



**PennState Health**  
Milton S. Hershey  
Medical Center

PATIENT INFORMATION GUIDE

# LIVER TRANSPLANT

DIVISION OF ABDOMINAL ORGAN TRANSPLANT

717-531-6092 or 1-800-525-5395

## **:: HOW TO CONTACT THE TRANSPLANT OFFICE**

Please call your specific transplant coordinator during office hours for all routine care or questions. Refer to the coordinator's business card or call 717-531-6092 and ask to speak with your coordinator.

**Location:** Penn State Health  
Milton S. Hershey Medical Center

**Telephone:** 717-531-6092 or 1-800-525-5395

**Fax:** 717-531-0124 or 717-531-3717

**Address:** Penn State Health  
Milton S. Hershey Medical Center  
Section of Transplantation  
Mail Code A520, Suite 4301  
90 Hope Drive  
P.O. Box 855  
Hershey, PA 17033-0855

**Office Hours:** 8 a.m. to 5 p.m. / Monday through Friday

**After Hours:** **WHILE WAITING FOR TRANSPLANT  
Holidays, evenings and weekends  
Call 717-531-8521 and ask for the  
hepatology fellow on call. Do not mention  
transplant to the hospital operator. After you  
are connected to the hepatology fellow, let  
them know you are in evaluation for liver  
transplant or on the transplant waiting list.**

## **:: IF YOU ARE ADMITTED TO THE HOSPITAL OR EMERGENCY ROOM**

Please call our office or have a support person call our office within 24 hours to let us know where you have been admitted.

Have your physician at the admitted hospital call the MD Network at 717-531-5880 and ask for the **hepatology attending** on call. They should not mention transplant to the hospital operator. After they are connected to the hepatology attending, they can let them know you are on the transplant waiting list or being evaluated, discuss your care and/or arrange for transfer to Milton S. Hershey Medical Center.



## **:: INTRODUCTION**

More than 4,000 liver transplants are performed in the U.S. each year. Greater than 90% of liver transplant patients are alive and well after five years. While there are some side effects from medications taken to suppress the *immune system*\* so the transplanted liver will not be rejected, most patients lead full, productive lives and are able to return to work. The use of new anti-rejection drugs and other medications are constantly improving the results of liver transplantation.

Like many individuals beginning the evaluation process for a liver transplant, you may have many questions and concerns. We encourage you to read this entire guide and ask questions of your doctors, nurses and other staff if there is something you do not understand. As your transplant team, we are aware that you and your family have likely encountered a great deal of stress and many hurdles related to your health. Living with serious health issues involves many physical, emotional and financial challenges. We are available to support you through this process as you gather information and face upcoming decisions.

This guide includes a brief discussion of what your liver does normally and what happens when your liver is damaged, as well as specific information about Penn State Health's Abdominal Transplant Program. It also describes the evaluation and selection process for an liver transplant, the wait for a donor liver and the operation and immediate post-operative period. The information regarding what you should do after transplantation is especially important because you must learn about your medicines and how to maintain good health with a newly transplanted liver. Being well-informed about how you can take good care of yourself before and after the transplant is a vital part of your recovery process. Remember, if you have any questions, call your transplant coordinator, who is available Monday through Friday from 8:00 a.m. to 5:00 p.m.

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\* Words found in the Glossary at the end of this guide are in italics the first time they are used.

The United Network for Organ Sharing (UNOS) provides a toll-free patient services line to help transplant candidates, recipients and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services telephone number is 1-888-894-6361.

***Please keep this guide handy and keep all of your correspondence regarding the transplant process with this guide. It will help you to know what to expect during each step of the process if you read the whole guide.***

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## **:: YOUR TRANSPLANT TEAM**

### **TRANSPLANT SURGEON**

Our transplant surgeons have advanced training in transplant surgery. The surgeon will meet with you before the transplant surgery to determine, with the help of other members of the medical team, whether transplant is the best treatment for you. He or she will speak to you about the risks and benefits of the surgery and answer any questions you may have about the surgery or follow-up care. The surgeon will perform the transplant surgery and oversee all aspects of your care during your hospital stay and the first year after your transplant.

### **TRANSPLANT HEPATOLOGIST**

Transplant *hepatologists* are doctors who are experts in liver disease and partner with the transplant surgeons to ensure you receive the best care possible. Our transplant hepatologists are responsible for determining your medical need for a transplant, making recommendations for your complex medical needs before transplant and managing your medical care one year after transplant.

### **TRANSPLANT NURSE PRACTITIONER/PHYSICIAN ASSISTANT**

Our transplant nurse practitioners (NPs) and physician assistants (PAs) are advanced practice clinicians with training in the care of transplant patients. The NPs and PAs work closely with the transplant surgeons to monitor your recovery and care for you during the first year after transplant.

### **TRANSPLANT COORDINATOR**

Your transplant coordinator is your main source of contact with the transplant team. The coordinator is a highly trained registered nurse who is an integral part of your transplant process, both before and after transplant.

Before transplant, your coordinator guides you through the education and workup process and is your contact person for any questions or concerns you

have while awaiting transplant. After transplant, your care is transferred to a post-transplant coordinator who educates you on how to care for yourself and how to take your medications properly. The coordinator also reviews your lab work in conjunction with our physicians and answers any questions that may arise.

### **TRANSPLANT SOCIAL WORKER**

Transplant social workers provide support, education, counseling and assistance throughout the evaluation and transplant process. They assist patients and families as they adjust to life with a chronic illness, living with a transplant and resuming life after a transplant. Social work services are available for all pre- and post-transplant patients and their families, as well as for living organ donors.

### **TRANSPLANT FINANCIAL COORDINATOR**

The transplant financial coordinator reviews your insurance coverage and explains what coverage you have available for transplant and medications after transplant. The financial coordinator also makes recommendations for additional coverage to minimize your out-of-pocket expense after transplant.

### **TRANSPLANT DIETITIAN**

A transplant dietitian provides nutrition counseling for patients awaiting transplant, post-transplant patients and living donors. Nutrition support is tailored to meet the needs of each patient.

### **TRANSPLANT PHARMACIST**

The transplant pharmacist has an in-depth knowledge of transplant-related medications. The pharmacist educates patients on anti-rejection medications, side effects of medications and proper dosing.

### **TRANSPLANT OFFICE ASSISTANT**

Our transplant office assistants work closely with our transplant coordinators, providing administrative support such as answering phone calls, scheduling, entering test results and patient information.

*Fellows, residents and medical students may also be involved in your care. We are an academic medical center, providing high-quality medical education training under the supervision of our expert physicians and staff.*



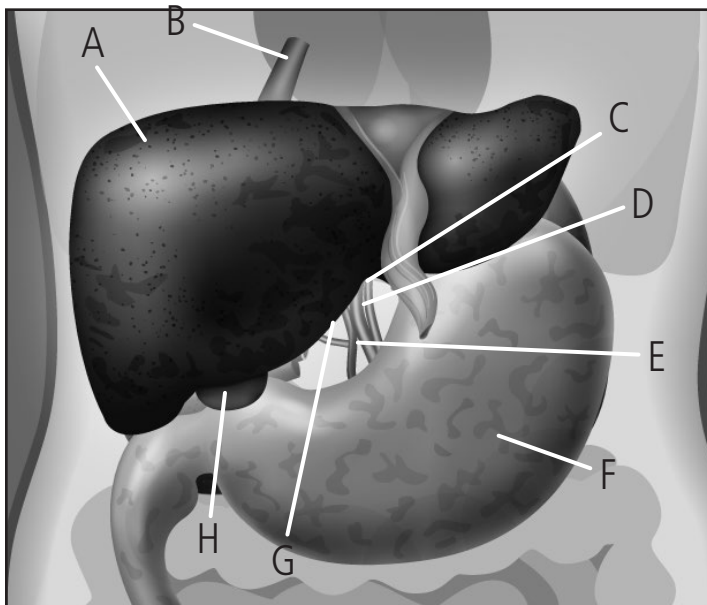


## :: YOUR LIVER FUNCTION

### HOW DOES MY LIVER WORK?

The liver is located on the right side of the abdomen, just behind the lower rim of the rib cage. It is the largest organ in the body and performs more than 500 functions. A brief list of some of these functions includes:

- Secretes *bile*, a yellowish-brown or green fluid that aids in the absorption of fats and minerals
- Converts and stores various foods into substances that are then used for life and growth
- Breaks down and excretes many waste products
- Manufactures proteins that are vital to normal clotting of the blood



- A: Liver
- B: Hepatic Vein
- C: Hepatic Artery
- D: Portal Vein
- E: Common Bile Duct
- F: Stomach
- G: Cystic Duct
- H: Gallbladder

## **WHAT IS LIVER DISEASE?**

Liver damage may occur with infections such as hepatitis, exposure to toxic chemicals or drugs like narcotics, alcoholism, genetic disorders, diabetes, obesity, heart failure, cancer and shock. In many cases, the liver is able to repair itself; in others, a variety of treatments may be effective.

As liver disease progresses, cirrhosis and end-stage liver disease may occur. Cirrhosis involves loss of liver cells and irreversible scarring of the liver. Cirrhosis can cause weakness, loss of appetite, easy bruising, yellowing of the skin (*jaundice*), itching and fatigue. End-stage liver disease is liver disease that has caused the quality of life to deteriorate to an unacceptable level, with the patient unable to perform his/her usual activities, such as work and caring for family or home.

## :: MANAGEMENT OF LIVER DISEASE

Complications associated with cirrhosis or end-stage liver disease are challenging and difficult to manage. The delicate balance of medications, fluid management, nutrition and education of the patient are best handled by a hepatologist and your local gastroenterologist.

### Common complications of liver disease include:

- **Encephalopathy**, which is caused by increased ammonia levels in the blood. It may cause confusion, memory loss, fatigue and agitation and can lead to coma.

#### Tips:

- Follow a balanced protein diet.
- Avoid large protein loads.
- Take lactulose at least once a day to have three to four bowel movements per day. You may need to adjust the dose of lactulose in order to meet this goal.
- **Esophageal varices**, which are extra blood vessels that form in the abdomen and esophagus from resistance of blood flow through the diseased liver. Vessels may easily rupture and cause vomiting of blood or passing of blood through the rectum.

#### Tips:

- Get an initial endoscopy or upper endoscopy (EGD) to screen for varices. An endoscopy is a procedure where a doctor passes a tiny tube with a camera on it through your mouth into your stomach.



- If you pass vomit blood or pass blood through your rectum, go to the nearest emergency room as soon as possible.
- If you have varices, you may not lift more than 25 pounds.
- **Ascites and edema**, which are collections of fluid in the abdomen or extremities and may require diuretic medication, salt restriction in the diet and/or a procedure called a tap (paracentesis) to remove fluid. During a tap, a doctor inserts a special needle into the abdomen to drain the excess fluid.

**Tips:**

- Follow a low salt diet (no more than 2000 mg per day).
- Watch food labels (mg of sodium and serving size).
- Take water pills (diuretics).
- Have paracentesis (tap) if short of breath.
- **Coagulopathy**, which is the inability of the liver to control blood clotting. This places patients at risk for bleeding and blood clots.
- **Malnutrition**, which results when the diseased liver is unable to store nutrients like protein.

**Tips:**

- Add supplements to your diet if not eating at least half normal meals (Boost, Ensure, Carnation Instant Breakfast).
- Eat small, frequent meals (every two to three hours).

- **Other complications may include:**
  - **Bacterial peritonitis**, which is an infection in the abdominal cavity.
  - **Hepatorenal syndrome**, which is a combination of kidney failure and liver failure.
  - **Hepatopulmonary syndrome**, which creates shortness of breath and low oxygen levels in the blood caused by enlarged blood vessels in the lungs in combination with liver disease.
  - **Splenomegaly**, which is an abnormal enlargement of the spleen.
  - **Liver cancer or hepatocellular carcinoma (HCC)**, which is a primary cancer of the liver and occurs mostly in patients with chronic liver disease and cirrhosis. If caught early, it can sometimes be cured with surgery or transplant. If the cancer grows too large, transplant may no longer be an option.

## :: **LIVER TRANSPLANT**

Transplantation is performed for acute (*fulminant*) liver failure, which occurs suddenly, or progressive chronic liver disease (*cirrhosis*) that is not able to be treated with medicine or surgery. It is assumed that without receiving a liver transplant, you will die from your liver disease and that the risk of death from the transplant operation is less than that of the liver disease. If you are approved for liver transplantation, it is believed that your life expectancy will be prolonged and that there is a good likelihood that you will be able to resume a productive life.

**Liver transplantation may be considered an acceptable treatment for patients under the following circumstances:**

1. Patients with irreversible advanced chronic liver disease—end-stage liver disease.
2. There is **no** reasonable alternative treatment for the patient's liver disease.
3. Debilitating itching (pruritus).
4. Development of kidney failure caused by the liver failure (hepatorenal syndrome).
5. Recurrent mental confusion (encephalopathy) not adequately managed with conventional therapy.
6. Fulminant or sub-fulminant hepatitis.
7. Inoperable, life-threatening non-cancerous tumors of the liver.
8. Certain inborn errors of metabolism.

9. Primary hepatic **cancer** which has not spread to other parts of the body, in certain patients.
  
10. **The patient must be considered an acceptable surgical risk, must be reliable and *compliant* and have an adequate support system sufficient to adhere to the required post-transplant treatment program.**

Before the decision to place you on the transplant list is made, a thorough evaluation of your case is made to determine the exact cause and extent of your liver disease.

## :: **PRE-TRANSPLANT EVALUATION**

The pre-transplant evaluation is completed on an outpatient basis over several weeks. A transplant surgeon, hepatologist, nurse coordinator, social workers, financial coordinator, pharmacist and dietician see candidates for transplantation. Other consultations may be requested as needed. The liver transplant coordinator is the key contact person who facilitates the evaluation process.

You and your family must understand the process of being evaluated, placed on the waiting list and then **the care that will be necessary after transplant** in order to make an educated decision about transplant being the right treatment for you. This is a lifestyle decision for you and your family as you will need to make a commitment to follow a **lifelong, disciplined medical program to prevent injury or rejection of the new liver**. This will require you to take prescribed medication and maintain close contact with your family doctor, hepatologist and transplant surgeon.

### **THE MEDICAL REVIEW**

The transplant team will perform a complete evaluation of your medical history and current health status. Among the many exams and tests you may undergo are:

- A detailed history, physical examination and laboratory tests to determine the factors responsible for your liver disease.
- A complete laboratory assessment, including blood and urine testing.
- Several radiological tests, including a chest x-ray, ultrasound to check blood flow to the liver and a CT scan to determine the size of your liver and the presence of any tumors.

- An electrocardiogram and echocardiogram to determine the status of your heart.
- Nuclear (chemical) stress test to determine how your heart functions under stress. This is not a treadmill stress test.
- Pulmonary function tests and/or arterial blood gases to measure the capacity of your lungs.
- EGD to determine if you have varices, inflammation or ulceration.
- Colonoscopy for patients over 50 years of age. This procedure passes a flexible tube into your rectum and colon to determine whether you have polyps or other abnormalities.
- Miscellaneous studies, including Pap smear and mammogram for women, DEXA scan to measure bone density and dental examination to detect cavities or infection.

## **THE PSYCHOSOCIAL ASSESSMENT**

A social worker, psychiatrist and possibly a drug and alcohol counselor will meet with you and your family to assess your psychosocial situation, which relates to social factors and behaviors, and support system. They will help to determine how your liver disease has affected you and your family in an effort to provide resources and coping techniques for dealing with stress and your health concerns. Recommendations will be made to both you and the transplant team for strategies to minimize the chances of recurrence of alcohol or substance abuse following transplantation. The psychiatric visit is also often a requirement of your insurance company.

Patients may be asked to undergo a drug and alcohol rehabilitation program, or continued counseling locally. Patients are expected to follow through with recommendations made by the psychosocial team and often will not be able to

be listed until these requirements are met. Your social worker will inform you of transplant support groups and financial resources available to you and is available by phone to assist you with completing listing requirements.

### **THE NUTRITIONAL EVALUATION**

A registered dietitian is available to review your dietary habits with you and your family and help you develop and maintain a healthful diet before and after the transplant. You may receive recommendations regarding protein intake and sodium restriction to help manage symptoms of liver disease.

### **FINANCIAL COORDINATION**

A financial coordinator will meet with you to discuss any insurance issues related to your medical care, both before and after the transplant. If you have private health insurance, the financial coordinator will contact your insurance company to determine your benefits for transplant. The financial coordinator will help patients with inadequate health insurance coverage review other insurance options.

*Please note that Medicare Part B will not pay for anti-rejection medications unless the transplant facility is Medicare approved. Hershey Medical Center is an approved transplant facility.*

As a transplant patient, you have an important role in the financial aspects of your surgery. You are responsible for reviewing your benefits and reporting any changes in your insurance coverage to the transplant team and your financial coordinator. Taking an active role in the reimbursement and payment processes for your particular insurance plan may help your financial affairs run more smoothly before and after your transplant. The financial coordinator is available to consult with you on any questions regarding your insurance coverage.

*If your insurance changes at any time during the transplant process, please call our office to speak to a financial coordinator.*

## :: PATIENT SELECTION FOR LIVER TRANSPLANTATION

The goal of the Liver Transplant Program at Penn State Health is to provide liver transplantation to those patients who will obtain the most benefit from having a transplant. The overall goal of receiving a transplant is to prolong life and to improve the quality of life.

At the Penn State Health, the final decision to place a patient on the liver transplant list is made by a Liver Transplant Selection Committee. This committee is composed of liver transplant surgeons, hepatologists, nurse coordinators, social workers, a financial counselor, a dietician and invited consultants. The purpose of the committee is to review the need for transplantation and the outcome of performing a transplant for each potential recipient

Once the final evaluation is complete, your case will be presented during a meeting of the Liver Transplant Selection Committee. Depending upon the findings of your evaluation, a decision may be made to either:

1. Accept you for transplantation.
2. Undertake additional studies.
3. Follow your case and possibly consider you for transplantation at a later date.
4. Not recommend transplantation because of a *contraindication*.



**The following contraindications may exclude some patients from liver transplantation:**

1. Active alcohol or other chemical abuse.
2. Liver cancer that has spread to other parts of the body (metastatic malignancy) or other cancer that originated elsewhere in the body (non-hepatic primary malignancy).
3. Other severe co-existing diseases.
4. History of noncompliance with medical regimen.
5. Inadequate family or other support system.
6. Human Immunodeficiency Virus (HIV)-positive status.
7. Overwhelming infection (sepsis).
8. Individuals of advanced age may be considered for transplantation, depending on their vigor and absence of complicating medical problems.
9. Evidence of active Hepatitis B virus.

If there are no contraindications and the evaluation is considered complete, you will be listed with UNOS for a liver transplant. There may be instances when all the studies are complete and the patient is considered acceptable, but requires rehabilitation or observation for a period of time. Those patients who have a history of alcoholism or drug use may need to be sober or drug free for a certain amount of time before being placed on the waiting list. Due to the high demand and low supply of organs, it is important to know that patients will not continue with the high-risk behavior that caused their liver failure. It is also important to know that patients will be compliant with the care of their transplanted organ

after transplant. Only patients having psychosocial factors predicting long-term sobriety are accepted for transplantation.

The transplant coordinator will contact you after the selection meeting to inform you of the team's decision and review the plan of care. This may involve coming to the clinic to have a discussion with the doctors, or your coordinator may need to schedule additional studies.

## :: **WAITING FOR A TRANSPLANT**

### **WHAT HAPPENS AFTER BEING LISTED FOR A LIVER TRANSPLANT?**

If you are accepted as a liver transplant candidate, you will be placed on the national waiting list in the UNOS national database. You will receive a letter from our office telling you that you are listed and the date your listing is effective. Organs are allocated based on the candidate's MELD (**M**odel for **E**nd stage **L**iver **D**isease) score.

The MELD score calculates the severity of your illness based on a formula that utilizes your bloodwork results total bilirubin, creatinine, sodium and INR.. Your albumin level is also reported to UNOS but not used in the calculation of your MELD score. It is important that all five of these lab values are checked every time you get bloodwork. The MELD score ranges from a low of six to a high of 40. Those with a higher score are the most ill. You are then ranked against other patients of your blood type in the region based on this score. MELD scores constantly change as patients get sicker or feel better and, therefore, your rank constantly changes. Most people will get transplanted when their MELD score is in the mid-20 to mid-30 range. How soon your MELD advances to that level varies as each patient's liver function will diminish at a different rate.

Enclosed with your listing letter there will be a lab prescription for your MELD bloodwork. **It is very important to get this bloodwork on time to keep your listing in the UNOS database current.** If lab results are not entered on time according to the UNOS schedule, your score will drop to the lowest rank of six until new bloodwork is entered. It is your responsibility to keep track of due dates for your MELD bloodwork.

**While waiting for your liver transplant:**

- Get blood work according to the MELD prescription sent to you.
- Continue to receive medical therapy supervised by your local gastroenterologist and family physician, with periodic visits to the transplant team.
- Keep your transplant coordinator informed of accurate telephone numbers where you can be reached.
- Contact your transplant coordinator prior to any non-urgent procedures to obtain clearance. This includes dental extractions, orthopedic surgeries, hernia repairs, joint injections, eye surgeries, etc.
- Be prepared to travel to the hospital the moment a liver becomes available.

## **IMPORTANT TIPS TO HELP KEEP YOUR LIVER FUNCTIONING WHILE WAITING FOR TRANSPLANT**

1. **Avoid alcohol of all types** (including beer, wine and mixed drinks). Do not drink “nonalcoholic” beer or wine, as they contain alcohol. Even if alcohol is not the cause of your liver failure, once you have cirrhosis, any type of alcohol will make your liver function worse. **The use of alcohol during your evaluation or while you are on the transplant waiting list is immediate grounds to stop the evaluation process or be removed from the transplant waiting list.**
2. **Receive vaccinations against Hepatitis A and B**, if not already immune (we will let you know your status after checking your blood). Also, the pneumonia vaccine should be repeated every five years and the flu shot should be obtained on a yearly basis.
3. **Avoid liver toxic medications.** \* Do not use aspirin-like medications. **Do not** use Excedrin, Anacin, Motrin, Aleve, or Advil (Ibuprofen). **\*Acetaminophen or Tylenol is safe.** Use no more than two grams per day. You may take **one extra-strength (500 mg) pill every six hours, if needed.** Review other medications with your doctor.
4. **Avoid use of sedatives/anti-anxiety meds**, such as benzodiazepines. Please inform your local doctors that you are to avoid these types of medications when they are prescribing medications for you. If you need sleep aids, you may try an over-the-counter histamine H1 blocker, such as diphenhydramine (Benadryl) or melatonin.
5. **Avoid narcotic pain medications**, such as oxycodone, hydrocodone, codeine, fentanyl and morphine.

6. **Avoid iron supplementation** unless your doctor has shown that you are iron deficient (if you take a multivitamin, there are brands that do not have iron as a component).
7. If you are having excessive muscle cramping, please talk with your doctor about the use of **magnesium supplements or zinc sulfate**. Most can be purchased over the counter without a prescription. For example: magnesium oxide 400 mg or zinc sulfate 220 mg tablets.
8. Follow a **low salt** diet (2000 mg sodium total for 24-hour period).
9. **Avoid herbal supplements** and other supplements that may damage your liver. If you are unsure about any herbal supplements, please ask our staff prior to use.
10. If you have swelling in your lower extremities, use a **urea-containing moisturizer**, such as Eucerin, to avoid cellulitis (infection/inflammation).
11. **Once cirrhosis develops**, you are at risk for developing enlarged blood vessels (varices) in your esophagus (the tube that carries food/fluids from your mouth to your stomach). You should have an EGD screening to follow your risk of bleeding. The frequency of follow-up EGDs depends on what is found during your examination. This study can be scheduled with your local doctor and does not have to be done at Hershey Medical Center.
12. You should have follow-up screenings with CT and/or MRI scans, along with a blood test measuring your alpha-fetoprotein levels (AFP) on a regular basis for the early detection of HCC. **The CT and/or MRI scans need to be done here at Hershey Medical Center** so they can be reviewed by our radiologists.

13. **General anesthesia is contraindicated with liver disease.** Do not have any non-urgent surgical procedures performed without the consent of the liver transplant team. (This includes everything from dental extractions to hernia repairs.)
14. Contact your transplant coordinator or the hepatology fellow within 24 hours of an admission to any hospital other than the Hershey Medical Center.
15. If your local doctor wants to transfer your admission to our hospital, he or she should **call the MD Network at 717-531-5880** and ask for the hepatology attending MD to discuss possible transfer.
16. You should **have routine screening for osteoporosis** by DEXA scan, both before and after transplant. This can be arranged through your local doctor.

*The more you know, the better you can take care of yourself!*





## **:: GOING TO THE HOSPITAL**

When called by your transplant coordinator, you will be instructed to come promptly to the Admissions Department at Penn State Health, located at the hospital main entrance. If you are arriving after hours, you will be instructed to report to the Emergency Department. A physician will review your record and start a variety of exams and tests. An intravenous (IV) infusion will be placed in your arm.

It is important to understand that you can be called in for a transplant, have the entire pre-operative work-up completed and actually be waiting to go to surgery, and then be informed that the transplant is canceled. Emotionally, this can be difficult, so it is good to be prepared for this possibility. If the liver is not in transplantable condition, you will be sent home until the next opportunity arises.

Packing for the hospital now will help ease the stress of going to the hospital for transplant. You may want to pack the following items for your comfort:

- A list of your medications
- Personal care items like a toothbrush, comb/hairbrush and deodorant
- Special pillows or blankets
- Robe and slippers
- Family photo(s)
- Charging cords for electronic devices
- Phone numbers for emergencies

## :: **WHERE WILL MY LIVER COME FROM?**

There are two basic types of liver donors:

1. **Live donor:** This is a person who chooses to give part of his or her liver to someone needing a liver transplant. This can be a family member or friend.

Not everyone is a suitable candidate for a partial live liver transplant. The transplant team will let you know if this is an option for you.

Anyone wishing to become a live donor must contact our office and speak with a member of the donor team. If, after reviewing their medical records, they appear to be a suitable donor for evaluation, they will be contacted to schedule a donor evaluation and testing. If a suitable live donor is approved for donation of a part of their liver, the surgery can be scheduled in advance.

2. **Deceased donor:** This is a person who has had a life-limiting injury and whose family wishes to donate their organs to others needing a transplant.

There are several types of deceased donors:

- **Standard Criteria Donors (SCD)**  
SCDs have died due to a fatal brain injury and have been declared brain dead. They remain on life support until the organs are removed for transplant. They do not have any known medical or social history that would have affected their liver. In general, these livers have lower rates of complications when compared to the other types of livers described next.

- **Extended Criteria Donors (ECD)**  
These donors have medical risk factors that may result in less than optimal liver function and increased risk of complications. These donor factors include age greater than 70, fatty liver, split liver, history of hepatitis C or B or history of certain types of cancer. A liver from one of these donors may shorten your waiting time for transplant.
  
- **Donors after Circulatory Death (DCD)**  
These donors have an irreversible injury that further medical care cannot correct. The patient's family and physicians have agreed to discontinue life support. These patients are only declared dead after removal of life support when the heart stops beating. Once this happens, the organs can be recovered for transplant. A liver from one of these donors may shorten your waiting time for transplant.
  
- **Public Health Service Increased Risk (PHS-IR) Donors**  
While receiving any donor organ carries a risk of disease transmission, some donors are at higher risk due to certain behaviors. The PHS has identified the following increased risk behaviors:
  - Men who have had sex with another man in the last 12 months.
  
  - Anyone who has had sex in exchange for drugs or money in the last 12 months.
  
  - Anyone who has had sex with a person known or suspected to have the HIV or Hepatitis B or C infection in the last 12 months.
  
  - Anyone who has injected drugs for non-medical reasons in the last 12 months.
  
  - Women who have had sex with a man who has had multiple male sex partners in the last 12 months.

- Anyone who has had sex in the last 12 months with any of the persons described above.
- Anyone who has been in jail or a correctional facility for more than three days in the last 12 months.
- A child who is less than 18 months of age born to a mother known to be infected with or at increased risk of HIV, or Hepatitis B or C infection.
- A child who has been breastfed within the last 12 months from a mother known to be infected with or at increased risk of HIV infection.
- Anyone newly diagnosed with or who has been treated for syphilis, gonorrhea, chlamydia or genital ulcers in the last 12 months.
- Anyone who has been on hemodialysis in the last 12 months (risk for Hepatitis C only).
- Anyone whose medical/behavior history cannot be obtained.
- Anyone whose blood specimen is diluted.

A liver from one of these donors may shorten your waiting time for transplant. In many cases, the risk of dying while waiting for a transplant is greater than the risk of disease transmission from one of these donors.

The transplant team will discuss these donor types with you in detail. Your surgeon will review all liver offers for you and you will only be called once the surgeon has agreed this is a good liver for you. You will be given the option to decline any offers that are not standard donors.

## :: **THE TRANSPLANT OPERATION**

Liver transplant surgery is extremely complex and may last **eight to 12** hours. Your entire liver will be removed and replaced by the donor liver. To do this, the surgeon must make a large incision in your abdomen (see Figure 1). You will also have scars in your shoulder and groin where the bypass cannulas are placed, as well as scars from various surgical drains. You will receive several units of blood and plasma during the operation.

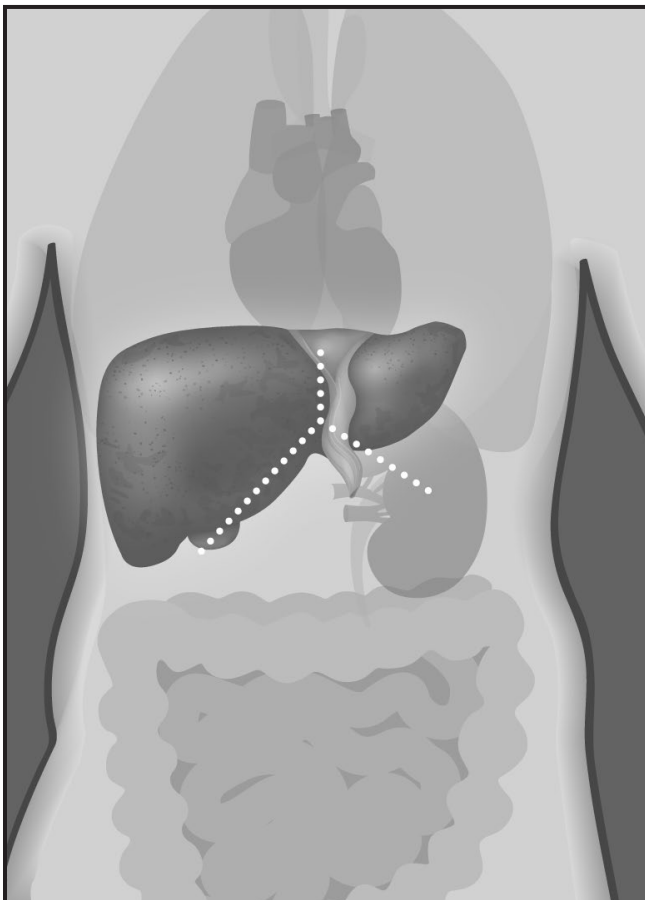


Figure 1:  
Mercedes Benz Incision

## :: THE INTENSIVE CARE UNIT

After surgery, you will be moved to the surgical Intensive Care Unit (ICU) for recovery, which is designed for 24-hour monitoring of your condition. The ICU has the necessary equipment and a specially trained nursing staff for quick response if a problem arises. You'll remain in the ICU until your condition stabilizes following surgery. This time period varies from patient to patient, but is usually two to three days. The sicker you are prior to transplant, the greater the likelihood that you will be in the ICU for a longer period of time. Family members are welcome to wait in the large waiting room outside the surgical ICU on the second floor, both during and after surgery. The hospital requests that only two people at a time visit; however, infants and small children are not permitted in the ICU. In addition, anyone suffering from a cold or individuals who feel sick should visit at a later time when they are feeling better.

### Some other things you should know while you are in the ICU include:

- You will be asleep for several hours after arriving, but your family may visit you.
- When you awaken, you will have an *endotracheal tube* in your mouth and throat, which is attached to a ventilator machine that breathes for you. After you are fully awake and are able to breathe on your own, this tube will be removed.
- There will be an IV catheter in your neck that passes into your heart and provides information on the function of your heart and lungs. Another catheter will be in an artery in your wrist connected to a blood pressure recording machine. A tube will be in your nose and throat, attached to a suction machine, to keep your stomach empty. While this tube is in place, you will **not** be able to eat or drink. A *Foley catheter* will be in your bladder to drain urine into a bag attached to the side of the bed. Small

tubes will be in your abdomen to drain accumulated blood or fluid. A *T-tube* will be in your bile duct to drain bile.

- In order to keep you from pulling out any of these catheters and tubes, your hands may be loosely bound until you are fully awake.
- Your family may visit for longer periods as you recover. To prevent infection, they should not send live flowers, plants or fruit baskets to you. However, balloons and cards are permissible.
- You will be asked to cough and breathe deeply using a special device called an “incentive spirometer” to expand your lungs.
- Soon after your operation, you will be instructed to begin getting out of bed with the assistance of your nurse.

## :: **THE RECOVERY PERIOD**

As soon as you are medically stable, you will be transferred to a hospital room. Specially trained transplant nurses and your transplant surgeons will care for you during your recovery. A dietitian and a pharmacist will give you special instructions for your diet and medications, and a physical therapist and occupational therapist will assist you with rehabilitation. A major part of your recovery after transplant will involve learning how to take care of yourself and how to take your anti-rejection medicine. It is important to have family members available to learn about your post-transplant care and medications during education sessions with your transplant coordinator, transplant dietitian and transplant pharmacist.

You will be taking anti-rejection medication for the rest of your life in order to prevent your body from rejecting your new liver. While hospitalized, we will provide you with education about these medications. You need to become familiar with the names, dosage and recording of all your medications.

### **TYPICAL MEDICATION LIST**

This is a standard list of medications that you may be placed on after transplant. These may or may not be in addition to medications you are currently taking. Each person is different and your doctor makes the final decision about the medications you are taking.

**Tacrolimus (Prograf)** – Used to prevent rejection of the new liver.

**Steroid medication (Prednisone, hydrocortisone)** – Used to prevent or treat rejection.

**Mycophenolate (Cellcept)** – Used to prevent rejection.



**Trimeth/sulfa (Bactrim)** – An antibiotic taken for the first year after transplant to prevent serious infections.

**Triamcinolone (Nystatin) or clotrimazole (Mycelex)** – One of these medications must be taken for the first six weeks after transplant to prevent a yeast infection in the mouth.

**Valgancyclovir (Valcyte)** – Taken for the first three months to prevent a serious viral infection.

**Other medications** – You will be given other drugs to counteract the side effects of the immunosuppressive agents, as well as for problems independent of the liver. A member of the transplant team will explain these drugs to you. They include:

- Anti-ulcer drugs, such as Prilosec, Prevacid, Protonix or Pepcid to decrease stomach acid production while on prednisone.
- Anti-hypertensive (high blood pressure) drugs, such as calcium channel blockers (Procardia), or beta blockers (Lopressor).
- Pain relief medications, such as Tylenol and Oxycodone. You may take up to 500 mg of Tylenol every six hours (**DO NOT TAKE MORE** than two grams (**1000 mg**) in one 24-hour period).
- Vitamin supplements, such as multivitamins with folic acid, magnesium or calcium, or phosphorus supplements.
- Stool softener, such as Colace.





## :: **COMPLICATIONS**

Complications can occur after your transplant surgery. Your transplant surgeon will review these with you during your transplant evaluation. In rare instances, heart attack, stroke or even death can occur. Surgical connections involving the bile duct or hepatic artery can leak or become blocked. Bleeding can occur in your abdomen after surgery, requiring another operation. Blood clots can form and block arteries and veins. Infections can occur in your abdomen or in your chest. On a rare occasion, the new liver will not start working right away and you may require a second transplant. Your condition will be constantly monitored with lab tests taken daily to determine your recovery.

### **REJECTION**

The biggest problem facing all transplant patients is the possibility of rejection. Rejection is the body's attempt to get rid of a foreign substance, in this case your new liver. There are several kinds of rejection, and they can be a common and life-long issue.

- **Acute rejection** is the most common type of rejection and, while it can happen anytime, it usually occurs during the first two weeks to six months after surgery.
- **Chronic rejection** can happen at any time, including years after the transplant.

A common cause of chronic rejection is not taking anti-rejection medication, skipping days or taking the wrong dosage. These medicines may not completely prevent rejection, but will help lessen the number or severity of the rejection episodes. Almost everyone has a rejection experience at one time or another. Most rejections that happen shortly after surgery can be treated medically.

Sometimes, it may be necessary to do a biopsy of the transplanted liver to determine if there is rejection or another problem that needs treated. During a biopsy, a tiny piece of the new liver is retrieved through a special needle placed in the abdomen. It is then examined under a microscope for signs of rejection.

### **INFECTION**

The medications taken to prevent rejection can also place you at greater risk for infection because they suppress your immune system. Common areas for infection are your lungs, bladder, intestines or the incision site.

Family members and friends who are ill should not come to visit you.



## :: **YOUR CARE AT HOME**

Provided there are no complications, your liver is performing well and your wound has healed, you will be allowed to go home about seven to 10 days after surgery. Before you can leave the hospital, you must have a thorough understanding of what you need to do to take care of yourself at home.

- **You will go home with a T-tube/biliary tube**, which provides a “window” into the liver by which studies can be done to assess your liver’s health. The tube provides support for the tissue where the two bile ducts (or the duct and the bowel) are healing. You will have this tube in place for an average of three months.
- You will not be able to lift anything over 10 pounds for 12 weeks.
- You will not be allowed to drive for one to two months from transplant date.
- **Staples from surgery will be in place for approximately three weeks.**

### **GENERAL GUIDELINES**

When you leave the hospital, you will need to take care to avoid infection. The following guidelines should become a natural part of your life:

- **Avoid mold.** Dust from construction sites may contain fungi, which may cause a serious infection, so you should avoid construction sites. Do not undertake renovation work in your home without consulting the transplant team. Barns and sheds should be avoided. If you must be exposed to any of these sites, you must wear a mask that is sensitive enough to protect against tuberculosis (please ask our staff for assistance if you need a mask).

- Wear gloves when working in wet soil.
- You may swim in the ocean or a pool. NO lakes or ponds (fresh water).
- **Do not handle pet waste.** It is advisable not to have birds or turtles as pets, as their waste contains a high level of germs. If you have a pet, make sure it is carefully screened by a veterinarian.
- A healthy diet, exercise and plenty of rest will help you avoid illness.
- **DO NOT SMOKE!** Smoking will place you at even greater risk of developing lung infections.
- Practice good hygiene. Shower or bathe daily. You will not be able to tub bathe until your incision is healed. Wash hands with antibacterial soap before meals and after using the bathroom.
- Wash all fruits and vegetables thoroughly. Molds and fungi may be present on their skins.
- **Do not** go near anyone who has a cold, flu or who does not feel well until that person is free of symptoms.
- Discuss any travel plans with your transplant team. Travel in underdeveloped countries is not advised.

### **MEDICAL IDENTIFICATION**

We recommend wearing a medical bracelet or necklace that identifies you as a transplant patient. In case of an accident, it is very important for healthcare personnel to know that you have had a liver transplant and that you are immunosuppressed.



## **RETURNING TO WORK**

Returning to work will depend on the type of job you have. You may be able to go back as quickly as four to six weeks after surgery, or you may have to wait three months if your job requires strenuous activity or heavy lifting.

## **SEXUAL ACTIVITY AND BIRTH CONTROL**

It is a good idea to wait four to six weeks after surgery before you have sexual relations. However, you will probably find that once you are feeling well that you are more interested in relations than when you were sick. Also, do not worry about hurting the new liver; you may be more comfortable, however, in using positions that do not place pressure on the liver.

Men should be better able to have an erection after transplant. If you are having problems with impotence, it may be because of your blood pressure medication. If this is the case, your transplant physician may order a different medication to remedy the problem. Never stop taking blood pressure medication because high blood pressure places you at risk for stroke.

Keep in mind because of the anti-rejection medications you are taking, you will be a greater risk for infection from sexually transmitted diseases such as AIDS, gonorrhea, syphilis, herpes, etc.

Women of child-bearing age should visit their gynecologist soon after leaving the hospital and be placed on the most appropriate regimen of birth control. Menstrual periods usually begin two to 12 months after surgery; however, it is possible to become pregnant before your period starts. While all types of birth control have risks, the best type for transplant patients are barrier methods, such as condoms and diaphragms. Birth control pills with estrogen and intrauterine devices should not be used.

Women age 40 and younger need to have a Pap smear and a breast examination once a year.

## **PREGNANCY**

While it is possible to become pregnant after transplant, it is not recommended during the first two years after transplant. Additionally, one of the medications you will be taking has been known to cause birth defects. It is recommended that you use two forms of birth control while taking this anti-rejection medication if you are of childbearing age. You will need to discuss any pregnancy plans with your transplant team before trying to become pregnant.

## **NUTRITIONAL COUNSELING**

Nutrition plays an important role in your care before and after transplant. A dietitian will review, in detail, the types of dietary changes you will have to make in order to stay as healthy as possible. In general, diet restrictions will depend upon the ability of your new liver to function properly. In addition, some restrictions will be necessary due to the antirejection medications you are taking.

You will need to eat additional protein during the first few weeks after transplant surgery. This is needed to maintain muscle mass and replace protein losses from steroid medications. You will need 50% more protein than you were allowed before your transplant surgery for about the first two months. Extra calories are also needed for those who lost a significant amount of weight before surgery and are now under their ideal body weight. The body needs these calories and proteins to heal, fight infection and maintain your nutritional status.

Dietitians are an important part of the transplant team, and your dietitian will work with you closely to ensure that you understand and follow instructions regarding your diet.

## **LONG-TERM FOLLOW-UP CARE**

After you have been discharged from the hospital, you will be monitored very closely by the transplant team for both medical and surgical complications and problems. The frequency of follow-up visits to the transplant team will depend upon your progress. You should plan on frequent visits for a period of eight months to one year after your transplant because this is the time period in which most common transplant complications occur. You will require life-time monitoring at scheduled intervals by your family physician and the transplant team. If you move out of the area, arrangements will be made with another transplant center for your ongoing care.

### **Follow-up with the Transplant Program:**

- First month: weekly visits on Wednesday
- Every two weeks for the second month
- Monthly during months three to six
- Every two months during months six to 12
- Every three months between one and two years
- Every six months between years two and three
- Then yearly

**Lab work:**

- Mondays and Thursdays for the first six months
- Weekly for months seven to nine on Mondays
- Every other week for months 10 to 12 on Mondays
- After 12 months, labs once a month
- After two years, labs every other month
- After three years, labs every three months

## **MEDICAL DISABILITY**

After a recuperative period of approximately three to six months is completed, it is important that you view yourself and encourage others to view you as a “normal” person. The transplant team encourages patients to return to a fully productive life, the ultimate goal of organ transplantation. Of course, if you happen to have a problem after transplant that prevents or delays resumption of normal activities, every effort will be made to lessen or resolve those problems.

Certification of medical disability will not be automatically given after a recovery period of six months, unless there are compelling reasons to do so. You must obtain long-term disability through your primary care physician.

## **YOUR NEW LIVER**

The liver transplant process will not be easy. You will certainly experience your share of stress and anxiety during this difficult period. You will be concerned and have many questions about your own health and future, as well as the impact the process will have on your family.

The Liver Transplant Program at Hershey Medical Center is committed to providing you with the best care possible. The entire team, including transplant surgeons and hepatologists from Hershey Medical Center, are equally concerned about providing you with the support you need to get through the transplant process successfully.





## **:: LIVER TRANSPLANT RESOURCES**

Penn State Hershey Medical Center Transplant  
[HMC.PENNSSTATEHEALTH.ORG/TRANSPLANT-SURGERY](http://HMC.PENNSSTATEHEALTH.ORG/TRANSPLANT-SURGERY)

Gift of Life, the Organ Procurement Center (OPO) for the Delaware Valley  
[DONORS1.ORG](http://DONORS1.ORG)

[OPTN.TRANSPLANT.HRSA.GOV](http://OPTN.TRANSPLANT.HRSA.GOV)

[MYAST.ORG/PATIENT-INFORMATION](http://MYAST.ORG/PATIENT-INFORMATION)

[TRANSPLANTLIVING.ORG](http://TRANSPLANTLIVING.ORG)



## **:: OTHER RESOURCES AT THE HOSPITAL**

### **CAFETERIA**

The cafeteria is located on the first floor by the rotunda. It is open from 6:30 a.m. to 2:00 a.m. At common meal times, you will find the largest selection of hot foods. Also located on the first floor, near the main entrance are the Information Desk, Gift Shop and ATM.

### **CHAPEL**

The chapel is located near the south entrance. Many chaplains are available at the hospital to offer you spiritual support, and can be reached by dialing x8177 from any hospital phone. The chaplains offer a variety of services, including:

- Catholic Mass (chapel): Noon on Monday, Tuesday, Thursday and Friday
- Catholic Mass (hospital auditorium): 6:00 p.m. on Sunday
- Ecumenical service: Noon on Wednesday

### **WALKING PATH**

For visiting family members who wish to exercise, there is a walking path in the front of the hospital, outside the north lobby entrance. The path, which circles around the water retaining pond, is approximately one-half mile in length.

## :: **LODGING**

**A hotel that consistently offers some of the best rates:**

Simmon's Motel  
355 West Chocolate Avenue  
717-533-9177

Other hotels in the area:

Hilton Garden Inn  
550 E. Main St.  
717-566-9292

Rodeway Inn & Suites  
1733 E. Chocolate Ave  
717-533-4533

Econo Lodge Hershey  
115 Lucy Ave.  
717-533-2515

Hampton Inn  
749 E. Chocolate Ave.  
717-533-8400

Holiday Inn Express  
610 Walton Ave.  
717-583-0500

Inn at Chocolate Ave.  
Rte. 422 & Sipe Ave.  
717-533-5665

Cocoa Motel  
914 Cocoa Ave.  
717-534-1243

Comfort Inn  
1200 Mae St.  
717-566-2050

Days Inn  
350 W. Chocolate Ave.  
717-534-2162

Fairway Motel  
1043 E. Chocolate Ave.  
717-533-5179

Hershey Lodge  
325 University Dr.  
717-533-3311

Howard Johnson  
845 E. Chocolate Ave.  
717-533-9157

Cocoa Country Inn  
1518 E. Chocolate Ave.  
717-533-2384

Super 8  
210 Hockersville Rd.  
717-508-7629

Rio Motel  
60 Washington Ave.  
717-534-1065

Simplicity Inn  
43 W. Areba Ave.  
717-533-7054

The Warwick Hotel  
12 W. Main St.  
717-566-9124

White Rose Motel  
1060 E Chocolate Ave.  
717-533-9876

America's Best Value Inn  
2651 Horseshoe Pike  
717-838-4761

**If financial constraints make it difficult to obtain accommodations at an affordable rate, please contact your social worker for assistance.**



## :: **GLOSSARY**

**Ascites** – Excess fluid in the abdomen.

**Bile** – A fluid produced by the liver, stored in the gallbladder and released into the small intestine to help absorb dietary fats.

**Compliant** – The act or process of conforming, submitting or adapting to a demand, proposal or regimen; being able to fulfill official requirements.

**Contraindication** – Any condition that makes some particular line of treatment undesirable.

**Edema** – Excess fluid in body tissues. Swelling of the ankles, for example, is a sign of edema.

**Endotracheal tube** – An airway tube inserted through the mouth leading to your windpipe to help you breathe during surgery.

**Esophagus** – The muscular tube connecting your throat to your stomach.

**Extremities** – The limbs of the body such as arms and legs.

**Foley catheter** – A tube inserted into the bladder to drain urine.

**Fulminant** – Sudden and severe.

**Hepatologist** – A physician who studies the liver and treats liver disease.

**Immune system** – The system that protects the body from the invasion of foreign substances, such as bacteria, viruses and from cancer cells.

**Jaundice** – A yellowish discoloration of the skin resulting from high levels of bilirubin in the blood.

**Metabolism** – The chemical processes that occur in the body in order to maintain life.

**T-Tube** – A tube placed in the bile duct that allows bile to drain into a bag outside the body.

**Varices** – Abnormally dilated and enlarged blood vessels.



















**PennState Health**

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[hmc.PennStateHealth.org/transplant-surgery](https://hmc.PennStateHealth.org/transplant-surgery)