

## Possible Liver Solutions

In 2009, 1,470 patients died in the United States while waiting for a liver transplant. Another 1,001 patients became too ill to receive their transplant. As of December 2013 there were 15,870 people awaiting a liver transplant from a deceased donor in the United States. Unfortunately, in 2012 only 6,256 liver transplants were performed in the United States, of which 6,010 were from deceased donors and 246 were from living donors. Because of the severe national organ shortage, alternative solutions to using deceased donors have been sought.

Advances in liver transplantation have provided new techniques that increase the number of livers available for transplantation. Some of those advances are explained here.



- Deceased Donors are donations after a cardiac or brain death.
  - *Whole Liver:* The majority of livers become available through deceased donors. Most donated livers are allocated to one recipient.
  - *Split Liver:* In some clinical situations it is possible to split a donated liver into two segments; allowing transplants for two recipients.

### *Increased Risk Donors*

Some donors have been determined by the Centers for Disease Control (CDC) to have an increased risk to transmit some viral infections, including HIV, hepatitis C, and hepatitis B because of certain lifestyle behaviors such as IV drug abuse, being in prison, or certain sexual behavior (e.g., prostitution). These donors are referred to as, “CDC high-risk donors.” All donors, whether they are high risk, or not, are tested for a number of transmissible diseases including hepatitis C, hepatitis B and HIV infection. These tests can detect a donor infection that may have been acquired as recently as one to two weeks before donation. The results of these tests are usually back before the organs are donated. High-risk donors who test negative for transmissible diseases carry a very low risk of transmission of infection and are therefore used as liver donors. The true risk of transmission is not known but is probably much less than one percent. Because the risk of dying on the waiting list before receiving a liver transplant is between 10 to 20 percent, it is reasonable to consider receiving a liver transplant from a CDC high-risk donor under certain circumstances.

In addition, some donors have been previously exposed to the hepatitis B virus and have positive antibody tests. In many instances, these donor organs are fully functional and work as well as donor organs from individuals not previously exposed to hepatitis B. Your doctor may recommend that you consider receiving an organ from a donor who previously had a hepatitis B

infection. If you receive an organ from a donor who was previously exposed to hepatitis B you will be given an additional medication following the transplant to prevent reactivation of the virus. Your doctor and the transplant surgeon on call will explain this to you in more detail should you have questions. In general, we recommend liver candidates on the waiting list keep all of their options open. The on-call transplant surgeon will always discuss with you if the donor organ carries a risk of transmitting a hepatitis B or C infection and will obtain your permission and willingness to receive such an organ before using it.

## Potential Cancellations or Delays

After the offer call comes and you have arrived at the hospital, there are still several factors that can either cancel or delay the transplant. The surgery may be delayed for many hours after you arrive at the hospital for reasons such as coordinating processes between hospitals and surgical teams. The team will proceed as quickly as possible.

### *Your Health Condition*

You must be healthy before an operation. The transplant cannot proceed if you have any heart or lung problems or any infections in your body. Since you will be taking medications that suppress the immune system, your body may not be able to actively fight an infection at the time of transplant.

### *Changes in the Condition of the Donor*

The medical condition of the donor can impact the availability of the donated liver. If the donor becomes unstable, the liver may not be retrievable. Another situation that can occur is that the surgeon may determine that the donated organ is not suitable for transplant. When the organ isn't suitable for transplant the reason is often some physiological detail that isn't apparent until the organ is visible to the surgeon.

Sometimes patients come to the hospital ready for their transplant, only to be sent back home for reasons beyond their control and when it does it can be disappointing and frustrating. It may help to remember the reasons for canceling a transplant are in your best interest – by either avoiding a potential health risk or waiting until a suitable organ becomes available.

## Arrival for Transplant/Once in the Room

After you have checked in at the nursing desk, you will be placed in a room and will begin to prepare for surgery.

- **History and Physical:** A resident will ask about your history, perform a physical exam, will order chest X-rays and an EKG. These are done before surgery to verify that there are no significant changes in the patient's heart or lungs.
- **Blood Draw:** Blood will be drawn for a variety of lab tests before surgery.
- **Shower:** You will be asked to take a shower with an antimicrobial soap prior to surgery.
- **IV Started:** An IV will be started in your arm.
- **Transplant Research Team:** A representative from the Clinical Research Team will meet with you to review the various clinical research studies available.

## Family Responsibilities

You are taken to the operating room approximately two hours before the start of the operation. Family members are allowed to walk with you to the operating room.

- **Waiting**

After you are taken to the operating room, your family will be asked to check in at the reception desk in the surgery family waiting room.

- **Be Available**

Families are asked to tell the receptionist in the surgery family waiting room where they will be if they choose to wait somewhere other than the waiting room. Following surgery, the surgeon will go to the surgery waiting room to speak with your family. If they are not present and cannot be located, they may miss the opportunity to speak with the surgeon immediately following your surgery.

- **Rest**

Families are encouraged to use the waiting time to rest. Some families use the time to get something to eat or to arrange for lodging. Whatever activity the family engages in during this time, the surgery waiting room must be aware of how to find the family.

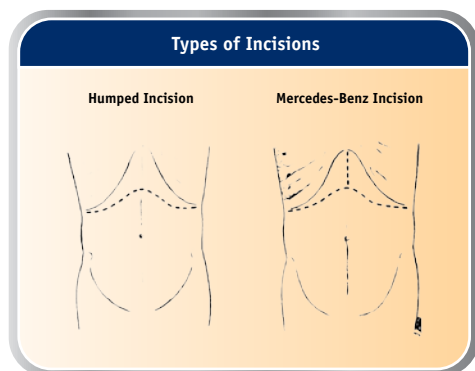
## The Inpatient Stay at the Hospital

### *Surgery*

The length of time you will spend in the operating room varies, but generally is between four and 12 hours. Just before or during surgery your physician will place many tubes and equipment to help in monitoring you. The following list includes the most frequently used.

- Central lines are inserted into the internal jugular vein in the neck or the subclavian vein in the upper chest.
- A catheter, inserted into a large blood vessel, is a special monitoring IV used to measure circulatory pressure and fluid volume.
- A catheter is placed in an artery at the wrist, elbow or groin area to constantly monitor blood pressure, and to act as a source for future blood draws.
- A ventilator or respirator is used to help you breathe. The breathing tube is inserted through the mouth into the lungs and is attached to a machine. This allows for optimal anesthesia, relaxation and sedation.
- A nasogastric tube (NGT) is placed through your nasal cavity into the stomach and is used to keep the stomach empty.
- A foley catheter is placed into your bladder to monitor urine output.
- A biliary drainage tube may be placed during the surgery into the common bile duct. It is used to monitor the bile output and protect the connections made during surgery. The tube stays in place for six weeks or longer, depending upon the type of tube used and the reasons for the tube.
- A JP drain may be placed during the surgery into the abdominal cavity to collect fluids.

The abdominal incision is quite extensive, often extending from one side of the upper abdomen to the other. The outer layer of skin is closed using staples, sutures or surgical glue which remain in place for approximately three weeks to give the incision time to heal. Internally the wound is closed with a suture that dissolves over time. It is not uncommon to have drainage from the incision.



### *Following Surgery – Surgical Intensive Care Unit (SICU)*

Following your liver transplant surgery you will be taken to the Surgical Intensive Care Unit (SICU) on the fifth level of University Hospital (5D SICU). You will not go to the Recovery Room.

The SICU team is a highly skilled team of registered nurses and physicians (called intensivists) that specialize in the care of complex and critically ill adults. The team is supported by a dedicated pharmacist (called a PharmD), a registered dietitian, a physical therapist, a unit host and clerks and patient care techs (similar to a nurse's aide). During your stay in the SICU your transplant physicians will continue to see you and make recommendations, but your immediate post-operative care will be managed by the intensivists in the SICU.

You may be in the SICU for several hours before your family will be able to visit you. Patients generally begin to “wake up” in one to two hours after arriving in the SICU and usually awaken with the ventilator in place. Because the ventilator tube sits between the vocal cords, you will not be able to talk. Until the ventilator tube is removed, usually within 24 hours, you will have to communicate by writing or non-verbal communications. Sometimes restraints are needed to remind the patient that they have tubes and lines in place.

The time spent on a ventilator varies by patient, but a patient who smokes is usually on a ventilator somewhat longer than a non-smoking patient. Since patients still have anesthesia and pain medication in their system from the operation, they often do not recall much from the first several days following surgery – even though they appear awake.

While you are in the SICU you will remain connected to many lines, tubes and monitoring devices. Patients receive a large amount of IV fluids during surgery. Most patients will look swollen as they tend to retain these fluids. This “fluid weight” will gradually go away but it may take several weeks. Coughing and deep breathing are exercises to help prevent pneumonia by keeping the air sacks open.

As you improve, equipment is removed and you will be encouraged to become more active. Patient activity and mobility is important to prevent pneumonia, reduce the potential for blood clots, and to increase strength and conditioning. The day after surgery you will be out of bed multiple times a day and sitting up in a chair. Increased mobility is dependent upon removal of lines and tubes. You will be encouraged to take deep breaths and use your incentive spirometer 10 times an hour while you are awake. You will be provided with a pillow to “splint” your incision area to reduce the discomfort.

The SICU is supportive of your family members and/or your advocates to visit and participate in your plan of care. There are no posted visiting hours. Courtesy behavior and respect for the privacy of others is necessary when in the SICU.

Patient rounds occur every morning in the SICU. The entire team assembles in the patient's room to review your status and to make goals for the day. An immediate family member or designed/advocate is invited and welcome to be present to answer any question the team may have or to voice input pertaining to the plan. Your bedside nurse can give you additional information about the time to be present for rounds.

Patients usually stay in the SICU for one to four days following liver transplantation and then are moved to the transplant general care floor, 5C.

The inpatient stay is designed to provide a significant educational opportunity for you to learn about maintaining your health following a transplant. You are expected to actively participate in your "care plan" as identified throughout the Patient Education Guide. Specifically, patients are expected to:

- Read the Patient Education Guide
- Learn about your medications and how to manage them
- Be out of bed multiple times each day, walking and/or sitting in a chair
- Participate in physical therapy
- Participate in prescribed diet regimens and blood draws

When you are medically ready, you will be discharged to your home. Occasionally, some patients require additional care and may be discharged to a rehabilitation center or extended care facility.

### *Mobility*

Increasing mobility is very important for you to prevent pneumonia, reduce the potential for blood clots, and to increase strength and conditioning.

The day after surgery, you will be out of bed and sitting up in a chair. While the pressure of lines and tubes is a factor, you will be encouraged to increase your mobility each day. When you move from the ICU to the general care floor, you will be encouraged to progressively increase your walking.

Some patients may need the assistance of physical therapy or rehab, either while they are in the hospital or when they return home.

### *Diet and Nutrition*

You will have a nasogastric tube in place until the function of your intestines resumes. The nasogastric tube may make your throat sore. While the tube is in place you may have ice chips

for your throat. Once the tube has been removed, you can begin with a clear liquid diet as tolerated. You will proceed to an advanced diet which should be a heart healthy diet, as you are able to tolerate it. You may be on a diet restricting salt, protein and fluids. Some patients who cannot eat may require a feeding tube (Dobhoff). This is uncommon, but it could occur.

### *Post-Operative Pain*

Our goal is to keep our patients comfortable following a liver transplant, but we cannot eliminate all pain. Pain tolerance differs significantly from person to person. Some patients experience back or rib pain. Some patients experience some numbness following surgery which is helpful with pain in the area of their incision. Pain related to pre-transplant conditions may not go away.

### *Post-Operative Pain Medication*

You will receive pain medications through an IV while you are in the ICU. Some patients have a PCA (Patient Controlled Analgesia) pump that allows them to self-administer pain medications within prescribed limits. Pain medications cannot eliminate all pain. You will be given oral medications for pain prior to being discharged from the hospital. Some patients may need to be referred to the pain clinic for chronic pain management.

## **Going Home**

The **RN Case Manager** assesses, develops, implements, coordinates and monitors a comprehensive plan of care for each patient/family in collaboration with the physician to plan for post-hospital care needs (such as home care nursing or therapies, sub-acute or acute rehab placements, home infusions, durable medical equipment) with regard to post-transplant care.

When you are ready to go home, it is important you take very good care of your new liver. While the transplant team and patient's family are available to help, it is **your responsibility** to know how to maintain a healthy lifestyle and to follow through with the activities. Several important ways to maintain a healthy lifestyle and a healthy liver are covered here.

### *Discharge Education for Transplant Patients*

You will receive several documents at the time of discharge that will help you in managing your care as you transition from the hospital to your home.

- The **Discharge Summary** provides discharge instructions, self-medication record
- The nursing staff will review this document with you and your support person(s) before discharge.

- Instructions specific to you are provided to you in the following areas:
  - Plan for my care, treatment and services
  - Tests and procedures
  - Treatments
  - Medications (see My Daily Schedule, a daily medication schedule personalized for each patient)
  - Diet
  - Home supplies/equipment
  - Pain
  - Activity
  - Follow-up care
  - Contact information for transplant team, holidays, evenings, weekends and emergencies
  - Community resources
  - Basic health practices and safety
  - Smoking cessation
- A nurse from the transplant team on the inpatient floor will provide this packet to you before discharge and will review the information with you.



### *Length of Stay*

The overall average length of stay for a liver transplant patient is between eight and 15 days. The following chart reflects the most usual course of stay for our patients.

<b>Location</b>	<b>Low Average</b>	<b>High Average</b>
Surgical Intensive Care Unit (SICU), taken there immediately following the operation.	1 day	3 days
General care transplant floor (5C), taken there when the equipment is removed and the patient is mobile.	7 days	12 days
Extended care facilities are medical institutions that provide prolonged care (as in cases of prolonged illness or rehabilitation from acute illness).	7-14 days	1-6 months



Home care services allows a person with special needs to stay in their homes to recover from surgery. Home care services include:

- **Skilled Nursing:** check vital signs; teach medications, diet, self care, signs and symptoms of infection; pain management; wound care; IV therapy if needed; nutrition; additional needs.
- **Home Health Aide:** help with activities such as bathing and dressing and they can provide services such as light housekeeping.
- **Physical Therapy:** assess mobility, home safety, physical strength.
- **Occupational Therapy:** the use of treatments to develop, recover or maintain daily living and work skills.
- **Social Work:** seeks to improve quality of life, help problem solve and cope with problems.
- **Dietitian:** advise what to eat in order to lead a healthy lifestyle or achieve a specific health-related goal through nutrition.
- **My Daily Schedule** contains the following information:
  - Each medication prescribed, dose prescribed, purpose of medication and time of day to take each medication.
  - Special instructions are included for each medication indicating generic names, dosages, form (i.e., tablet, capsule), manufacturing company, and comments on how to take the medication (such as take with food).
  - **Transplant Home Monitoring Record** is available to record your daily readings of pertinent medical information, such as weight, temperature, blood pressure and blood sugars if necessary.

### *Transition of Care Following Discharge*

One of the first changes you will encounter after your liver transplant is that several of your healthcare providers will change.

- Immediately after surgery, your care will be directed by the transplant surgeons. This will continue until all surgical issues are resolved, usually for two to three months.
- In addition to the surgeons, you will be cared for by one or more surgical physician assistants or nurse practitioners.
- You will receive a new nurse once you are discharged from the hospital. The outpatient nurses are assigned by hepatologists. Your nurse will be the one assigned to work with your hepatologist. Once transplanted, you will no longer be followed by your previous nurse.

- For any questions or problems, please call **(800) 333-9013**. This is the telephone number to the Liver Transplant Clinic Office. Contacting any other number will cause a delay in response time. Office hours are 8 a.m. to 4:30 p.m. Monday through Friday.
- To contact someone after regularly scheduled office hours, on weekends, or on holidays, please call the transplant resident-on-call at **(734) 936-6267**.
- At discharge, a clinic appointment will be made for you. If you do not receive an appointment, call the Liver Transplant Clinic to have them arrange it.

#### *Follow-Up Care for Patients Who Received a Liver from a CDC Increased-Risk Donor*

If you received a liver from a donor that the Centers for Disease Control (CDC) classified as an increased-risk donor, you will have your blood checked intermittently for early signs of possible but unlikely infection. You will have blood tests at one day, three months, six months and one year after transplant. Since these donors are screened carefully prior to donation, it is likely you will not need any additional medications.

#### *Follow-Up Care for Patients Who Received a Liver from a Donor with Prior Hepatitis B Infection (also known as a hepatitis B core positive donor)*

If you receive a liver from a donor that had prior infection with hepatitis B, you will need to take a daily oral antiviral medication following the transplant to prevent the virus from reactivating. In addition, you will need to have your blood checked frequently every three months up to the first year and then every six months for life for early signs of infection.

#### *Your First Clinic Visit Following Discharge*

Your first clinic appointment following discharge will be in the Post-Transplant Clinic. Here's what to expect:

- The clinic is located in Reception Area G on the first floor of the Taubman Center.
- The clinic hours are based on the surgeon and hepatologist scheduled times.
- Go have your blood drawn at the blood drawing station on either the first, second or third floor of Taubman Center. Do not take your morning medications until after your blood is drawn.
- U-M labs are computerized. They will need your name and birthday.
- Confirm with the lab technician which drug you are taking: tacrolimus, sirolimus, cyclosporine or everolimus

### **Taubman Center Labs**

*Taubman Center, Floor 1, Reception D*

Phone: **(734) 647-6304**, Fax: **(734) 647-6779**

Hours: Monday-Friday, 7am-6pm

*Taubman Center, Floor 2, Reception H*

Phone: **(734) 936-6781**, Fax: **(734) 764-3225**

Hours: Monday-Friday, 8:30am-3:30pm

*Taubman Center, Floor 3*

Phone: **(734) 936-6760**, Fax: **(734) 936-7419**

Hours: Monday-Friday, 7am-6pm

- After your blood draw, return to the waiting area in Reception Area G on the first floor of Taubman Center.
- You will be called and placed in an examination room.
- You will be seen by a physician's assistant or nurse practitioner, a Nurse (RN) \_\_\_\_\_, or a surgeon, \_\_\_\_\_ and pharmacist \_\_\_\_\_.
- Together, the PA, nurse and pharmacist will review your medications and the results of your blood work and your physical examination.
- Your care will be discussed with the transplant surgeon, but you may not be seen by a surgeon during this visit.

Please bring the following contact information to your appointment:

- Your current home telephone number
- Your current cell phone number
- The telephone number of any other location you may be staying
- The name, address, telephone number and fax number of the lab you plan to use
- The name, address and telephone number of the pharmacy you plan to use
- The name, address, telephone number and fax number of your primary care physician

Points to remember for this first clinic visit following your transplant:

- A detailed explanation of your post-transplant care will be provided during this visit.
- Your support person(s) should attend this visit with you.
- Do not take your tacrolimus (Prograf®) or cyclosporine (Neoral®, Gengraf®) before you have your blood drawn the morning of your visit. Bring it with you and take it after you have your blood drawn.
- Bring all your medications and medication containers each time you come to clinic – until instructed otherwise.
- Bring your medication record sheet to each clinic visit as changes made in clinic will be recorded at that time.
- This visit may take several hours as your lab tests need to be reviewed before you are discharged from the clinic.
- Bring your pain medications and a snack if you haven't eaten.
- Bring any records such as your daily weights, temperatures, etc.
- If you do not have voicemail on your phone(s), please let us know as it is very important to reach you after each clinic visit and after you have had blood work done. Your voicemail should identify you by name and/or number.
- If you need any prescriptions renewed, please tell us at the beginning of the visit and do not leave without them. Some medications require a paper prescription to be filled at the pharmacy.
- If you have an insurance or disability form that needs to be completed please allow several days for them to be completed.
- If you have billing or insurance issues that need to be discussed, please ask to have the financial coordinator paged.
- Expect to have a clinic appointment once or twice a week for one to four weeks, then every two weeks, then monthly. The frequency will depend on your condition and recovery.
- Incisional staples/sutures are usually removed about the third week after surgery, if they have been placed.

### *Develop Plan for Outpatient Blood Work*

Blood tests provide information about liver and kidney function. Since these tests are so important to the success of your transplant, you must develop a plan for getting routine blood work.



- **Frequency of tests** – Initially, you will need blood work twice a week. As time passes and you become stable, the frequency is reduced so blood tests are needed every month or every three months. Never go past three months without getting your blood work.
- **Reason for testing** – Transplant patients are always at risk for complications, such as rejection, problems with the bile duct or circulation to the liver. Abnormal blood results are one of the first indicators of problems. Identifying problems early may prevent permanent damage.
- **Find a blood drawing lab** – You must find a blood drawing lab near your home. It does not have to be a University of Michigan lab. However, the University of Michigan does have several satellite lab sites in lower Michigan. (See Resources section for U-M labs.)
- **Before going to the lab** - The transplant team will provide you with lab orders to take with you to the blood drawing lab. Tests to be done routinely will be marked on the lab order. Labels and mailing packets will be provided for patients to take to the lab, if you do not use a University of Michigan laboratory.
  - You are responsible for marking the box on the lab order indicating the drug you are taking; cyclosporine, tacrolimus, and/or sirolimus (if not already marked).
  - You are responsible to take the labels and mailers if you are going to a blood drawing lab outside the University of Michigan Health System.
  - **REMEMBER – DO NOT TAKE SIROLIMUS, EVEROLIMUS, PROGRAF® OR CYCLOSPORINE UNTIL AFTER BLOOD HAS BEEN DRAWN!**
- At the blood drawing lab, multiple tubes of blood will be drawn: two lavender-topped tubes and one red-topped tube. Sometimes coags are drawn to measure your clotting factors. This is a blue top tube. This test is ordered usually when you are followed by the surgeon.
  - *University of Michigan Lab*
    - Your labs will be on the computer.
    - You must confirm with the lab which drugs you are taking: tacrolimus, cyclosporine, sirolimus or everolimus.
    - Once the tests are completed the results will appear on your medical record and the transplant team can review them.

- *Local Lab (non-U of M)*
  - The local lab will run all the other blood tests and will fax the results to the transplant team office. The transplant team office telephone and fax numbers appear on the lab order slip. When the results are received, they will be entered into your medical record, also known as the “lab flow sheet.” Local labs should complete and fax test results within 24 hours. At times, this is not automatically done. When this occurs the transplant team contacts the local lab to request the results, which is why it is important to have the name and telephone number of your local lab.
  - One lavender tube (measures your tacrolimus, cyclosporine, sirolimus or everolimus) must include an identifying label. This lavender-topped tube will be placed in a cylinder, put in a mailer box and shipped to the University of Michigan. You should verify the identifying label that has been affixed to the tube. The results from this test will appear on your medical record approximately three days after the test for the transplant team to review.
- Lab results - The transplant team will call you if your results indicate an abnormality and/or to make changes in medications. **Patients with normal blood results are not routinely called.**
- Timing lab work – You should plan to have your blood work done to allow the results to be available for review by the transplant team on the date of your clinic visits.
  - Local lab – You need to have your blood drawn at least three to four days before your clinic visit to allow the results to be available to the transplant team during your visit. NOTE: You can use your standing orders at any lab. A copy of a standing order lab requisition can be seen in the Resources section.

### *Transition of Care to Post-Transplant Hepatology*

After all the surgical issues are resolved, your care will return to the hepatologist.

- Transplant nurses work as a team with specific doctors. Although you will be assigned a nurse who works with your physician team, you should feel free to speak with any of the nurses if you have a question or concern. To contact the post-transplant team:
  - Call **(800) 333-9013** and leave a message. The message should include your name and telephone number.
  - The transplant office receives a high volume of calls daily therefore, provide a brief description of the problem or concern to allow accurate prioritization of the call.

### *Follow-Up Care for Patients with Cholangiocarcinoma*

Patients who have had a liver transplant due to their cholangiocarcinoma have agreed to specific follow up procedures after transplant, which includes making and keeping their follow up appointments and completing the necessary blood work. In addition, you will need to have frequent ultrasounds of your liver. An ultrasound examines the blood flow of your liver. The ultrasounds will be performed on the first day after surgery, at one week after surgery, at three weeks after surgery, at three months after surgery, then every three months for the remainder of the monitoring. Other testing may be required based on liver cancer protocols.

### *Transplant Ambulatory Care Unit (TACU)*

The TACU is an outpatient clinic located at University Hospital on 5C. The TACU offers expert care for transplant patients who would benefit from infusion therapy or special procedures in an outpatient setting. The clinical team of nurses and medical staff specially trained in transplantation care for the special needs of transplant patients. Services you may receive through the TACU include:

- Infusions to treat rejection, dehydration and infections
- Transfusion of blood products
- Blood draws
- Physical examination
- Biliary tube or drain removal
- Education for patients and families
- Management of immunosuppression

The TACU has reclining chairs and a stretcher bay. It is open every day of the year, including holidays and weekends. The TACU has extended hours of operation Monday through Friday with shorter hours on weekends.

You must bring all your regular medications for the entire day when you are seen in the TACU. Many TACU appointments are quite lengthy and you are **NOT** allowed to leave the area during your stay. Beverages are available in the TACU, however, food service is not provided. It is suggested that you bring a lunch or plan to have a support person accompany you to obtain food from the cafeteria during your TACU stay. The TACU telephone number is **(734) 647-5688**.

Patients who experience problems after normal business hours should call Hospital Paging at **(734) 936-6267** and ask for the transplant doctor on call. The operator will take the patient's name and contact information and the physician-on-call will return the call.

### *Infusion Clinics*

You may be asked to go to an infusion clinic other than the TACU for treatment. Outpatient infusion clinics are designed for any adult patients. They are specifically designed to administer infusions in a soothing and caring environment. Staff at these clinics consist of specially trained infusion nurses, medical assistants and pharmacists. They are located throughout the Medical Center.

### *Policy on Wearing Masks*

While in the hospital it is recommended you wear a mask to protect yourself from airborne contaminants.

We recommend you wear a surgical mask in waiting rooms and when you leave your hospital room during your inpatient or TACU stay. You will be provided with a supply of masks when you leave the hospital. In addition, you will be given information about where masks can be purchased and their approximate cost.

The transplant clinic in the Taubman Center will have masks available for patients while in the waiting rooms. The TACU has no waiting room; therefore, masks are not required.

Construction areas, especially when digging up soil, may have airborne particles that may cause a patient to become sick. We recommend patients wear surgical masks around construction sites.

Suggested suppliers for face masks (called Procedure Ear Loop Face Mask) include:

Mitchell Home Medical  
**(734) 572-0203**

**(800) 420-0202** toll-free

\$0.34 per mask

Can be ordered individually

Masters Medical Supply

**(800) 286-9989** toll-free

\$8.95 for box of 50



## *Special Care*

### **Incision/Wound Care**

Your incision may be closed with staples. The staples will be removed in the clinic about three weeks after your surgery. Alternatively your incision may be closed with sutures under the skin which will absorb over time.

Sometimes your healthcare provider will re-open part of or the entire incision if it is red, draining, or the appearance is otherwise suspicious for an infection. The purpose of opening the incision is to allow for drainage of trapped fluid and/or to clean out any bad tissue so the healthy tissue can heal. Once the incision is opened, it heals from the inside out. This may require doing dressing changes at home several times a day.

You and your family member will be taught how to change a dressing. A visiting nurse may be ordered to help you care for the wound at home.

You may shower using a mild soap while the staples are in place. Surgical tape may be used to close the skin layer and will fall off over time.

Patients may experience fluid drainage from their incision due to ascites. Drainage due to ascites can take several months to resolve.

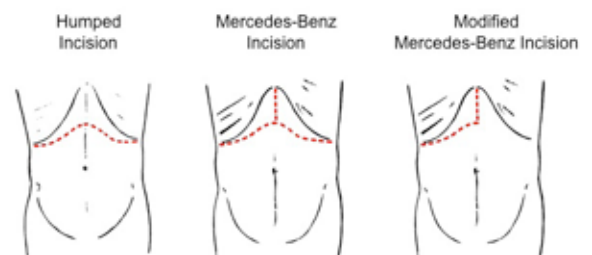
All incisions are very extensive, usually from one side to the other. The incision is close to the diaphragm, which is under the rib cage. This is why deep breathing is important to prevent pneumonia.

### *You Should Monitor Your Own Health*

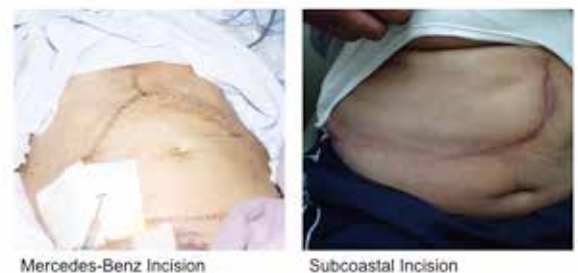
Patients who become aware of their health and monitor changes in their body will be in a better position to respond quickly and appropriately to any issue that may arise. It is recommended that you follow these steps to routinely monitor your health.

- Check temperature twice each day – at the same time each morning and evening
- Check temperature any time when feeling ill

### **Types of Incisions**



### **Photos of Different Incisions**



- Notify the transplant office when temperature is greater than 100.5°
- Check weight every morning – using the same scale every day.
- Notify the transplant office of a sudden weight gain. A sudden weight gain would be two to three pounds overnight or five pounds in a week.
- Check blood pressure twice daily.
- If you have diabetes, you should check your blood sugars as instructed – usually before meals and at night.
- Keep a record of temperature, blood pressure, weight, pulse and blood sugars. Bring this record to office visits.

You should call the transplant office if any of the following symptoms occur:

- Sores or rashes in the mouth or on the skin
- Redness, swelling or drainage from the incision
- Nausea, vomiting or diarrhea
- Burning or pain on urination
- Persistent headaches
- Sore throat
- New onset of pain
- Any feelings of being sick that you cannot explain
- Changes in vision – double vision, etc.
- Blood in urine or stools
- Shortness of breath
- Increased swelling of legs or abdomen

### *You Need to Reconnect with Your Primary Care Physician*

You are encouraged to return to your **primary care physician**. If you do not have a **primary care physician**, you are encouraged to find one now. Medical care related to liver transplant will be handled by the transplant team, but all other issues need to be managed under the guidance of a **primary care physician**.

### **You Should Know**

Every transplant patient is required to have a primary care physician.

It is in your best interest for there to be coordination of care between the transplant team and the **primary care physician**. This is best achieved through good communication. For this purpose, you are asked to provide the name and telephone number of your **primary care physicians** and clinics where you are being seen. You are encouraged to provide the transplant office with updated information if you change physicians.

**IMPORTANT:** In the course of providing medical care, your **primary care physician** is likely to prescribe medications for various illnesses. You should contact the transplant office before taking new medications. While most medications can be taken safely with anti-rejection medications, there are a few that can cause harmful side effects.

**AVOID:** Erthromycin, Biaxin®, Ketoconazole, Cardizem, Verapamil, Diflucan.

If you need to take these medications, contact the transplant office so an adjustment can be made in the dosages of anti-rejection medications while on the medications listed above.

Over-the-counter medications also can have harmful effects.

**AVOID:** Non-steroidal anti-inflammatory drugs such as Motrin®, ibuprofen, Advil®, naproxen and Aleve®. When in doubt, call the transplant office.

It is important to remember that following transplant the transplant team will only write prescriptions for immunosuppressive medications. Patients are often discharged on newly prescribed medications, such as insulin or anti-hypertensives for high blood pressure. You are responsible for contacting your **primary care physicians** to follow up on these conditions.

### *Resuming Life After Transplantation*

The goal of the transplant team is to improve your quality of life. We want you to be able to return to work or school, as well as be able to do activities that you had previously been able to do, such as hobbies or traveling.

**Lifting:** Do not lift, push or pull anything over 10 pounds for approximately six weeks after surgery and nothing greater than 25 pounds for at least 12 weeks.

**Physical Activity:** You may walk up and down stairs if you need to. If you need physical therapy, an exercise program will be prescribed. Regular exercise is encouraged as a lifelong habit, but should be resumed gradually. Examples of aerobic exercises are walking, running, bicycling and swimming.

#### **You Should Know**

A list of the most common drugs to avoid is provided in the Medication section. Share this with your primary care doctor.

**Driving/Travel:** You may resume driving after you are off all pain medication and have been cleared by the doctor. You do not have to stay home if you feel well enough to go out in public. It is advisable to avoid close contact with anyone who is sick with a cold, the flu or any other contagious illness. If you need to travel long distances by car, you need to clear this with your doctor and remember to get out of the car and stretch every two to three hours. You can travel by airplane once you have recovered from the surgery and do not have complications that require close monitoring. If you plan to travel outside the United States, you should discuss this with your doctor. You may need to receive additional vaccinations. Like any traveler, you must be careful with food and water.

**Bathing:** You may shower every day, even if your incision is open. Tub baths are not recommended until after the incision is healed. Do not use spas or hot tubs. Do not swim in lakes or ponds. Chlorinated pools are acceptable after the incision is healed and you don't have any external tubes or drains.

**Dental Care:** It is recommended you wait six months before having any dental work done. Good dental hygiene is important as infections can start in the mouth. **Most patients DO NOT need antibiotics before a dental procedure.** If your dentist thinks antibiotics are necessary from their point of view, please call the post-transplant office to make sure the antibiotic will not interfere with the medications you are taking.

**Prevention:** Since your immune system is suppressed, you need to avoid people (both adults and children) with colds, the flu or other contagious illnesses. The best way to avoid transmission of illness is by frequent hand washing, using tissue when coughing or sneezing, and by refraining from touching your face with your hands.

**Gardening:** You may return to gardening, but should wear gloves and always wash your hands when finished. You should wear a mask when stirring up very dry and dusty soil.

**Pets:** Cats and dogs are generally considered acceptable pets. Birds, reptiles and rodents are not recommended. Make sure your pet receives routine veterinary care. **DO NOT** handle pet waste, such as feces, and **DO NOT** clean the cat's litter box or fish aquarium.

**Physical Appearance:** Weight gain can be addressed through a good diet and exercise. Prednisone can make your face look very full and also contributes to weight gain. When the dose of prednisone is lowered, this effect should decrease. Unwanted facial hair can be removed by use of wax, etc. Loss of hair may need to be addressed by a dermatologist.

**Moods:** Having a liver transplant does not change a person's basic personality. However, drugs such as prednisone may cause fluctuations in moods. Emotional effects of these medications are reversible and are dose dependent.

**Sexual Activity:** You can resume sexual relations when you feel comfortable doing so.

**Pregnancy:** Pregnancy can increase the rate of rejection and the medications can be associated with fetal abnormalities. While pregnancy is not recommended, it is not always contra-indicated. You are encouraged to discuss this with your doctor as everyone needs to be evaluated on an individual basis.



**Return to Work and Disability:** Your disability status will change after you have had a liver transplant. The purpose of getting a transplant is to restore a patient to a healthier life. We will complete the necessary insurance and disability forms immediately after surgery. **If you DO NOT have complications from the transplant and the liver is working, you WILL NOT be considered disabled from the liver disease or the transplant surgery.** The post-liver transplant team will not provide statements verifying a disability if it is not liver related. Remember to allow several days to complete the paperwork.

## Biliary Drainage Tubes

Internal biliary drainage tubes (also called biliary stents) are occasionally placed during or after the transplant operation to protect the bile duct where it was sutured. These tubes are usually removed or changed during an outpatient visit six to 10 weeks following surgery or when the problem that caused it to go in is resolved. They can be internal or external.

**Internal Biliary Stents** are inside the body. They are placed by endoscopy (going down the mouth) into the bile duct to bridge if there is a leak or obstruction caused by a narrowing of the bile duct. They are removed once the problem is resolved.

**Internal/External Biliary Stents** are placed if the problem in the bile duct is higher up in the liver and they can't reach it by endoscopy. This stent is placed by going across the liver and down the duct to the problem. Part of the stent is inside the body and part outside the body. It is usually hooked to a bag to provide drainage if there is a leak or the bile duct is too narrow to drain. It is removed once the problem is resolved.

**JP (Jackson Pratt) Drain** is in abdominal cavity to facilitate drainage. Once the drainage is down to minimal it is removed either before discharge from hospital or in clinic.

## Complications After Transplant

Potential complications will be discussed with you during the education sessions and before surgery. As is the case with all major surgeries, you may experience problems with bleeding, your heart and/or kidneys. The complications noted in this section are more specific to liver transplantation.

### *Complications Following Surgery*

The liver is dependent on blood for survival. The hepatic artery is the main artery that feeds the liver. If the hepatic artery is damaged you could suffer liver damage with eventual liver failure. The portal vein carries blood away from the liver. If there are problems with the portal vein the patient usually suffers ascites and fluid accumulation in their lower extremities. Blood flow problems in the hepatic artery or the portal vein are frequently monitored by an ultrasound.

Two of the most serious immediate complications following a liver transplant are primary non-function liver failure (PNF) and hepatic artery thrombosis (HAT). Primary non-function occurs when the newly transplanted liver simply fails to work. This is a rare complication, but if it occurs, you will need another transplant. In hepatic artery thrombosis, the arterial blood supply to the liver is stopped. If this condition is not corrected immediately, another transplant may become necessary if not reversed.

If these complications occur, you will be immediately re-listed as a **Status 1**, which gives you a high priority for the next compatible organ.

### **Definitions**

**Primary Non-function (PNF)** is when the new transplanted liver does not work. This is a medical emergency needing a new transplant.

**Bleeding** can happen after surgery requiring a trip back to the operating room.

**Abscess** is a fluid collection inside the body. This is also called a pus pocket. It is not uncommon to place a tube to drain the abscess.

**Infections** can be in different areas of the body. Wound infections are at the surgical site that requires a dressing change. Blood infections are in the blood stream requiring IV and oral antibiotics.

**Death** is not a desired outcome but can happen with even the best interventions.

## *Infection*

Most of the infections seen in the post-operative period are related to immunosuppression drugs necessary after liver transplantation. You will receive higher doses of anti-rejection medication right after surgery and are at the highest risk in this immediate post-operative period.

Infections seen immediately are usually related to the surgical procedure. You could develop an abscess in the wound or anywhere in the body – even in the new liver. You also could develop pneumonia, a urinary tract infection or a blood infection.

During this period, bacterial or yeast infections are more common than viral infections. Viral infections are more likely in the period of one to six months following transplant. Viral infections include CMV, herpes simplex and herpes zoster. Shingles will be discussed later.

After six months, the rate of infections in liver transplant patients is similar to the general population with the exception of those individuals who still require high doses of anti-rejection medications.

## *Acute Rejection*

Acute rejection is a natural response by the immune system when the body sees something it considers foreign. Up to 30% of liver transplant recipients have at least one episode of acute rejection in the first six months. This condition is reversible if treated early. Early treatment is dependent upon early diagnosis. Frequent and routine blood work is important to identify abnormal liver enzymes. Elevated liver enzymes are an early warning sign that something is wrong. A liver biopsy is ordered to make an accurate diagnosis of acute rejection.

**Acute rejection can happen at any time after the transplant, even years later.** One of the ways to stop this process once it has begun is to increase anti-rejection drugs. One common treatment is to give high doses of steroids.

For most episodes of acute rejection, a “steroid pulse” will be ordered. An IV dose of 250 mg of Solu Medrol® is given once a day for three days, usually in the TACU. This is usually followed by oral prednisone at a high dose that is gradually tapered down. How quickly this will be done will be determined by blood work that measures the liver enzymes.

If the rejection, per a biopsy report, appears less severe, just an oral dose of prednisone may be ordered. This dose is higher than what you may have been taking and may be as high as 80 mg. The dose will be tapered down if acute rejection seems to be improving based on blood work.

### **You Should Know**

Rejection can only be diagnosed with a liver biopsy. Blood work can tell us there is something wrong, but a liver biopsy will indicate WHAT is wrong.



### *Chronic Rejection*

Chronic rejection is a slow process in which the bile ducts dissolve, also known as ductopenic rejection. Abnormal lab values indicate a problem exists and a liver biopsy is done to confirm the diagnosis. Tacrolimus (Prograf®) is the medication prescribed to slow this process. A person can live many years with chronic ductopenic rejection.

### *Encephalopathy*

Following liver transplant surgery you may experience encephalopathy or ascites similar to symptoms experienced before surgery.

- **Encephalopathy** is a condition of the brain that is demonstrated as confusion and can be experienced by any patient following transplant. Confusion is caused by toxins not being filtered out of the blood by the liver and may be related to the impaired liver function, sleep deprivation, pain medications or prednisone. Patients may need to be restrained during periods of confusion.

Confusion also can be caused by either sleep deprivation or the use of pain medications, or it can be aggravated by the use of steroids. Confusion from these causes is usually relieved by treatment of the cause. For instance, allowing more time for sleep, and decreasing pain medications or steroids at the direction of your physician. Usually the confusion after surgery is caused by a combination of these factors.

- **Ascites** is an accumulation of fluid in the abdominal cavity and may occur following liver transplant surgery. Ascites is generally managed with medication, usually Lasix or Aldactone. Patients who experience difficulty breathing due to ascites, may need to have an abdominal tap (Paracentesis).

### *Bile Duct Problems*

Bile duct problems are caused by either a leak or by a stricture – or narrowing of the bile duct. Bile ducts are the tubes through which bile moves from the liver into the small intestine (bowel). Bile is made continuously in the liver and flows through the small bile ducts to larger bile ducts and empties into the small bowel. Normally bile that is made in the liver is stored in the gall bladder. However, **the gall bladder is removed during liver transplant**. It is important that bile not remain in the liver and that it is transported to the small intestine.



**Bile leak** – A leak can develop where the two bile ducts are sutured together. At times, surgery may be able to repair a leak in the bile duct. However, treatment generally consists of placing a stent or a tube across this area until it heals. Stents are placed internally through a procedure performed in the Medical Procedure Unit called an Endoscopic Retrograde Cholangiopancreatography (ERCP). The stent remains in place until there is a confirmation the leak has sealed itself. Internal biliary stents need to be changed every four to eight weeks, but leaks usually heal without further treatment within a few weeks.

Some patients, who cannot have an internal stent, are treated with a Percutaneous Transhepatic Cholangiography (PTC) tube. The PTC tube is inserted through the skin by interventional radiology. It is considered an internal/external tube since part of it is inside the patient and part of it remains outside the abdomen. This tube needs to be changed every four to eight weeks.

**Biliary strictures** - Biliary strictures can develop for several reasons. Bile ducts need a constant blood supply from the hepatic artery. Any interruption of the blood flow will cause damage to the bile ducts. The most common problem in the bile ducts is that they become narrowed. This narrowing can occur where they are sewn together or it can occur within the smaller bile ducts within the liver. If the stricture is at the suture site (called the anastomosis), a stent is placed after it is ballooned open. Sometimes, this process is done several times. If it is unsuccessful, surgery may be able to correct the problem.

Strictures that are near the liver or within the liver (intrahepatic) are more of a problem, since they tend to be more permanent and are not usually corrected by surgery. Treatment is usually a percutaneous transhepatic cholangiopancreatography (PTC) tube as this type of tube can get into the liver and it forms a path from the liver to the bowel allowing the bile to flow out into the bowel.

If bile accumulates in the liver it can become thick like sludge and can form stones. This can cause a condition called cholangitis which can lead to a serious – perhaps life-threatening – infection. Inadequate bile flow can be identified through lab results. If this is suspected, you will be scheduled for an endoscopic retrograde cholangiopancreatography (ERCP) or a PTC tube. Liver transplant patients are asked to come to the University of Michigan to have these procedures performed by our doctors who have experience in performing them on liver transplant patients.

When lab work indicates the patient has a bile duct problem, it is likely the patient will be prescribed the medication Actigall or Ursodiol to help thin the bile.

## Treatment of Biliary Leaks and Strictures

The goal for treating biliary problems is to provide a free flow of bile from the liver to the bowel. An endoscopic retrograde cholangiopancreatography (ERCP) is a test that combines the use of x-rays and a long flexible lighted tube to allow the doctor to see inside your digestive tract. A process called ‘ballooning’ may be used to open the stricture, place a stent in the narrow portion and/or remove stones or sludge that has accumulated in the bile ducts. Stents inserted during an ERCP will always be internal and temporary.

If the ERCP indicates a Percutaneous Transhepatic Cholangiography (PTC) is necessary, an appointment will be made for you with Interventional Radiology. A PTC Radiologist specializes in using PTC to evaluate the bile duct system and place internal/external PTC tubes if they are necessary. An internal/external biliary stent (PTC) is used when the problem is high in the liver. A PTC tube may require a longer treatment time and may, in rare situations, become permanent. Your surgeon and your hepatologist will confer with the radiologist who performs the PTC procedure, and the placement and removal of PTC tubes. The initial PTC and tube placement will be done as an inpatient. An overnight admission is required to monitor for complications. With the exception of the initial placement, PTC tube changes are generally performed on an outpatient basis. You will be given conscious sedation or general anesthesia for these procedures. Nurse practitioners will provide information about PTC, will answer questions and will provide follow up care after the procedures.

An external drain called a JP is used in the abdominal cavity when there is a need for drainage from that area. It is usually removed before discharge, but can be removed in clinic as an outpatient.

### Internal/External Biliary Tube Care (PTC Tubes)

If you have an internal/external PTC tube placed, you will need to take the following steps to care for yourself:

A dressing will be placed over the insertion site. The dressing will need to be changed every one to two days for a period of two weeks or until the site is healed. To change the dressing:

- Wash your hands
- Remove the old dressing
- Clean around the tube site daily with a clean washcloth and a mild liquid soap

**PTC & JP Drainage Tube**



- Pat dry with a new clean washcloth
- You may apply over-the-counter antibiotic ointment, such as Neosporin® or Bacitracin
- Apply a clean new dressing being careful not to twist or kink the tube

Daily care of your PTC tube includes:

- Tubes are usually flushed twice each day. Flushes are done using a 10cc syringe with normal saline.
- Flush by connecting the syringe to the end of the tube and GENTLY pushing (not forcing) the saline solution into the tube as fast as possible without causing discomfort.
- **Do not pull back on the syringe.**

The radiologist will give you a prescription for all the supplies you will need to care for your PTC tube. If pain medications are needed, a prescription will be provided for a short period of time after insertion.

Avoid activities such as bending forward or lifting heavy objects. Avoid any activity that causes a pulling sensation or pain around the tube.

For the first two weeks you may shower, however, you need to cover the dressing with a double layer of plastic wrap (like Saran Wrap) and tape the edges to your skin. After the site has healed, plastic wrap is not necessary to take a shower.

Occasionally a tube may become blocked. The signs of a blocked tube include fever, chills, dark urine, light colored stools, yellow skin, leakage of bile around the tube that requires frequent dressing changes, difficulty flushing the tube, or leakage when the tube is flushed. If any of these occur, contact Interventional Radiology.

#### You Should Know

Signs that a tube is blocked may be fever, chills, leakage of fluid around the tube, requiring several dressing changes per day and difficulty flushing the tube.

If the PTC tube falls out, it must be replaced within 24 hours. Cover the insertion site with a gauze pad and call Interventional Radiology at (734) 936-4536. On weekends, holidays or after hours call (734) 936-6267 and ask for the interventional radiologist on call.

PTC tubes are generally changed every four to six weeks, if they are needed. The goal of treating biliary leaks/strictures with a PTC tube is to correct the problem and remove this tube. Some patients may require several PTC appointments, but the radiologist will assess the improvements in your bile ducts and remove the tube once the problem is corrected.

### *Blood Flow*

Patients may experience problems with blood flow to or from the liver. Since these blood vessels are sewn together problems can occur at or near the suture sites. Problems may be the result of a clot formation or a narrowing of the blood vessel. Treatment consists of opening the blood vessels either by removing a clot, ballooning open the vessel and/or inserting a stent. These procedures are performed by interventional radiology or surgery.

### *Hypertension*

Hypertension is high blood pressure. Approximately 70% of liver transplant patients develop high blood pressure after a transplant. Hypertension may improve in liver transplant patients as the doses of anti-rejection medications are reduced. Hypertension is treated using anti-hypertensive medications.

### *Diabetes*

Diabetes is an elevation of blood sugar which frequently occurs as a result of anti-rejection medications, especially prednisone and tacrolimus (Prograf®). Approximately 20–30% of liver transplant patients have diabetes before transplant and 40% develop diabetes after transplant.

### *Renal Insufficiency*

Renal insufficiency is defined as an increased serum creatinine level and can develop as a result of anti-rejection medications and can range in severity from very mild to the point of needing dialysis. The goal is to closely monitor blood work so anti-rejection medications are given at the lowest possible dose to prevent rejection and have the least harmful effect on kidneys. To minimize the risk of kidney failure, it is important to maintain good blood pressure and good blood sugar controls.

### *High Cholesterol, High Lipids*

Liver transplant patients should follow the guidelines for the general population and have their cholesterol/lipid profile done once a year. As many as 40% of liver transplant recipients will develop high cholesterol levels. Patients are encouraged to keep their cholesterol and lipids under control by:

- Controlling weight through a good diet and exercise program
- Use of anti-cholesterol and anti-lipid medications
- Smoking cessation

### *Osteoporosis*

Previous liver disease and the use of medications, such as prednisone, make liver transplant patients very susceptible to thinning bones. Bone density tests, ordered by the patient's primary care physician, are recommended at regular intervals. Over-the-counter medications that include calcium and vitamin D, as well as prescription drugs such as Fosamax® or Actonel®, are used to prevent and treat osteoporosis. Weight-bearing exercises also are very helpful.

### *Cancer*

The risk of cancer is three to five times greater in transplant patients than in the general population. The most common forms of cancers in transplant patients are skin and lip cancers. Transplant patients need to:

- Avoid direct, prolonged sun exposure
- Use sunscreen, at least SPF 30, on exposed areas
- Wear hats and long sleeves if possible
- Wear sun glasses
- Avoid tanning salons
- Have annual examinations by a dermatologist

Other rare types of cancers include:

- Lymphomas – which make up 57% of all post-transplant tumors.
- Colon cancers – especially for patients with primary sclerosing cholangitis and ulcerative colitis.

Transplant patients need to follow the routine cancer screening recommendations for the general population, for:

- Mammogram
- Gynecology
- Colonoscopy
- Prostate

### *Recurrent Disease*

**Autoimmune hepatitis** can return. Patients will need higher doses of anti-rejection medications for their lifetime, especially steroids.

**Primary sclerosing cholangitis** recurs in approximately 20% of liver transplant patients.

**Primary biliary cirrhosis** recurs in approximately 20% of patients within five years of the transplant, and in 45% of the patients within 15 years of the transplant.

**Hepatitis B virus** - Patients with recurrent hepatitis B virus can expect the following treatment regimen following transplant. They will receive the first dose of Hepatitis B Immune Globulin (HBIG) during transplant surgery. They will continue to receive HBIG daily for post operative days one through six. Starting at post operative day 30, they will receive HBIG intravenously each month for one year, administered in the TACU. Usually they will also receive HBIG by intramuscular injections each month for one year. Patients will need to take anti-viral medications for life, most frequently entecavir. Other medications may include lamivudine, adefovir, and tenofovir. Blood tests will be done monthly for the first two years, then every three months in years two through four, followed by testing every six months. Oral anti-viral medications will be required for life with blood testing of the virus every six months, in addition to the blood tests necessary to monitor the health of your new liver.

**Hepatitis C virus** - Post-transplant therapy may be as short as six months or as long as two years.

There is treatment available for recurrent hepatitis C post liver transplant. The protocol will be different than what patients experienced pre-transplant. Patients are closely evaluated for their willingness to comply with the program and also for the necessary prescription coverage to cover the cost of the medicines as these drugs are quite expensive. The peginterferon is an injection taken once a week while the ribavirin is in pill form and taken twice a day. Many times, additional medications are also required due to these drugs side effects. Injection may be required to build up the red blood cells and also the white blood cells. That can mean three shots per week. Blood tests can be as frequent as weekly since close monitoring is necessary. Note: Newer drugs may be available. Talk to your hepatologist for the latest treatment options.

**Cancer** of the liver rarely comes back. Patients are screened before surgery to be sure they have no other tumors before transplant. Patients will be screened using CT and blood tests for recurrent cancer for five years following transplant. The testing will be most frequent the first three years. A schedule will be provided to the patient at the first post-op visit. Patients are requested to have the scans performed at the University of Michigan to ensure the same technique is used in the event comparisons needed to be made.

### *Cholangiocarcinoma and Hepatocellular Carcinoma*

Cholangiocarcinoma is a cancer that starts in the bile ducts. When it is at the branch points of the right and left bile ducts, it is called hilar cholangiocarcinoma. In some patients, hilar cholangiocarcinoma may be cured by combining chemotherapy and radiation followed by liver transplantation. Hepatocellular Carcinoma is a cancer that starts in the liver cells and is often associated with cirrhosis. A liver transplant may cure this cancer in some patients by removing all of the cancer along with all of the old liver and replacing the old liver with a new one.

**A return to substance abuse** will cause damage to the transplanted liver much quicker than what was experienced before transplant. Patients who return to substance abuse will not be a candidate for re-transplantation. Substance abuse is a clear example of non-compliance.

**Fatty liver**, BMI (Body Mass Index) is a calculation that is your weight from your height. It is used to define overweight and obesity. A BMI of 25 or greater is defined as overweight and a BMI of 30 or more is considered obese. Obesity is the leading cause of disease conditions, such as diabetes, kidney disease, heart disease and strokes. The buildup of fat affects not only your heart and blood vessels, but it also accumulates in the liver. A fatty liver is called steatosis. A more serious condition occurs when the fatty liver becomes inflamed, called steatohepatitis. Steatohepatitis can cause liver failure which can lead to liver transplantation. Steps to prevent a “fatty liver” include diet, exercise and control of your blood sugars and cholesterol and lipids.

### *Re-Transplantation*

Certain liver diseases can re-occur in the liver and cause liver failure again. If this happens, another liver transplant may be considered. The process for re-transplantation is similar to the first transplant in that a patient will be evaluated by the transplant team after having all the same testing as before. Because re-transplantation is more difficult to do and has a higher mortality rate associated with it, several additional factors are looked at closely:

- How compliant has the patient been since their first surgery?
- How quickly and how severe the disease is that has returned after surgery?
- How sick the patient is presently – can the patient survive a second transplant surgery?

## Immunizations and Vaccines

### *Live vs. Dead Virus*

Immunizations or vaccines consist of viruses – either “live” or “dead.” Most vaccines are made from a “killed – or dead – virus” and are safe for patients to take themselves or to be around a recently immunized individual. Common examples of vaccines made from dead viruses include:

- Cervical Cancer vaccine
- DPT
- Hepatitis A
- Hepatitis B
- Influenza “flu” shot (but not Flumist nasal vaccine)
- Pneumococcal
- Polio
- H1N1 Vaccine



Some vaccines are made from a live virus. The vaccine from a live virus can rarely cause the actual disease in a person. Patients who are immunosuppressed are less able to fight the disease and can become sicker. Patients who have had a transplant should not have vaccines from a live virus. It is very unlikely that a transplant patient would get an infection from contact with a person who received a live vaccine. Still, it is a good idea for transplant patients who never had chicken pox to avoid contact with a recipient of the shingles or chicken pox vaccine who develops a rash. Patients also should avoid direct contact with the body fluids (such as changing diapers) from a recently vaccinated individual.

Examples of live virus vaccines include:

- Chicken pox
- Flumist (nasal flu vaccine, flu shot is OK)
- H1N1 nasal spray
- MMR (Measles, mumps and rubella)
- Shingles vaccine
- Small pox



### *Flu Shots and Pneumonia Shots*

Transplant patients are encouraged to receive a **flu shot every year** and a **pneumonia shot every five years**. Close contacts of transplant patients should also receive flu shots so they do not get the flu and transmit it to the transplant patients. It is recommended that all persons over the age of six months receive a flu shot.

### *Tetanus and Pertussis Booster Shots*

Transplant recipients should receive a tetanus booster (dT) every 10 years. On one occasion, the tetanus shot should include a pertussis booster (dTAP).

### *Chicken Pox*

If you have never had chicken pox or been vaccinated against chicken pox, you should avoid exposure to any person with chicken pox. Chicken pox is contagious for one or two days before the rash occurs and remains contagious until the sores crust over. If such an exposure occurs and you are not immune to chicken pox, you should contact your doctor to arrange treatment to prevent chicken pox, which can be very severe in transplant patients.

### *Shingles (Varicella Zoster)*

It is estimated that up to 50% of immunosuppressed persons develop shingles. **Shingles is NOT caused by a new virus; it is caused by reactivation of the chicken pox virus.** Shingles is caused by the reactivation of the chicken pox virus that remains in the body after the disease appears to have gone away. Even though patients recovered from chicken pox many years ago, the virus remains in the body without the patient being aware of it. The chicken pox virus can become active again and when it does, it is in the form of shingles.

Shingles starts out as a pain or a tingling sensation, followed by blisters. It is treated with anti-viral medication and pain medication. Patients are contagious while they have blisters. This means they can give the chicken pox virus to someone else who does not have adequate immunity for this virus. The shingles vaccine is a live virus and transplant patients cannot receive this vaccination.

## **Lifetime Commitment**

It is important to recognize that a liver transplant is more than a single surgical event. Liver transplant is not a cure for liver disease; it is a treatment. A successful liver transplant is a group effort that requires a lifetime commitment by the patient to adhere to a healthy lifestyle and receive on-going medical care. The following areas are examples that require an on-going commitment.

**Medications** to suppress the immune system will be required for life. The types of medications and the dosages may change over time, but some level of medication will always be needed. Generally, the number of medications and the dosages are highest immediately following the transplant.

**Lab work** will be required on a regular and on-going basis for life. Lab tests are required to monitor the level of medications and the functions of the liver.

**Medical procedures** will be needed on an on-going basis – generally they are most frequent following the transplant surgery or during a rejection episode.

**Clinic visits** will be required on a regular basis. Some problems are detected just by observing the patient. Visits are usually weekly at first, but over time clinic visits will be yearly.

The members of the group needed for a successful liver transplant include the transplant professionals, the patient, the patient's family or caregiver, and the patient's primary care physician.

Liver transplant patients must establish a relationship with a **primary care physician** who will manage their non-transplant health issues.

The support you receive from your family and caregiver team is crucial to your success. The support will be needed on an on-going basis.

## Transplant Specialty Pharmacy Services

The University of Michigan has a Transplant Specialty Pharmacy whose only focus is to serve transplant patients, ensuring they have ongoing and timely access to their medications. The specialty pharmacy makes available financial counseling and support services to assist transplant patients in navigating through the complexities of insurance coverage and allows patients to obtain answers to questions regarding their medication regimen and medication side effects. A representative from the Transplant Specialty Pharmacy will meet with you while you are in the hospital to review the program and discuss your pharmacy options. If you have questions about the UMHS Transplant Specialty Pharmacy, please call **(866) 946-7695**.