will make sure the foods you eat have the vitamins and minerals you will need during the transplant process.

During your evaluation, the dietitian will

check your weight, lab results, and eating habits. The dietitian will create an eating plan just for you. You may be asked to lose weight before the transplant. This will help you to get the most out of your transplant.

In the hospital after the transplant, the dietitian will check your lab results and make sure you get the nutrition you need. Your dietitian will also teach you how to eat a healthy diet before you go home. After you go home, you can still meet with the dietitian in the clinic.

THE TRANSPLANT PROCESS

A liver transplant is more than just a surgery. It is a process that includes these phases:

- Referral.
- Evaluation.
- Waiting.
- Hospital stay for transplant.
- Care after transplant.

REFERRAL

The process starts with a referral. Before a transplant is needed, doctors may be able to manage your liver failure with lifestyle changes and medication. When that no longer works, the doctor will refer you for a liver transplant.

EVALUATION

After referral, we will schedule a visit to the transplant clinic. There you will meet with members of the team, such as surgeons, hepatologists, and your transplant coordinator. This evaluation will tell us whether you are a candidate for a transplant. You will have many tests that may require several visits to the clinic. We will check the health of all your vital organs. We have to be sure that:

- A liver transplant is the best treatment for you.
- Your other health problems will not keep you from a successful transplant.

You will meet with many members of our teams. The transplant team includes

doctors, nurses, dietitians, social workers, psychologists (if needed), and the financial coordinator. They will ask for information from you and tell you about the liver transplant.

Here are some of the tests you will likely have during the evaluation. Depending on your health problems, you may need other tests. Your coordinator will also give you a list of tests you need from other doctors. The testing will take several days, and sometimes you may need to stay overnight in the hospital.

BLOOD TESTS

- Liver function.
- Kidney function.
- Nutritional status.
- Blood cell count.
- Blood clotting ability.
- Tissue/blood typing.

IMAGING TESTS

- Abdominal ultrasound.
- Abdominal CT scan.
- Chest X-ray.
- Chest CT.
- Cardiac stress test.
- Echocardiogram.
- Cardiac Coronary CTA.
- Pulmonary function test.

ALCOHOL AND DRUG TESTS

Before you can be placed on a transplant list, you cannot have used any alcohol or drugs for at least six months. You also must stop using any tobacco products. We have programs and referrals to help you with these issues.

- Drug and alcohol screens. This will be done at each visit. Screens may also be requested randomly.

TRANSPLANT CANDIDACY

Our team meets each week to discuss our patients. During this meeting, we will discuss your need for a liver transplant. We will go over your evaluation and discuss if there are any reasons a transplant would be too risky.

Sometimes patients need more tests to help us decide on the best option. If more tests are needed, we will call you to schedule them.

After we decide on a plan of care, the transplant coordinator will discuss the plan with you. Here are the possible results:

- You are a candidate. The transplant coordinator will then explain the listing process.
- You are not a candidate at this time. 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.





THE LISTING PROCESS

We place transplant candidates on a national waiting list. The United Network for Organ Sharing, or UNOS, keeps this list. It is a fair and organized process for transplant patients. Each organ has its own listing process. For more information, visit www.unos.org.

The wait for a liver transplant can be as short as one day or it may take months. Being on the waiting list may be the toughest part of the process. The wait may seem to go on forever. But we are here to help, and you can take steps to deal with your stress. Here are some tips:

Stay healthy and educate others

- Talk about your feelings with family and friends.
- Eat healthy meals.
- Exercise as much as you can.
- Take all medicines as directed.
- Encourage others to be organ donors.
- Start or take part in activities that encourage organ donation.

Keep in touch with the transplant team

- Talk with the transplant team about your health. Tell your team about new medicines, hospital stays, infections, or planned surgeries. Contact your coordinator with these updates as soon as possible.
- Always be near a phone and check your answering machine or voicemail. We need to be able to reach you 24 hours a day, seven days a week.
- Tell your coordinator if you will be traveling out of town. You may need to go on the inactive transplant waiting list until you return.
- Go to all transplant clinic appointments. Once you are on the waiting list, you will need ultrasounds and CT scans of your liver every six months and heart tests every year.
- Tell your employer that the call for your transplant could come at any time.



Choose your main support person

You will need a person or people to support you emotionally and to help you during the waiting period and after surgery. These support people must be willing to stay with you full-time for four to six weeks after your transplant. If you live more than an hour and a half away from the Transplant Center, both of you must plan to stay in Lexington during that time. Support people need to have a reliable phone line with a voicemail option. Some of the things they will do can include:

- Taking you to the Transplant Clinic.
- Getting groceries, picking up medications, and doing laundry.
- Helping you check your blood pressure, temperature, and weight.
- Encouraging you to exercise.

Prepare financially

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

Plan for the day we call you to come to the hospital for the transplant. Keep a packed suitcase ready for 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. The more prepared you are, the less stress you will have.

THE DAY OF THE TRANSPLANT

As soon as there is a liver for you, the transplant coordinator will call you. Once you get this call, come to the hospital as soon as you can. We plan for your travel time, so do not drive over the speed limit. Once 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.

For your safety, we will do many tests before surgery, including:

- Chest X-ray.
- Blood work.
- Physical examination.
- Other tests requested by the transplant surgeon.

We will also 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 liver transplant. The testing process may take several hours. Once you go to the operating room, or OR, we will take your family members to a waiting room and give them a pager. The OR nurse will update your family in the waiting room during surgery. A volunteer is available to provide extra support if your family wants that. The operation may take as long as 4 to 6 hours.

IN THE OPERATING ROOM

Your anesthesiologist will meet you in the OR area, discuss the procedure and ask you

questions. Doctors and nurses will prepare you for surgery. The anesthesiologist will give you medicine to help you relax and sleep.

The start time of your transplant will depend on the donor's surgery. That surgery is done by the donor team. The donor team keeps your team at UK informed about the progress. Once the donor team decides that the new liver is right for you, they will tell us. If the organ will not work for you, the donor team will tell us. In that case, we will have to cancel your transplant, and you will remain on the waiting list. If that happens to you, don't be discouraged – view it as practice for the next time you are called in.

The transplant is done by the transplant surgeon with two other surgeons helping. The surgeons will make an incision from the bottom of your rib cage on the right side over to the rib cage on the left side. Your diseased liver will be removed. The new liver is put into place and the blood vessels and bile duct are reconnected. The incision is then closed.

AFTER SURGERY

You will recover in the surgical intensive care unit, or SICU. Your family will be able to visit you here. The transplant team will see you at least twice a day while you are in SICU. The team will talk to your family members after seeing you to update them on your progress. You will be allowed to get out

of bed and sit in a chair or walk one to two days after your surgery. A physical therapist will begin working with you.

When you are ready, we will move you to the transplant unit. The nurses in these units are trained to care for transplant patients. Soon after you arrive, you will walk or sit in a chair. Walking as soon as possible after your surgery helps you recover faster. You will also be asked to do deep breathing exercises. These will expand your lungs to their fullest. This will help prevent pneumonia and will strengthen your breathing muscles. Most patients stay in the hospital for five to 10 days after a liver transplant. The length of stay will depend on your needs.

We may need to limit how many visitors you have. Please try to limit visitors to family and close friends. This will help protect you from infection. More visitors mean more risk of infection. If your loved ones are sick, they should not visit you. Instead, they may talk to you by phone. Children age 12 and under cannot visit unless the transplant team says it's OK.

We will keep a close watch on your health. You will notice a lot of equipment in your room. These machines help us keep an eye on important vital signs, such as blood pressure, heart rate, breathing, and oxygen levels. As you heal, you will not need all that equipment.

You will be given a special diet after transplant. You will start with clear liquids and will begin eating regular foods when you start to feel hungry. To heal, you need a well-balanced diet.

LAB TESTS

Each morning, we will draw blood for laboratory tests to check your liver and kidney and your overall health. Occasionally, a chest X-ray will be taken. You may have an ultrasound and liver biopsy to check that your body is accepting your new liver.

Each day the transplant team will check your progress and update you on the plan of care. This is the best time to ask questions.





LEARNING TO CARE FOR YOURSELF **AT HOME**

As soon as you are ready, we will teach you how to care for yourself at home. Tell your nurse when your main support person is in the hospital. The nurse and the nurse coordinator will teach both of you at the same time.

The coordinator will bring you your post-op liver transplant guide. You will go over important information, such as:

- Things you can and cannot do.
- Diet instructions.
- Symptoms to be aware of.
- Follow-up visits with the doctor.

You will get a binder from the pharmacist with a diary. In it you will record the medicines you take and your vital signs each day. It is your job to use the diary to learn how to take your medicines.

When you leave the hospital, you can go home if you live within an hour and a half of the Lexington area. If you live farther

away, you and a support person must stay in the Lexington area for four to six weeks. The housing costs are your responsibility. Your social worker can help you with these arrangements.

You will visit the Transplant Clinic twice a week for about four to six weeks. After that, you will come once a week for two months. After three months, you should have most of your strength back and your family doctor will take over your care that is not directly related to your transplant. You will return to the transplant clinic for an appointment six months after your surgery and again one year after transplant. We will then continue to see you in the clinic on an annual basis.

The things you learn will help you extend the life of your new liver. You will need to make some big changes, and our team will help you prepare. We are always here as you need help along the way.

POSSIBLE COMPLICATIONS AFTER TRANSPLANT

Most patients do well after transplant; however, some can develop complications resulting in long hospital stays and even death. Possible complications include:

PRIMARY NONFUNCTION

A rare but serious condition in which the transplanted organ did not start working immediately after surgery. It can be caused by multiple factors.

BLEEDING

As with any surgery, there is a risk of bleeding. It is possible that after surgery, bleeding may still occur and you may have to return to the operating room.

REJECTION

This term is used to describe how your body responds to anything it recognizes as “foreign.” Your body will not recognize the new organ as being part of you. Anti-rejection medicine, called immunosuppressants, will help your body accept your new liver. Rejection is the easiest problem to treat and can happen any time after the transplant.

- Rejection has no symptoms, although some patients experience discomfort in the abdomen, as well as a slight fever.
- Lab tests will become abnormal. If this happens, you may need a biopsy.

- You may need to be admitted to the hospital for treatment.
- When you are discharged, you may have medication changes and require more frequent follow-up – labs and clinic visits, etc.

INFECTIONS

Immunosuppressant medicines reduce your body’s ability to fight infections, so you should stay away from people who have colds, flu, or any other contagious illnesses. You should also avoid people who have recently received flu shots or other vaccines. Anyone who comes around you should wash their hands often. This is especially important immediately after your transplant.

Viral – Two common viral infections are cytomegalovirus (CMV) and the herpes virus (HSV). Most people have been exposed to these viruses during normal daily activities. With anti-rejection medication, the viruses can be reactivated and cause significant illnesses that may require treatment. Medicine is available to treat those infections. If the infection is severe, you may need to be hospitalized to receive this medicine intravenously.

Bacterial – Wound infections can occur after a transplant. These usually will require antibiotics. Sometimes, they may require additional operations.

Fungal – Fungal and yeast infections may happen. Medicine and good hygiene will help prevent infections. Fungal infections of the lungs can be very serious and may be contracted by inhaling dust or mold.

BLOOD TRANSFUSION

Almost all patients who receive a liver transplant will need a blood transfusion during their operation.

BILE DUCT PROBLEMS

Sometimes the bile duct may leak where it was sewn together. This may require you to go home with drains and tubes. Additional instructions will be given when you are discharged from the hospital.

BLOOD SUPPLY

Blood supply to your new liver may become compromised after surgery, requiring an additional operation.

TUMORS

After a transplant, you take immunosuppressant medication that will stop your body from rejecting your new liver. Your body's immune system naturally fights tumors and cancer cells. However, the immunosuppressants may keep your body from doing this in some cases. If a tumor develops, your team will carefully monitor the situation.

DEPENDENCE ON THE VENTILATOR

Some patients may have a difficult time with removal of their breathing tube. This could be from pre-existing lung problems, pneumonia, or smoking.

POOR NUTRITION

This may happen because of poor appetite or general weakness after your transplant. It's important to eat to help your body heal.

KIDNEY DYSFUNCTION

Kidney damage or failure, which may require dialysis.





LIVER TRANSPLANT TEAM
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