

**THE LIVER INSTITUTE** AT METHODIST DALLAS MEDICAL CENTER

# Liver Transplant Patient Handbook

Offering hope through an extraordinary commitment to clinical excellence.



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# OUR COMPREHENSIVE TRANSPLANT CARE



rgan transplantation is a serious undertaking that requires the focus of highly skilled physicians and staff. In choosing Methodist for your transplant, you can be confident that:

- We have one of the largest, most active, and most highly respected transplant centers in the southwestern United States.
- The doctors on staff at Methodist Dallas Medical Center, along with the transplant coordinators, nurses, social workers, dietitians, and other health care providers, work as a team to help patients through the transplant process.
- We actively participate in transplant research.

Our Liver Institute provides a full spectrum of hepatobiliary and liver health care. You will find that we combine our clinical success with a caring family atmosphere.

#### Some History

The transplant programs at Methodist Dallas have enjoyed many firsts. In 1992, the world's first heart-kidney-pancreas transplant was successfully completed at Methodist. Since our first kidney transplant procedure in 1981, we have made an ongoing investment in the resources and technology that make it possible to sustain this important program, now one of the most active transplant centers in the southwestern United States. The liver transplant program was added in 2003, and the science of medicine continues to advance through ongoing research at The Liver Institute at Methodist Dallas and the Methodist Dallas kidney and pancreas transplant programs.

- 1981 First kidney transplant performed at Methodist Dallas
- 1986 First pancreas transplant in the Dallas-Fort Worth area
- 1992 World's first simultaneous heart-kidney-pancreas transplant
- 1999 First successful laparoscopic nephrectomy (minimally invasive kidney removal) in Texas
- 2003 New antibody-lowering therapy began
- 2009 First HIV-positive kidney transplant recipient in the Dallas-Fort Worth Metroplex

Thank you for your interest in The Liver Transplant Program at Methodist Dallas Medical Center. This handbook is designed to answer some of your questions and to help you throughout the transplant process.



# CHOOSING TO HAVE AN ORGAN TRANSPLANT

### An Option, Not a Cure

Once your doctor has determined that you have an organ that is severely diseased, you will be given treatment options. One of these options is organ transplantation, but it is not for everyone. A transplant means a lifetime commitment to medications, doctor visits, and a healthy lifestyle. Transplantation is a treatment option, not a cure.

# Handling Your Other Health Problems

Diseases and conditions such as pancreatitis, lupus, and stomach ulcers must be treated and controlled before you undergo a transplant. You must also be free of any infections.

## **Know the Risks**

There are risks with any surgery, but transplant surgery is a particularly high-risk proposition. The medicines used after transplant are powerful and can have serious side effects. [See "Possible Side Effects of Antirejection Drugs" in the After Your Transplant section.] In addition to possible side effects, there is an associated risk of infection. And there is always the chance that your body may reject the transplanted organ. [Please refer to the *Complications* section of this handbook.] Organ transplants are not guaranteed. Not all organs will work perfectly, and in rare cases some transplanted organs do not work at all. Your transplant physician can give you the most up-to-date statistics for all types of transplants.

# Following Orders and Making Lifestyle Changes

It is important that you follow the medical orders prescribed by your doctor. The better care you take of yourself, the better the transplanted organ should work. A transplant can offer you a better quality of life, and often a longer life, but you must always think of yourself as having "special health care needs." You will have to make lifestyle changes that include diet, exercise, and refraining from smoking and drinking alcohol. [This is explained in more detail in the *Diet* and *Exercise and Activity* sections.]

#### **Transplant Evaluation**

Before you can undergo a transplant, you must complete a transplant evaluation so we can determine whether a transplant is a safe, suitable option for you. The length and complexity of the evaluation will vary by individual. [The process is explained more fully in the *Transplant Evaluation* section of this handbook.]

# How to Apply for the Transplant Program

If you are a potential liver transplant patient, you or your doctor should call 877-42-LIVER or 214-947-4400 to begin the application process.

If you are a potential kidney or pancreas transplant patient, the first step in the transplant process is to fill out the application, which is included in the back pocket of this handbook. Return the application to your doctor or to The Methodist Dallas Kidney and Pancreas Transplant office. If you have any questions about the application or if you need help filling it out, please call us at 214-947-1800.

### If You Need More Information

*If you need more information about any part of the Methodist Transplant Program, please ask a member of your transplant team or call 1-877-42-LIVER or 214-947-4400.* 

# **TRANSPLANT COSTS**

n organ transplant costs anywhere from \$50,000 to more than \$250,000, depending on the organ transplanted. The severity of your condition will also affect the cost of evaluation and postoperative care. Although a transplant is expensive, it is generally cost-effective over the long term.

#### You Will Need Insurance

Some form of medical insurance is absolutely necessary to have a transplant. Also, the medications required after a transplant are expensive, so it is important that you stay insured. At Methodist Dallas Medical Center, we will work with you and your insurance company to help make the insurance reimbursement process go smoothly. Medicare covers all types of transplants, but a supplement will help with expenses. Medicare Part B pays 80 percent of the cost of immunosuppressive medications as long as you are a Medicare recipient. Our transplant financial coordinators will obtain approval from Medicare and/ or your insurance company. The process can take a few weeks, so it is important to submit your paperwork promptly and completely. Social workers and financial specialists are available to help you with financial and insurance concerns.

## **Sources of Transplant Financial Information**

Medicare Health Plan	800-633-4227	www.medicare.gov
Medicare TTY/TDD	800-633-4227	
Social Security Administration	800-772-1213	
National Transplant Assistance Fund	800-642-8399	www.ntafund.org
American Kidney Fund	800-638-8299	www.kidneyfund.org
Texas Health Insurance Risk Pool	888-398-3927	www.txhealthpool.org
American Cancer Society	800-227-2345	www.cancer.org
National Foundation for Transplants	800-489-3863	www.transplants.org
National Organization for Rare Disorders	800-999-6673	www.rarediseases.org
Partnership for Prescription Assistance (PPA)	888-477-2669	www.pparx.org
Veterans Administration	800-827-1000	www.va.gov
Medigap Plan		www.medicare.gov/ medigap/default.asp



# **TRANSPLANT EVALUATION**

Before you have an organ transplant, you must be evaluated. We want to make sure a transplant is the best option for you. It is our responsibility to assess your situation and to inform you about the risks and benefits that are associated with an organ transplant.

### How Long Does an Evaluation Take?

The length of time it takes to complete the evaluation depends on which organ you are receiving and how sick you are.

### **The Evaluation Process**

The evaluation process consists of medical evaluations, consultant evaluations, and committee selection.

#### Medical Evaluation

- Complete medical history
- Complete physical examination
- EKGs, chest X-rays, lab work, and other test and procedure results

Some tests and procedures can be performed by local physicians, but others must be completed at Methodist Dallas Medical Center. If you require dialysis, your testing schedule will allow for dialysis time. We will arrange dialysis for longdistance patients.

#### Consultant Evaluations

- Transplant surgeon evaluation (liver, pancreas, and some kidney patients)
- Transplant nephrologist consultation (kidney and some liver patients)
- Transplant hepatologist consultation (liver and some kidney patients)
- Transplant social service evaluation
- Psychosocial evaluation
- Dietary consultation
- Meeting with transplant coordinator
- Dental exam and clearance
- Other specialist consultations, depending on your medical condition

#### Committee Selection

Once your medical and consultant evaluations are completed, your transplant coordinator will present the findings to the transplant selection committee, who will either accept you as a transplant candidate, schedule more tests before they make a decision, or tell you that you are not a transplant candidate. You and your physician will be informed of the reasons if you are not accepted for an organ transplant.

# WAITING LIST

If you are accepted as a transplant candidate, your name will be placed on the United Network of Organ Sharing (UNOS) waiting list, which has strict regulations. Several factors, including which organ is required, affect your placement and priority on the list.

## **Factors Affecting the Waiting List**

Once your evaluation is complete and the transplant committee has decided that you are a liver transplant candidate, you will be placed on the liver transplant waiting list with UNOS.

Your place on the waiting list is determined by your Model for End-Stage Liver Disease (MELD) score. This score roughly correlates with the severity of liver disease, ranging from <10 (not severe) to 40 (very severe). Your individual MELD score will be calculated by entering your lab test results into a formula.

The lab tests used are the bilirubin, creatinine, and INR. As your lab results change, so will your MELD score. As you become sicker and in greater need of a transplant, your MELD score will increase and lab tests will be done more often. A higher MELD score will result in higher placement on the list, thus resulting in a higher priority for a transplant.

When an organ becomes available, the patient with the highest MELD score within the same or compatible blood group will be offered the organ. Unlike other organ transplants, the liver recipient and the liver donor do not have to be a perfect match. There are, however, certain conditions that must be met.

If you require a liver and kidney transplant, both organs will come from the same donor once you have been called for the transplant.

#### While You Are on the Waiting List

- Keep your contact information current with us (telephone, pager) so we can notify you when an organ is available.
- Keep up with your lab work and testing.
- Stay healthy and work on improving your health to help prevent complications.
- Keep your doctor and your transplant coordinator apprised of changes in your health.



#### **Organ Sources**

Deceased donors are individuals who have died and whose families have chosen to donate their organs.

- Deceased donors represent about 99% of all livers donated in Texas.
- National patient survival for deceased donor liver transplant is about 87% at one year, and about 78% at three years.
- Waiting for a deceased donor liver transplant can take weeks to years, depending on the severity of your illness.



# LIVER TRANSPLANT SURGERY

# When the Donor Organ Becomes Available

When a liver becomes available, your name will be reviewed along with others on the UNOS computerized waiting list. If your illness places you as the highest priority, you will be identified as the recipient and contacted by the transplant coordinator.

## At the Hospital

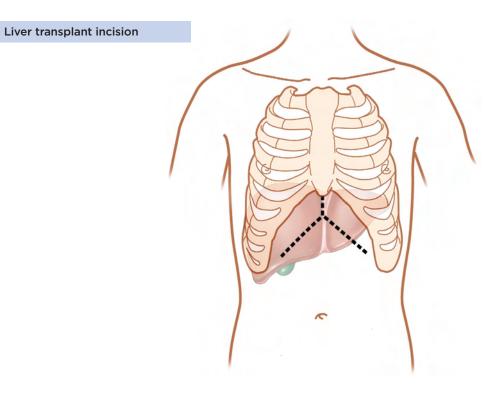
Once at the hospital, you will be prepared for surgery. It is both an exciting and a frightening time, so it is important to have someone with you for support. When everything is organized, you will be told the scheduled time of surgery. The surgery is performed under general anesthesia and usually takes between five and seven hours.

## **After Surgery**

After surgery, you will be admitted to the Surgical Intensive Care Unit. You may not awaken from the anesthesia right away, so a breathing tube will be kept in place until you are awake. When you are able to breathe normally on your own, the breathing tube will be removed. Over the next several days, most of the other tubes will be removed as well. Generally, all the tubes are removed before you go home.

The function of the transplanted liver will be monitored very closely in the first 24 hours. If everything is working well, you may be transferred to the Transplant Unit after 24 to 48 hours of stay in the Surgical Intensive Care Unit. You will receive immunosuppressive medication and be monitored very closely for any side effects.

In some cases, you may need to return to surgery or undergo liver biopsies.





# AFTER YOUR TRANSPLANT

# Length of Stay

How long you remain in the hospital after your surgery depends on the type of transplant. Most patients remain in the hospital for five days to two weeks after a routine liver transplant. If you have complications [see the *Complications* section of this handbook] or other medical problems, your length of stay may vary. You may be hospitalized longer if you receive more than one organ.

#### Aftercare

Before you are discharged, you will be given extensive instructions to follow at home. Your transplant coordinator will make sure you are familiar with all the requirements to care for yourself and take your medications.

If you live more than one hour from Methodist Dallas, you will need to stay in the area until your condition is stable. On-site accommodations are available, as well as comfortable hotel suites near the hospital. Shuttle service is provided to and from the hotel and the hospital. Once your condition is stable, you can see your local doctor.

## Lab Work and Physical Exams

Following your discharge, you will be followed very closely by your transplant doctors and coordinators at The Liver Institute. To ensure that your transplanted organ works for as long as possible, you must continue with regular lab tests and physical exams. The first 90 days following a transplant are the most critical. During the first month, there will be frequent blood tests to monitor drug levels and to detect any early rejection episodes. If the liver is functioning well and you are doing well without adverse reactions and infections, the blood tests and visits to The Liver Institute will be slowly tapered off in the following months. One year after the liver transplant, you will be expected to have a monthly blood test and return to The Liver Institute every six months.

# **Other Health Restrictions**

In addition to taking medications, there are other requests and restrictions for transplant patients such as regular exercise, avoiding weight gain, wearing sunscreen, and avoiding infections. If you have had a kidney transplant, you will want to drink plenty of water. In general, following good health practices will help ensure a more successful result. Most patients feel better and have more energy after their transplant.



# **POST-TRANSPLANT MEDICATIONS**

### A Lifetime Commitment

Receiving a transplant means making a lifetime commitment to taking care of your health. You will need medications to prevent rejection or malfunction of your transplanted organ, probably for the rest of your life. Skipping doses or taking medications off schedule can cause your organ to fail. Your transplant coordinator and transplant pharmacist will ensure that you know how to use your medications before you leave the hospital. The medications can be expensive, but insurance and drug programs help with some of the cost.

## Possible Side Effects of Antirejection Drugs

Most of the drugs you will take are antirejection drugs or immunosuppressants. These drugs are very powerful and can have side effects such as:

- High blood pressure
- Weight gain
- Nausea and vomiting
- Diarrhea
- Diabetes or elevated blood sugars
- Increase in cholesterol level

Depending on your illness and the side effects of the antirejection medications, other medications may be needed. Some of these medications will be temporary, while others you will have to take for the rest of your life.

## When to Call the Doctor

If you should become ill or experience any side effects while taking these medicines, it is important to contact your transplant doctor or coordinator as soon as possible. Get your lab work completed on time as ordered to help the team monitor your medications. Monitoring your medication levels closely can help avoid or prevent side effects and complications.

# Using a Chronic Care/Specialty Pharmacy

We suggest that you begin using a chronic care or specialty pharmacy at the time of your transplant, unless your regular pharmacy provides pharmacy services for your special needs. Specific pharmacy information will be provided to you at the time of your transplant. Your transplant team will help you maximize your prescription benefits by accessing a specialty pharmacy immediately after your transplant. Specialty pharmacies offer services to patients with chronic diseases. In addition to these specialty pharmacies, your insurance carrier may provide a mail-order service that you can access soon after your transplant. Your transplant coordinator will facilitate the transition for you.

# COMPLICATIONS

## Rejection

Rejection is the body's attempt to identify and expel what differs from itself, which can result in loss of organ function. Many transplant patients experience an episode of rejection after a transplant. Fortunately, rejection can usually be controlled with medications.

# Acute Rejection

Acute rejection generally happens in the first few months after a transplant. There may be obvious signs, or there may be no indication at all. A biopsy is performed to diagnose acute rejection. During a biopsy, a very tiny piece of the organ is examined under a microscope. Usually we can determine why the rejection occurred, treat it successfully, and improve organ function.

#### Chronic Rejection

Over a period of years, small rejection responses slowly destroy the organ. This type of rejection is hard to prevent, detect, or treat. This is one reason it is important to maintain a relationship with your local doctor and transplant program. New treatments and medications are continually being developed that may slow chronic rejection.

## Infections

The drugs used to prevent organ rejection can affect your ability to fight infections, so you will be given some medications to help prevent infections. If you are diabetic, you can help prevent infections by controlling your blood sugar. Blood work will be performed regularly to catch early signs of infection. As long as you take immunosuppressants, you must watch for and prevent infections. We will



teach you how to avoid infections, how to monitor yourself for signs and symptoms, and when to call us. Most infections can be treated and cured, but some require long-term medication.

#### **Other Complications**

Other complications may include bleeding, difficulty with blood sugars, or other conditions associated with surgery. There is also a chance you may develop stomach ulcers or experience weight gain, high blood pressure, and elevated cholesterol. Long-term complications are generally related to medication side effects. Following your transplant center's advice and good follow-up with your doctor can help us recognize complications early and possibly avoid them altogether.



# RECURRENCE OF DISEASE AFTER YOUR TRANSPLANT

#### **Possibility of Recurrence**

In most cases, a liver transplant does not cure the primary cause of liver disease. As a result, nearly all diseases that caused your organ to become diseased can recur after a transplant. Unfortunately, the return of the original disease may become a threat to the long-term success of the transplant. The severity of this recurrence may vary. It is not known why some people have a return or worsening of their original disease.

#### Most Common Recurring Diseases

- The most common diseases that return include viral hepatitis B and C. You may need to take medicine to treat or prevent hepatitis B after liver transplantation. As for hepatitis C, recurrence in the blood is universal. There are no effective measures to prevent this. After a liver transplant, treatment of hepatitis C with medicine is possible.
- Liver tumors may return after transplantation. The risk is higher in patients with larger tumors or those whose blood vessels were affected. For this reason, there are strict rules for choosing liver cancer patients for liver transplantation.
- Autoimmune liver diseases such as primary biliary cirrhosis (PBC), primary sclerosing cholangitis (PSC), and autoimmune hepatitis may return. In most cases, the immunosuppressive medicines used to prevent rejection of the new liver can also prevent damage to the new liver.
- Alcoholic liver disease may occur after liver transplantation if the patient starts drinking alcohol. This has been shown to lead to noncompliance with the transplant medications. These patients then have a higher rate of medical problems and infections.

### **Other Conditions and Diseases**

Some conditions such as hypertension and elevated cholesterol will remain with you despite a transplant. If you have diabetes, you may have a worsening of blood sugars. If you have received a pancreas transplant, you will check blood sugars as directed by your transplant doctor. You will be monitored for the return or worsening of any conditions or diseases that affect your health. As you can see, staying in touch with your referring physician and your transplant physician will be necessary. Getting your lab work as ordered and taking your medications properly will also be critical. As a result of many advances in liver transplantation, most liver transplant recipients enjoy long-term success.

# DIET



he more you know about living a healthy lifestyle, the easier it will be to make the changes necessary to take the best possible care of yourself and your new organ. At Methodist Dallas Medical Center, we can provide you with the education you need to make the best choices for a healthy life.

A healthy diet is as important after your transplant as it was before. Eating well will make a difference in your overall health and well-being.

- Avoid gaining weight (weigh yourself every day; report a change of 2 to 3 pounds in 24 hours).
- Add protein to your diet to enhance healing, fight infection, and increase energy.
- Drink plenty of water every day.
- Limit sugar, fat, and cholesterol intake.
- Monitor your electrolyte levels.
- Restrict salt intake.
- You may continue on Weight Watchers or an ADA-recommended diet, but discuss other diets such as vegetarian or low-carbohydrate with your health care team.
- Do not take dietary supplements without the consent of the transplant team.
- Avoid fruit juices, soft drinks, and other high-calorie liquids.
- No alcoholic beverages.
- No smoking.

Each person has a unique set of circumstances, so diet instructions will be tailored to meet your individual needs.

# **EXERCISE AND ACTIVITY**

fter your transplant, we want you to return to a normal life, including travel, work, play, community involvement, and all the other activities you enjoy. It is important to be as active as possible once your physician approves.

#### **Benefits of Exercise and Activity**

- Help control appetite
- Limit weight gain
- Promote a sense of well-being
- Improve sleep and mood
- Improve self-esteem and body image
- Help prevent long-term complications

#### **The Right Exercise**

Many patients can eventually participate in major sports and athletics after a transplant. Begin with a walking program and add more activity and exercise as your stamina and endurance improve.

#### Rehabilitation

If rehabilitation is necessary after the transplant, the physical therapy staff at Methodist Dallas will provide an appropriate exercise prescription.

#### Travel

If you plan to travel, take special care to make sure you have enough medicine. Always store medicines at room temperature. Sunscreen should always be used to reduce the risk of skin cancer.

## **Returning to Work**

The goal of transplant is to return you to as normal a lifestyle as possible. In some cases, this means you may be allowed to return to work. A transplant does not guarantee disability insurance. Medicare insurance coverage may be discontinued, depending on your individual health and circumstances. In addition to work, returning to a normal lifestyle also means you can travel and more easily participate in family and social activities.



# Websites and Telephone Numbers

The Liver Institute at Methodist Dallas	214-947-4400 877-425-4837	www.MethodistHealthSystem.org/Liver
Methodist Dallas Kidney/Pancreas Transplant	214-947-1800 800-284-2185	www.MethodistHealthSystem.org/Kidney
Alcoholics Anonymous	212-870-3400	www.aa.org
Alpha-1 Advocacy Alliance	866-367-2122	www.alpha1advocacy.org
Alpha-1 Association	800-521-3025	www.alpha1.org
Alpha-1 Foundation	877-228-7321	www.alpha-1foundation.org
American Association for the Study of Liver Diseases	703-299-9766	www.aasld.org
American Hemochromatosis Society	888-655-4766	www.americanhs.org
American Liver Foundation	800-223-0179	www.liverfoundation.org
American Society of Transplantation	856-439-9986	www.a-s-t.org (ast@ahint.com)
HCV Advocate		www.hcvadvocate.org
Hemochromatosis Information Center	888-565-4766	www.hemochromatosis.org
Hepatitis B Foundation	215-489-4900	www.hepb.org
Hepatitis Central		www.hepatitis-central.com
Hepatitis Foundation International	800-891-0707	www.hepfi.org
Hep C Alert	877-435-7443	www.hep-c-alert.org
Hep C Connection	800-522-4372	www.hepc-connection.org
HepNet		www.hepnet.com
Liver Cancer Network	412-359-6738	www.livercancer.com
Minority Organ Tissue Transplant Education	800-393-2839	www.nationalmottep.org
National Library of Medicine	888-346-3656	www.nlm.nih.gov
Organ Transplant Support, Inc.	630-527-8640	www.otsfriends.org
PBC Foundation		www.pbcfoundation.com
PBCers Organization		www.pbcers.org
Primary Biliary Cirrhosis Organization		www.pbcers.org
Sarcoidosis Awareness Network		www.sarcoidosisnetwork.net
National Hepatitis C Coalition	951-766-8238	www.nationalhepatitis-c.org
Department of State Health Services	888-963-7111	www.dshs.state.tx.us
Transplant Experience		www.transplantexperience.com
TransWeb (transplantation/donation information)	734-232-1113	www.transweb.org
TRIO (Transplant Recipients International Organization)	800-874-6386	www.trioweb.org
Wilson's Disease Association	1-866-961-0533	www.wilsonsdisease.org



# MORE ABOUT ORGAN TRANSPLANTS

# What The Liver Institute at Methodist Dallas Offers

We provide ongoing education during the transplant process to patients and their families. We offer classes, booklets, manuals, one-on-one instruction, and a support group. Interpreters for almost any language are available, and psychosocial support is also provided.

#### **Special Services**

- Tour of Methodist Dallas Medical Center
- Comfortable living accommodations at affordable rates
- Language interpreters for more than 28 languages
- Methodist Dallas cafeteria food vouchers for in-need patients
- Easy access to transplant coordinators and social workers
- Assistance with completing financial, private insurance, and Medicare forms

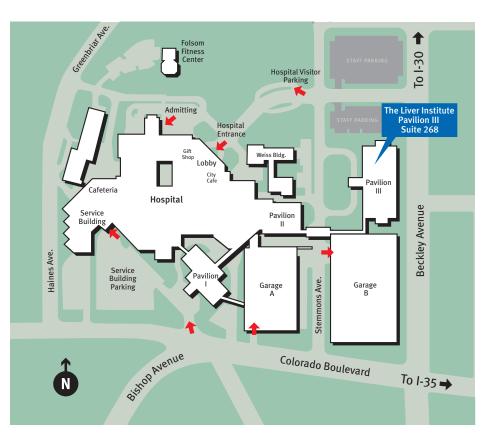
# CONTACT

The Liver Institute at Methodist Dallas Medical Center 1411 North Beckley Avenue Pavilion III, 2nd Floor, Suite 268 Dallas, TX 75203

214-947-4400 Fax: 214-947-4404 Toll free: 1-877-42-LIVER

www.MethodistHealthSystem.org/ Liver







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