Liver Transplant
Pre-operative Teaching Manual

This is the first step in your transplant journey.
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INTRODUCTION

The purpose of this handbook is to introduce you and your family to the Liver Transplantation Service of the Global Integrated Liver Care Program at BGS Global Hospital in Bangalore. You need a liver transplant because you have advanced liver disease. This manual will provide you with information about the process of liver transplantation to help you make informed decisions about your care.

Liver Transplantation is done in carefully selected patients at the appropriate time. Timely liver transplantation can cure the underlying liver disease and provide a patient with longer and better quality of life. It is important to recognize that receiving a liver transplant requires a lifetime of commitment to medical treatment such as taking daily medications, periodic blood tests and regular visits to the liver transplant clinic.

When you have finished reading this manual you will be able to:
• Understand the symptoms of liver disease
• Understand how the transplant process works
• Find the information you need to cope with your illness
• Know when to go to the hospital emergency or call your doctor

The first part of this teaching manual explains about liver disease and the things that can make you ill. The second part of the manual explains about liver transplantation and how it works. It is our hope that by the time you reach the end of this manual you will know what you can expect on your transplant journey.
What Does the Liver Do?

The liver is the largest organ in the body weighing 1200-1500 grams. It is located on the right upper side of the abdomen and behind the lower ribs. Liver is supplied blood by two major blood vessels – the portal vein and the hepatic artery.

The liver is made up of several segments and can be divided into two lobes, the right and left. The liver serves as the body’s factory and waste processing system.
A few of the main functions of the liver are to:

1. Help absorb food and convert food into nutrients that the body can use. For example, the liver makes bile that breaks down fats and fat soluble vitamins such as vitamins A, D, E, K in the intestines and allows their absorption.

2. Store fats, sugars, iron, and vitamins for later use by the body.

3. Filter the blood to remove substances like drugs, alcohol and other toxins, that can be harmful to the body.

4. Make proteins needed for normal blood clotting, normal blood pressure and helping the immune system.

WHAT ARE COMMON TERMS USED IN LIVER DISEASE PATIENTS?

CIRRHOSIS: This is the term given to the liver when it gets scarring and is unable to perform its functions. A normal liver is soft like a sponge and has got a smooth surface. A liver with cirrhosis is hard and has an irregular surface. Cirrhosis is the end result of any form of long standing liver damage. Common causes of cirrhosis include excessive alcohol intake, chronic hepatitis B and C infection, fatty liver disease and autoimmune liver disease. Once a patient develops cirrhosis, complications are the same irrespective of the cause of cirrhosis. A patient with cirrhosis also has an increased risk of developing liver cancer. “Well compensated cirrhosis” implies to a patient with cirrhosis without any complications, while in “decompensated cirrhosis” a patient has developed one or more complications as below.
PORTAL HYPERTENSION: Liver is a filter through which blood flows. When the liver is cirrhotic, it is very hard and rigid, more like a rock than the sponge it should be. In such a hard liver, there is increased resistance to blood flow. This increased resistance leads to increased pressure in the blood vessels supplying blood to the liver, mainly the portal vein. This is called “Portal Hypertension”. This high pressure is the main reason for vomiting of blood from dilated veins in the food-pipe and the fluid collecting in the belly called ascites.

VARICES: These are dilated blood vessels (also known as varicose veins) that form in the food pipe (esophagus) and stomach in patients with cirrhosis and portal hypertension. These blood vessels get dilated due to increased pressure in the portal vein. These blood vessels can rupture and cause life threatening bleeding. The patient may vomit a large quantity of blood or pass black tar like stools. Repeated coughing, straining, or lifting heavy weights can cause these varices to rupture.

ASCITES: This is the term used for collection of excess fluid in the abdominal cavity. This causes visible swelling of the abdomen. Excess fluid collects as a result of increased pressure in the portal vein (portal hypertension). Patients with cirrhosis also have an inability of their kidneys to excrete salt and water that also contributes to ascites.

SPONTANEOUS BACTERIAL PERITONITIS (SBP): This is the term used for infection of the fluid in the belly (ascites). This is a very common complication and if not recognized and treated in time, can be life threatening. Common symptoms are abdominal pain, fever, worsening jaundice or mental confusion.

SPLENOMEGALY: This is the term used for enlargement of the spleen. The spleen gets enlarged because of back pressure effect of portal hypertension. An enlarged spleen can lead to low hemoglobin and platelet levels.

HEPATIC ENCEPHALOPATHY: Patients with cirrhosis can develop periods of mental confusion or even complete unconsciousness. This is due to failure of the liver to remove ammonia and other toxins from the blood.

HEPATORENAL SYNDROME (HRS): This is the term used for kidney failure in patients with cirrhosis and ascites. Patients may have decreased urine formation and worsening of ascites. Infection of the ascites (SBP) is the most common cause of hepatorenal syndrome. Patients who develop HRS are at an extremely high risk of other complications. This type of kidney failure usually recovers if liver transplantation can be performed in time.
WHAT ARE THE SYMPTOMS OF END STAGE LIVER DISEASE?

Symptoms in patients with end stage liver disease or cirrhosis develop only when the liver is about 80 percent damaged. It is important to remember that patients with early cirrhosis may have no symptoms at all. Below is a list of symptoms experienced by people with End-Stage Liver Disease.

- Yellowing of eyes and skin known as jaundice
- Dark coloured urine
- Pale or clay-coloured stools
- Severe itching
- Easy bruising and tendency to bleed
- Malnutrition and muscle wasting
- Difficulty in sleeping
- Mental confusion
- Accumulation of fluid in the belly (ascites) and feet (edema)
- Vomiting of blood or passage of black tarry stools

WHAT ARE THE LIFE THREATENING SYMPTOMS OF CIRRHOSIS?

The three life threatening symptoms of cirrhosis disease are:

1. Vomiting of bright red blood, vomiting of dark coffee like material or passing black tar like stools. This is suggestive of gastrointestinal bleeding
2. Mental confusion, forgetfulness or abnormal sleeping which untreated can lead to a coma
3. Fever with or without abdominal pain, that may signify infection of the fluid in the abdominal cavity.

We recommend you to contact us urgently and to go to a hospital’s emergency department if you become confused, vomit up blood, pass black stools, or develop a fever. A doctor must assess you urgently if you develop any of these. If you have already been listed for transplant, your family member must contact our transplant coordinator and inform of your admission to hospital on the same day. This will help us coordinate treatment with the doctors in the hospital where you are admitted.
WHAT ARE THE TREATMENTS AVAILABLE FOR CIRRHOSIS?

There is no cure for Cirrhosis. However some patients with cirrhosis are able to live well for many years without a transplant. These patients do not have a complication of cirrhosis and are said to have well compensated cirrhosis. These patients do not need a liver transplant but they still need close medical follow-up so that any complication can be detected early. Once patients with cirrhosis develop any complication such as bleeding, ascites, infection, jaundice, or mental confusion, it is time to consider Liver Transplantation. All patients with cirrhosis with or without complications should be under the regular treatment of a Hepatologist. These are special doctors who experts in the treatment of liver disease. Even if you have no symptoms and have well compensated liver cirrhosis, you should be seeing your doctor at least once every three months. Patients with cirrhosis need the following:

1. Nutritional support (high protein diet)
2. Multi-vitamin and multi-mineral supplements
3. Treatment of the cause of cirrhosis like hepatitis B and hepatitis C
4. Vaccinations to prevent certain infections
5. Good control of diabetes, if present
6. Strict abstinence from alcohol and smoking
7. Regular blood tests to assess the condition of the liver
8. Regular ultrasound scans of the liver to detect small cancers that may develop at any time in a patient with cirrhosis
9. Early detection and management of complications
10. Early referral to a transplant centre

We would like to emphasize there are no “Liver Protective” medications. Many drugs that are advertised to protect the liver do not have scientific basis. Many herbal medications that people take to protect their liver have unknown toxicities and may cause more harm than benefit to the liver.

You can detailed information about the complications of cirrhosis and the management of these complications at our website www.transplantationliver.com
There are two common ways of performing a liver transplantation:
(a) Cadaveric or Deceased Donor Transplant, and
(b) Living Donor Transplant.

**Cadaveric or Deceased Donor Transplant**

In this form of transplant, the family of a person who has been declared “brain dead” agrees to donate the person’s organs. This would mean that you would get a complete liver. The donor would have to match your blood group and general size. Adults usually receive the entire liver from a deceased donor. Sometimes only a portion of a whole liver from a deceased donor is used to fit a smaller person. This is known as Split Liver transplantation. In some cases, a liver from a deceased donor is split into two parts. The smaller part may go to a child, and the larger part may go to an adult.

The deceased donor is tested for infections (such as active hepatitis B, hepatitis C and HIV) before a decision is made to remove the organ. The liver is also screened for severe fatty liver or cirrhosis, and only used if it is healthy. There are some situations in patients can receive a liver from a person with past hepatitis B or C infection. These options will be discussed with you and specific risks explained to you. Please discuss this with the transplant team if you have further concerns.

After the pre-transplant evaluation, patients are registered with the Zonal Transplantation Committee of the government and placed on a waiting list. The priority on the waiting list is predominantly determined by how sick a patient is. This ensures that sicker patients get organs earlier. The transplant team will explain to you in detail how the allocation system works.

**Living Donor Liver Transplant**

A healthy living person may opt to donate part of his or her liver to a patient, usually a family member. A living donor liver transplant can help to avoid a long cadaveric transplant waiting list. The donor must be of the same or compatible blood group, usually between the ages of 18 – 50 years, should not be overweight, and should not have diabetes, major cardiac or respiratory problem or a psychiatric disease. Appropriate blood tests and abdominal scans are done on the donor to assess suitability and safety for donation. The donor will have to undergo major abdominal surgery to remove the part of the liver that will be transplanted into the patient. About 60 percent
of the donor’s liver can be safely removed for transplantation. Within 6-8 weeks, the remnant liver of the donor regenerates to normal size.

For further information on “Living Donor Liver Transplantation” you may contact the Transplant Hepatologist or visit our website [www.transplantationliver.com](http://www.transplantationliver.com)
STEPS TO TRANSPLANTATION

Referral for Liver Transplantation

Comprehensive Pre-transplant Assessment

Listing for Transplant

Assessment of Living Donor

Waiting List (Cadaveric Organ)

Suitable Living Donor

Phone Call (Organ Available)

Liver Transplantation Surgery

Admission

Dry Run

YES

NO
Your family physician or a specialist has referred you for liver transplantation because you have end-stage liver disease or liver cancer. **Liver transplantation is the only treatment for cirrhosis with complications.** Liver transplantation requires a serious commitment to your health and to lifelong daily medications, periodic blood tests to see how your new liver is working and regular follow-up visits to the transplant clinic. Your assessment usually starts with an interview with a liver specialist on the transplant team, called hepatologist. You will be admitted to our dedicated Liver Unit where various members of the Integrated Liver Care Team will evaluate you and decide if you meet the requirements for liver transplantation.

**SUPPORT**

Learning that you may need a transplant is very stressful. For this reason it is mandatory that Liver Transplant candidates have a support person throughout the whole process of transplantation. There is a lot of information that the patient and family need to learn about liver disease and liver transplantation, about the surgery and its complications and about the medications and life after liver transplantation. The process of transplantation can be overwhelming and a supportive family makes a big difference to your outcome.

A support person is anyone you choose who will be there for you during all phases of transplant, both before and after. The support person should be able to provide you with the physical and emotional support needed at all times during the transplant process. You could choose someone like your spouse, a family member, or a good friend. Choose someone who knows you well and is willing to make the long-standing commitment.

It is expected that the assessment will take about 4-5 days to complete. Once it is complete, the decision is made about whether transplant is the appropriate treatment for your condition. It is also determined during this assessment if you have any other associated diseases (like heart disease) that require specific attention and treatment before the transplant surgery. The waiting time for transplant varies from few weeks to months. During this period you need regular follow-up with our team.

You will need your support person to encourage you, listen to your concerns, and help you cope with emotions. After transplant they should be with you in the hospital while you recover. They are responsible for helping you to learn how to take your medications, keep clinic appointments, and be an emotional support. **After transplant we expect the patient and support person to stay here in Bangalore for up to two months before allowing them to return to their hometown.**
The assessment is an information gathering stage. The purpose of the assessment is to help us determine if a liver transplant is the best option for your medical condition. It also helps us to determine the condition of your other body organs as well as your psychological status. You and your support person will meet various members of the transplant team. Several blood tests, X-rays, and scans will be done.

It is very important to remember that no decisions about listing you for transplant will be made until all the information requested is received and the whole team has had a chance to meet and discuss your case. We will notify you of our decision once we have determined whether or not you are suitable for transplantation or not.

“WHO IS WHO” ON THE TRANSPLANT TEAM?

The Transplant Team is a multidisciplinary group made up of doctors, nurses, social workers, physiotherapists, occupational therapists, dietitians, managers and coordinators. Together we will determine the best course of action based on your particular circumstances. During your assessment you will see the following team members:

1) Transplant Hepatologist
   A hepatologist is a doctor who specializes in liver diseases. The transplant hepatologist will meet you and your family to discuss your medical condition. He will decide on the medical care you require till you reach the stage of surgery. He will advise you on the medications you need and the tests that need to be done periodically. After the transplant you have to follow-up with your transplant hepatologist for the rest of your life.

2) Transplant Surgeon
   The transplant surgeon is the actual person who performs the liver transplantation surgery. Our transplant surgeons will meet you and your family to discuss your medical condition and explain about the transplant surgery. They will explain to you about the course and outcome of the surgery as well as the possible complications of the surgery. They will ask you to sign a consent form where all the aspects of liver transplantation surgery and its complications are printed in detail.
3) **Transplant Coordinator**  
The transplant coordinator helps you understand the transplant process. The transplant coordinator is your point person of contact with the liver transplant program for all your queries. He will periodically call you and remind you to do blood tests and other investigations as required from time to time. He informs you about the documentation required to list you with the Zonal Transplantation Committee. He submits these documents to the committee.

4) **Social Worker**  
The social worker provides emotional support and counseling to you and your family. The social worker also assesses your psychological state and your understanding of the transplant process. This assessment helps you in coping with the change experienced by you and your family as a result of your illness or the transplant. It is important to know where you will be staying after transplant, who will support you in your family and your financial means. You should meet the social worker at each clinic visit in the pre-transplant period.

5) **Dietitian**  
The dietitian will meet with you and your family to review what you normally eat and counsel you on how to improve your diet before transplant. You will be given a proper diet plan. Diet is extremely important while you are waiting for the transplant because most patients with cirrhosis suffer from poor nutrition. Patients who have a good nutritional status prior to transplant do better in the recovery period after the transplant surgery. It is important to adhere to the dietician’s advice regarding food intake and use of food supplements. You should meet the social worker at each clinic visit in the pre-transplant period.

6) **Physiotherapist**  
The physiotherapist teaches you various exercises including breathing exercises, limb movement and muscle strengthening exercises. You will also be provided with a printed manual where detailed instructions are given. Patients with cirrhosis lose their muscle mass very rapidly and it is extremely important to perform regular exercises to maintain mobility, retain adequate muscle power and improve breathing capacity. This is important to improve outcome after surgery. You should meet the physiotherapist at each clinic visit in the pre-transplant period.

7) **Team Manager**  
The team manager helps you arrange logistics like accommodation and transport. You should call the team manager to book follow-up appointments prior to visiting the transplant clinic. In case the coordinator cannot be contacted, you can call the team manager to address your queries.
8) Finance Counselor
The finance counselor helps you understand the costs involved in the pre-transplant evaluation, transplant surgery, post-transplant hospital care and long term costs involved for lifelong medications and investigations. Since the process of evaluation and actual Liver Transplantation involves many specialists and hospital departments, the entire service is usually offered as a single financial package. You must clarify all your concerns about payments with the finance counselor. You should also discuss insurance and third party reimbursements as the case maybe with the counselor.

9) Other Medical Consultants
You will be seen by a heart doctor (cardiologist), lung doctor (pulmonologist), psychiatrist, kidney doctor (nephrologist), dentist, diabetes doctor (endocrinologist), gynecologist (for female patients) and several other medical consultants depending upon other illnesses that you may have. This is to ascertain that all your body organs and systems are adequately assessed and specific treatment started to optimize body functions prior to transplant.

**POLICY ON ALCOHOL AND DRUG USE**

You will be required to sign a contract with the liver transplant program stating that you will never drink alcohol or use recreational drugs. Patients who use alcohol and drugs before transplant are at high risk of restarting use of alcohol and/or drugs after transplant also. This seriously interferes with the function of the transplanted organ and may even lead to failure of the new liver. Therefore such patients have to undergo a rigorous psychological and psychiatric evaluation during the pre-transplant evaluation process. Such patients may also be required to attend a formal alcohol and drug rehabilitation program before they can be put on the waiting list. We randomly do blood and urine tests to check for level of alcohol or drugs in your blood stream to make sure that you are not using these substances. **If we are of the opinion that you are drinking alcohol or using drugs despite counseling, we will not be able to offer you liver transplantation and you will be taken off the waiting list.**

You will also be **required to stop smoking and oral tobacco use completely** before you are able to go on the waiting list for transplantation.
EXAMINATIONS AND DIAGNOSTIC TESTS DONE
DURING PRE-TRANSPLANT ASSESSMENT

Several tests will also be done during the pre-transplant evaluation process. These include but are not limited to the following:

1. Ultrasound of your liver
2. CT and/or MRI scan of the liver
3. Chest x-ray, Dental X-rays
4. Bone Density Scan
5. Blood test
6. Urine tests
7. Sputum tests
8. Electrocardiogram
9. Echocardiogram
10. Cardiac stress test
11. Endoscopy and colonoscopy
12. Mammogram and PAP smear (for females)

It may be decided that you have other medical problems need further evaluation, such as suspected heart disease. You may be referred for additional tests and/or consultations with other specialists. You will also receive appropriate vaccinations as per our protocol. If you have any questions or concerns regarding the pre-transplant evaluation process or any particular blood test or investigation, you can talk to the transplant coordinator or the hepatologist.

Remember that no decision about placing you on the waiting list for transplant will be made until all the information is received by the transplant team.

Do not assume that you are on the transplant list when you finish your pre-transplant evaluation. Each patient’s case is discussed by the transplant team before a decision to list is made. Our decision will be communicated to you by the transplant coordinator.
LISTING FOR TRANSPLANT

How is the Decision Made to Transplant?

It will take some time for all the information to be collected and reviewed. Once this is done, your case will be presented to the entire transplant team. The transplant team meets once every week to discuss patients. All the members of the team that you meet during your assessment are present at the meeting. The transplant team reviews information from the various examinations and tests and then decides to place you on the transplant waiting list.

People are listed according to three criteria:
   1. Blood group
   2. Status (urgent vs. routine)
   3. Disease severity score (based on blood test results)

There are four separate liver transplant lists, one for each of the four blood types (A, B, O, and AB). The surgeons also determine the weight range of acceptable donors for you. This allows them to match the size of the donor liver to your body. Patients who are sicker get priority on the list over patients who are less sick. This is determined by a disease severity score known as MELD score (see below). Higher your MELD score, higher will be your priority on the waiting list.

What is the MELD score?

MELD stands for "Model for End-Stage Liver Disease." It is a liver disease severity scoring system used for patients more than the age 12 years. MELD score ranges from 6 (less ill) to 40 (gravely ill). MELD score predicts the three month mortality rate in patients with advanced liver disease and signifies how urgently a patient needs a liver transplant. Patients with higher scores have increased risk of complications and death, if not transplanted early. A patient’s score may go up or down over time depending on the status of his or her liver disease. The MELD score is periodically assessed a number of times in patients while they are on the waiting list. MELD scores are used to prioritize organ allocation between patients. This will help ensure that donated livers go to the patients in greatest need at that moment. The MELD is calculated using a complex mathematical formula using three routine laboratory test results (a) bilirubin, (b) INR and (c) creatinine.
INSTRUCTIONS FOR PATIENTS ON THE WAITING LIST

Once you have been listed for liver transplantation at our hospital, it is absolutely essential that you remain in close contact with our team so that we are aware of your current state of health.

As a listed transplant patient you must be reachable by phone at all times. This is because there is no way to predict when you may be called. If we cannot contact you at the time of an organ offer we will have to move on to the next person on the waiting list.

While you are waiting, it is important that you visit our transplant clinic regularly (once every 2-4 weeks as advised by us) as well as perform regular blood tests and scans and inform us of the results.

We advise you to do the following blood tests every 2-4 weeks or as advised by us. These results should be sent by e-mail.

1. Complete blood counts
2. Liver Function Tests (Bilirubin, AST, ALT, Albumin)
3. Serum Electrolytes (Sodium, Potassium)
4. Kidney Function Tests (Serum Creatinine and Blood urea)
5. Prothrombin Time and INR
6. Other tests as advised by us
7. Ultrasound scan of the abdomen with Liver Doppler (every 3 months)

Please also note the following:

1. Kindly update us about all medication changes that you make.
2. Keep us updated about any changes in your contact details (telephone number and email ID).
3. Provide us with the contact details (telephone number and email ID) of your gastroenterologist whom you are following up with in your home town.
4. Inform the transplant coordinator in case you get hospitalized or if there is any unexpected deterioration in your condition.
5. If you are staying in Bangalore you must visit us with prior appointment, once every month or as directed by your treating doctor.
6. If you are staying outside Bangalore and following up with a local gastroenterologist, please get the above mentioned tests and ultrasound scan done regularly and email us all reports.
How long do I have to wait for an organ?

There is no way to tell how long you will wait for an organ. When a suitable organ becomes available, the transplant coordinator will call you. Your most important responsibility during the waiting period is to stay as healthy as possible, eat diet and supplements as advised, perform exercises as advised, do regular blood tests and visit the liver transplant clinic as advised.

PLANNING AHEAD

Now is also the time to plan ahead. Remember, if you do not live in Bangalore, both you and your support person are required to stay here for up to two months after your surgery. You need to think about how to manage your personal affairs while you are away from home. Talk about these things with your family or friends and make a plan. It is important to plan ahead because after your surgery you must not worry about these kinds of things and your focus should be on getting well.

Once you receive the call that a liver is available for you, you will not have much time to prepare. Here is a checklist to help you what you must bring with you when you get the call:

- Have a list ready for the items you will need to pack at the last minute.
- In advance, pack a small suitcase including slippers and loose clothing.
- Bring a small amount of cash in case you need to take a taxi or buy some things in the hospital.
- Bring a list of all medications you are using.
- Bring all your hospital records, blood test results and CT scan films.
- Don’t forget your mobile phone and charger.
- Decide before hand who will accompany you to the hospital.
WHAT HAPPENS WHEN A LIVER BECOMES AVAILABLE?

The phone call

The Transplant coordinator will contact you to come to the hospital. The first attempt will be made to reach you directly at your home number or personal cell phone number. If you are not reachable, all alternate contact numbers provided by you will be tried.

If we have a cadaveric liver organ available for you, we will inform you and ask if you are ready to go ahead with transplantation at this time. If you are ready to go ahead we will give you instructions about what time to be at the hospital what time we think the operation will be.

Remember the following:

- Do not eat or drink anything after receiving the call.
- Bring the bag you have packed, all your medical records including any CT scans or MRI scans, all the patient teaching material that we have given you, a list of medications you are presently taking, and your cell phone.
- When you reach the hospital, go directly to the Liver Transplant Unit on the 4th floor of the hospital.
- In case of any delay due to traffic or other reasons, inform the transplant coordinator

At the hospital

When you arrive at the hospital, you will be admitted to a single deluxe room in the Liver Transplant ward. The nurse will check your vital signs and draw blood samples for tests. You will undergo an ECG, ultrasound scan, echocardiogram, and a chest X-ray. The hepatologist, transplant surgeons and a member of the anesthesia team will assess you. Thereafter you will be asked to take a scrub bath and shower with special soap and change into hospital dress.

You will be explained about the transplant surgery, anesthesia and post-operative care in detail and asked to sign a consent form. This process will be video recorded for legal purposes. You can ask any questions and clarify any doubts before you sign the consent form.
After this, you should try to rest until you are shifted to the Operating Room. Quite often it may take a few hours before we actually shift you to the operating room. Sometimes the surgery may be cancelled. This can be because of several reasons including unsuitability of the cadaver organ as assessed by the transplant team at the last moment. Be prepared for these eventualities and make plans for getting home again if this happens. You should not feel discouraged with these dry runs.

**What happens in the Operating Room?**

When you are taken into the Operating Room, the anesthetist will ask you a few questions and then administer medication to put you to sleep. After you are asleep, the following tubes will be inserted:

1. Intravenous lines - these lines give you fluid, salts, sugar and medications
2. Central venous lines - these lines measure the volume of fluids in your body
3. Arterial line - this line measures your blood pressure
4. Endotracheal tube (breathing tube) - assists your breathing, it is attached to a breathing machine (a ventilator)
5. Nasogastric tube - drains the contents of your stomach
6. Urinary catheter - drains urine from your bladder

Following surgery, you may also have some abdominal drains which drain blood and body fluids from around the surgical area. You may have one or more of these tubes.

**What Happens during the surgery?**

During your operation, the surgeon will remove your diseased liver and reattach a new liver. They will attach the blood vessels (portal vein, hepatic veins, and hepatic artery) and common bile duct of the donor liver. The operation takes about 6-8 hours. You will have a large incision on the upper part of your abdomen. Staples will hold your incision together. As it heals, these staples will be removed, usually after two weeks after the surgery. A large bandage called a “dressing” will cover the incision. The dressing serves as a protection and will be changed by the nurses regularly.

**Where do I go after surgery?**

After surgery you will be taken to the Transplant ICU (Intensive Care Unit). You may remain in the transplant ICU for 5-7 days. The breathing tube is usually removed on the first or second day. The other tubes are removed over the next few days. Once you are
stable, moving around and eating on your own, you will be sent to your room in the liver transplant ward. You will be weak, but will gradually resume an active role in caring for yourself. You will be taught to take your own medications and to recognize the signs of infection and rejection. You will have physiotherapy sessions every day. This will help you in mobilizing, gaining strength and deep breathing exercises to prevent lung infection.

**When will I go home?**

You will go home when:

1. You have learned how to take your own medications.
2. You are able to recognize the signs of infection/rejection.
3. You are physically stable.
TIME TO GO HOME

Medications

You will be on a number of medications when you leave the hospital. At home, you will continue taking most of the medicines. The most important of these medications are the ones that are used to prevent rejection of the new organ. These are known as anti-rejection drugs or immunosuppressant drugs. You will have to take one or more of these drugs for the rest of your life, in addition to other medications. For the first few months you may be given antibiotics to help protect you against infection. You will multivitamin supplements, calcium supplements and drugs to protect your stomach from ulcers caused by other medications. The transplant team and the nurses on the ward will teach you how to take medicines. Before discharge itself, we expect you to be taking your medications yourself. Initially it may seem a little overwhelming, but with time you will become very comfortable with the routine. We want you to become responsible for taking your own medications and you must call us if you have any doubt about your medications.

You should talk to your physician, pharmacist, transplant nurse, and/or coordinator to understand fully:

- The name and purpose of each medication
- When to take each medication
- How to take each medication (empty stomach or after meals)
- How long to continue taking each medication
- Important side effects of each medication
- What to do if you forget to take a dose
- When to order more medication so it doesn't run out
- Contact numbers of local pharmaceutical dealers who can supply you the medicine at short notice.

Guidelines for taking medications

- Always take your medications at the same time every day.
- Remember the exact dose of each medication. We will provide you with an updated medication chart at each visit that will state the name, dose and timing of each medication.
• Never skip a dose. If you accidentally miss a dose, and it is less than 12 hours, take the same dose again. If it is more than 12 hours since the time you took your dose, call the transplant team.
• Do not stop taking or change the dose of any medication without informing the transplant team.
• Call your transplant team if you are experiencing side effects from your medications, or are having vomiting or diarrhea.
• Never take medications other than those prescribed by your transplant team, including over-the-counter medications or those prescribed by other physicians without first calling the transplant team.
• Do not substitute the brands of medications without informing the transplant team.
• Store your medications out of reach of small children.
• Store medications in a cool, dry place.

The following are a list of common post-transplant medications. You may be taking only a few medications out of these

**Immunosuppressant Medications**

• Tacrolimus (Prograf, Pangraf)
• Cyclosporine (Neoral, Gengraf, Sandimmune)
• Mycophenolate (MyCept, Myfortic)
• Prednisolone
• Azathioprine (Azoran)
• Sirolimus (Rapamune)

**Other medications**

• Anti-Fungal Medications (Fluconazole)
• Antiviral Medications (Valcyte, Valgan)
• Antibiotics (Septran)
• Anti-Ulcer Medications (Pantodac, Neksium, Razo, Rantac)
• Calcium, vitamin D, multivitamin and multi-mineral supplements
• Blood thinning medications (Aspirin, Warfarin)

Remember: Not taking medications as prescribed is the most common reason for transplant failure.
What can I expect after discharge?

The first few months after transplant are the most critical. This is when the rates of rejection and infection are highest. It is important that you remain in the Bangalore area so you have quick access to the necessary expertise. Regular visits to the transplant clinic visits and blood tests will now be part of your life. You should continue with dietary precautions as advised by the nutritionist at home. You should also do the exercises taught by the physiotherapist at home so that you are strong enough to manage your daily activities.

What should I do when I go home?

After transplantation you will continue to improve. To assist your recovery you must follow a few basic rules:

- Follow the instructions of your doctors and transplant coordinators.
- Eat a balanced diet and ensure that you maintain a healthy weight.
- Eat well cooked food at home and avoid eating food outside.
- Find a healthy balance between exercise and activity; follow the guidelines provided by your therapists and doctors.
- Do not drink alcohol.
- Do not smoke or chew tobacco.
- Avoid places with pollution such as smoke, excess dust, construction areas and heavy vehicular traffic.
- When traveling always carry enough medication for unexpected delays. Always carry a written list of medications with you.
- Start planning for future occupational activity. Our social workers can help you assist with this.
INSTRUCTIONS FOR PATIENTS – LONG TERM FOLLOW-UP

Lifelong monitoring is essential. This helps to ascertain that your transplanted liver is functioning well. This also helps in early detection of medical problems such as diabetes, high blood pressure, high cholesterol, kidney disease, recurrence of liver disease and drug adverse effects. Monitoring includes regular visits to the transplant clinic and periodic laboratory tests.

You must also have regular follow-up with a local gastroenterologist at your place of residence. It is ideal that the transplant team coordinates with your local gastroenterologist to optimize your medical care.

You must do the following blood tests once every 2 months (lifelong) and send us the reports by email.

- Complete blood counts
- Liver function tests
- Serum creatinine
- Electrolytes (Sodium and Potassium)
- Fasting blood sugar
- Tacrolimus levels

In addition to the above the following tests should be done at the specified intervals:

*Once every six months*

- Lipid profile
- HBA-1C

*Once every year*

- Thyroid test (TSH)
- Vitamin D levels
- Cardiac echocardiogram
- Chest X-ray
- Ultrasound scan of the liver
- Bone scan (DEXA)
- Special kidney tests: urine microalbumin and GFR assessment
- Mammogram (for females above 40 years)
- Cervical PAP smear (for females above 30 years)
- Skin examination by Dermatologist
- ENT examination
- Dental examination by Dentist
Once every three years

- Cardiac Stress test (Treadmill test)

Once every five years

- Colonoscopy (if you are above 40 years)
- Other specific tests recommended by us

You must avoid gaining weight beyond your ideal recommended body weight. You must check your weight every month and if you are gaining unexpected weight you must inform us and start an active exercise and diet program. Our team will assist you in designing a diet and exercise plan for you.
OUR TEAM

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