My Liver Transplant Journey:

Getting Started on My Pathway to Wellness
I NEED A TRANSPLANT?!? WHAT EXACTLY DOES THIS MEAN? AM I GOING TO BE OK?

These and many other questions may be swirling through your head. Finding out you need a transplant can be a time of mixed feelings – from fear about the unknowns to excitement over new beginnings – and every emotion in between.

You have just found out you need a liver transplant. Starting the transplant process can be a challenge. There is so much to plan for and remember. Having a brief overview of what lies ahead helps you get started.

We prepared this guide just for you. We hope it helps you on your liver transplant journey.
WHY YOUR LIVER IS SO IMPORTANT

You cannot live without your liver. Your liver does three important things:
1. Breaks down your food and drugs. Stores them for later use. Gets rid of used food and drugs.
2. Cleans your blood.
3. Makes bile, an important liquid needed for digestion.

Your liver lies on the right upper side of your stomach. It is your largest organ.

WHEN YOUR LIVER CANNOT DO ITS JOB

Your liver can usually heal itself after most illnesses. But your liver may be too damaged from illness or other problems. Then, it cannot do its job anymore. We call this liver failure.

WHAT YOU MAY FEEL WHEN YOU HAVE LIVER DISEASE

<table>
<thead>
<tr>
<th>Your liver does not</th>
<th>You may feel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Break down food like it should</td>
<td>Low energy</td>
</tr>
<tr>
<td></td>
<td>Confusion</td>
</tr>
<tr>
<td></td>
<td>Swelling in legs, feet and stomach</td>
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<tr>
<td></td>
<td>Bruise easily, bleed longer than normal</td>
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<tr>
<td></td>
<td>Brittle bones or other bone problems</td>
</tr>
<tr>
<td></td>
<td>Night blindness</td>
</tr>
<tr>
<td></td>
<td>More infections</td>
</tr>
<tr>
<td></td>
<td>Loss of muscle control</td>
</tr>
<tr>
<td></td>
<td>Anemia (not enough healthy red blood cells)</td>
</tr>
<tr>
<td>Break down drugs like it should</td>
<td>Too much of your medicine stays in your body</td>
</tr>
<tr>
<td>Clean your blood like it should</td>
<td>Fever, feel sick</td>
</tr>
<tr>
<td>Get rid of bile like it should</td>
<td>Skin turns yellow and itches</td>
</tr>
</tbody>
</table>
YOUR OPTIONS FOR A LIVER TRANSPLANT

Liver transplant is the surgery where a person’s sick or injured liver is replaced with a healthy liver. This new, healthy liver can be donated from a person who has died or from someone who is still living. A liver transplant is needed when your liver fails to do its job like it should.

DECEASED DONOR LIVER TRANSPLANT

Deceased donor liver transplant is a transplant using the liver from someone who has died. Most donated livers come from people who recently died. Deceased donor livers are matched with people on a national transplant waiting list. The people on this list have been evaluated and are considered to be good candidates to receive a liver transplant.

LIVING DONOR LIVER TRANSPLANT

Living donor liver transplant is a transplant using part of a living person’s liver. There are not enough deceased donor livers available on the national waiting list for the people who need them. One option for people today is a transplant that uses part of a liver from someone who is still alive.

A healthy liver is able to re-grow because the liver can make new cells. This means part of a living person’s liver can be taken out and put into another person’s body. The healthy liver can grow back to its needed size in both the person receiving the liver transplant and the person donating part of their liver for the transplant.
ADVANTAGES OF A LIVING DONOR LIVER TRANSPLANT

1. HIGH QUALITY NEW LIVER
We know more about a living donor’s past and present health. This means we are better able to make sure the donor’s liver is the right match for you.

2. TIMELY TRANSPLANT FOR PATIENTS WITH LOW MELD SCORES
Your living donor transplant can be done before you get sicker if you have a low MELD score. This means you can have the transplant done at the best time for you.

3. SHORTER WAIT TIME
You do not have to wait on a list when you have a living donor. This means you are in better health when you have your transplant.

4. TIME TO PLAN
You have more time to plan with a living donor. This means your transplant can be done when you and your donor are in the best health possible.

5. UNIQUE GIFT FROM THE LIVING DONOR
This is a special time for the donor to offer the gift of better health to his or her loved one.

People can be living donors if:
• They are at least 18 years old.
• They are in good health.
• Their blood type is compatible with the person needing a new liver.
• Donating part of their liver is something they really want to do.

Talk to us to learn more about this option to decide if it is right for you. We are here to answer all your questions!
YOUR TRANSPLANT WORK-UP

We know you have a sick liver. Now we want to be sure you are a good transplant candidate. We call this your transplant work-up or evaluation – just a fancy word for how we decide if a liver transplant is right for you.

ONE TO TWO-DAY WORK-UP
We know how important it is for you to be listed for transplant as soon as possible. We are able to complete your transplant work-up in one to two days in most cases. Our innovative work-up means our patients can be transplanted sooner.

Example of a FastPass One-Day Work-Up Schedule

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 am</td>
<td>Registration, Vital, Labs, Consents</td>
</tr>
<tr>
<td>9 am</td>
<td>Group Education</td>
</tr>
<tr>
<td>10-12 pm</td>
<td>Hepatologist, Social Worker</td>
</tr>
<tr>
<td>12 pm</td>
<td>Break for Lunch</td>
</tr>
<tr>
<td>1-3 pm</td>
<td>Surgeon, ID, Dietician, Financial</td>
</tr>
<tr>
<td>3:30-4:30 pm</td>
<td>Ultrasound, CXR</td>
</tr>
<tr>
<td></td>
<td>Some patients come back the next day for stress test and CT scan if needed</td>
</tr>
</tbody>
</table>
WE LOOK AT THREE AREAS TO DECIDE IF TRANSPLANT IS RIGHT FOR YOU.

1. MEDICAL
Make sure you are healthy enough for transplant surgery and life after transplant.
- We collect important information about your health from several medical tests and visits.
- We look more closely at your liver and body.

2. PSYCHOLOGICAL AND SOCIAL
Make sure you are prepared for the lifetime commitments needed for a transplant.
- We ask for important information about your past and present life.
- We look more closely at your life to be sure you:
  - Are mentally and emotionally prepared for life with a new liver.
  - Have enough people to care for you before and after transplant.

3. FINANCIAL
Make sure you are financially ready for the lifetime costs of a liver transplant.
- We give you important information about costs before and after transplant.
- We look more closely at your insurance and finances to be sure you can pay all transplant costs.

EXCELLENT MEDICAL CARE
“As our transplant program continues to grow both regionally and nationally, we remain committed to providing the best service and care for our patients. We work with so many patients and families over long periods of time, so we know what a difference a successful transplant can make in someone’s life. That’s why we work so hard to be the best.”

— Nigel Girgrah, MD, PhD, Medical Director of the Ochsner Multi-Organ Transplant Institute, Chairman, Gastroenterology & Hepatology
Medical tests and visits give us a better picture of your liver and health. Every person is different. Your specific medical tests and visits are unique to you.

Some common tests in the work-up are:

<table>
<thead>
<tr>
<th>Type of Test</th>
<th>Reason for the Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood work</td>
<td>See how well your body works</td>
</tr>
<tr>
<td>Urine collection (24-hour)</td>
<td>See how well your kidneys work</td>
</tr>
<tr>
<td>Chest x-ray</td>
<td>Make sure your lungs are fine</td>
</tr>
<tr>
<td>Pulmonary function test/ Blood gases</td>
<td>More lung tests to see how well your lungs work</td>
</tr>
<tr>
<td>Echocardiogram (EKG)</td>
<td>See how well your heart works</td>
</tr>
<tr>
<td>Abdominal ultrasound</td>
<td>Examine and check blood flow to your liver</td>
</tr>
<tr>
<td>Shots</td>
<td>Protect you from infectious diseases (like flu, pneumonia)</td>
</tr>
<tr>
<td>Upper endoscopy</td>
<td>See if there is any bleeding in your throat and belly</td>
</tr>
<tr>
<td>Stress test</td>
<td>Look at how well your heart handles activity and exercise</td>
</tr>
<tr>
<td>Cat scan/MRI of stomach</td>
<td>Check for liver cancer</td>
</tr>
<tr>
<td>Bone density</td>
<td>See how strong your bones are</td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>Check for colon cancer</td>
</tr>
<tr>
<td>Mammogram</td>
<td>Check for breast cancer (women ages 40 and older)</td>
</tr>
<tr>
<td>Prostate screening</td>
<td>Check for prostate cancer (men ages 50 and older)</td>
</tr>
</tbody>
</table>

**YOU MAY SEE MORE DOCTORS:**

- **Cardiologist:** Checks to make sure your heart is in good condition.
- **Infectious Disease Doctor:** Checks to make sure you do not have certain infections.
- **Gynecologist:** For female patients only.
- **Anesthesiologist:** Tells you about any risks with medicine used to put you to sleep during surgery.
- **Psychiatrist:** Checks how mentally and emotionally ready you are for a transplant.
MEETING WITH YOUR SOCIAL WORKER
Your work-up includes a meeting with your transplant social worker. Your transplant social worker helps you and your family handle the changes in your life as a transplant patient.

You and your social worker meet to:
• Make sure you are prepared for the lifetime commitments needed for a liver transplant
• Confirm your caregiver plan
• Talk about how you are dealing with life changes as a transplant patient
• Identify any needs you might have
• Connect you with helpful resources

BEING READY FOR A TRANSPLANT INVOLVES

You as a person
Your mental and emotional health is just as important as your physical health.

Your caregiver support
“It takes a village” to care for a liver patient as our patients and caregivers remind us.

Your daily life
How you live your life helps us better understand your specific needs.
MEETING WITH YOUR FINANCIAL COORDINATOR

Your work-up includes a meeting with your transplant financial coordinator. Your transplant financial coordinator helps guide you through the financial side of transplant as you do your financial part.

You and your financial coordinator meet to:
- Go over your insurance benefits
- Help you plan for your transplant costs before and after transplant
- Talk about other helpful resources

Your financial coordinator helps in many ways. Your financial coordinator:
- Contacts your insurance company to find out exactly what your insurance plan pays
- Gets approvals from your insurance company for any medical services you need
- Confirms that you are covered for any needed clinic and hospital services

Transplant Costs Include
- Medicines, medical visits, tests and procedures you need before and after transplant
- Care you need before and after transplant
- Insurance deductibles and co-pays
- Travel, food and housing for:
  - You and your caregivers before, during and after transplant
  - Your caregivers while you are in the Intensive Care Unit (ICU)
- Costs of caregivers to be with you

AFTER YOUR WORK-UP IS COMPLETE

You have completed the following:
- Met with transplant staff members to look more closely at your medical, psychological, social and financial situation
- Completed all needed medical testing
- Confirmed who your primary caregivers are
- Submitted any needed paperwork

You have finished your work-up. Now, the transplant staff meets to review your medical, psychological, social and financial information.

The transplant staff talks with you after this review. You and the transplant staff together agree on your next steps.
“How long will I have to wait before I get my new liver?”

This is one of the most common questions we hear from patients on the transplant waiting list. Wait times are different for each person on the list because each person’s situation is different.

Your wait for a new liver may be as short as a few days or as long as several months. Some factors that can affect a person’s wait time include:
- Blood type
- Height and weight of the person
- Size of the donated liver
- Medical urgency (How soon a person needs a transplant)
- Distance between the donor’s hospital and the patient’s transplant hospital

Unfortunately, there are more people on the liver transplant waiting list than there are available livers. This means it is impossible to know exactly how long you wait for a liver that is the right match for you. You can talk to your transplant team anytime about where you are on the transplant waiting list.
YOUR TRANSPLANT TEAM

KEY MEMBERS OF YOUR TRANSPLANT TEAM:

YOU – THE MOST VALUABLE PLAYER (MVP)!
Why are you the MVP of your transplant team? Because your actions impact your health from now until after transplant. Patients who actively take part in their care and carefully follow their treatment plans are the patients who usually feel and do better.

YOUR CAREGIVERS
Choosing your caregivers is a very important decision. These are the people available at all times to help you before, during and after transplant. Your caregivers may be a spouse, partner, parent, family member or close friend, or some combination of these persons.

THE REST OF YOUR TRANSPLANT TEAM
The transplant process is truly a team effort: You give it your all, and we do the same! You and your transplant team work together as you go through the transplant process. Some team members you see often. You may see others less often. All team members are here to help you!
LET US TAKE A CLOSER LOOK AT WHAT EACH TEAM MEMBER DOES.

**Transplant Surgeon**
Doctor trained in transplant surgery. Follows you before, during and after your transplant.

**Hepatologist**
Doctor trained in treating liver disease. Sees you regularly before transplant. Helps the transplant surgeons with your care after transplant.

**Advanced Practice Clinician**
Nurse practitioner or physician assistant skilled in the treatment of liver disease. Works closely with your doctors to assess and treat you before and after transplant.

**Nurse Coordinator**
Nurse skilled in liver disease. Coordinates all aspects of your care during these stages of your transplant:
- **Pre-Transplant Coordinator:** Before transplant
- **Hospital Transplant Coordinator:** In the hospital
- **Post-Transplant Coordinator:** After transplant

**Hospital Nurse**
Hospital staff nurse who helps you while you are in the hospital.

**Social Worker**
Helps you and your family handle the changes in your life as a transplant patient. Listens to your concerns. Gives support. Tells you about helpful resources.

**Medical Fellows and Residents**
Doctors-in-training who work closely with the surgeons and hepatologists to assess and treat you.

**Other Healthcare Staff**
Some team members work behind the scenes. You may not meet them in person. All of them are working together to make sure you get the best, complete care!

**Financial Coordinator**
Talks to you about transplant costs and insurance coverage.

**Pharmacist**
Helps you with medicines you take before and after transplant.

**Scheduler**
Makes your appointments. Lets you know when and where to go for your visits.

**Prescription Assistance**
Program (PAP) Coordinator Helps you sign up for programs that may help pay for your medicines, if you qualify.
OCHSNER’S LIVER TRANSPLANT PROGRAM

We believe very strongly in treating more than just liver disease. We treat the whole person. We aim to restore the quality of your liver, health and life as a whole.

We offer:

- The #1 liver transplant program in the nation for four years in a row

- Performed the most liver transplants in the nation in 2012, 2013, 2014 & 2015

- Shorter wait times for transplant than the national median

- Survival rates exceeding expected and national rates

- Innovative surgical procedures

- Shorter surgery times

- Shorter hospital stays

- Staff always available to patients

- On-site hotel

- Near-campus housing options

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**2014 PATIENT SURVIVAL AFTER LIVER TRANSPLANT**

<table>
<thead>
<tr>
<th>Time</th>
<th>National</th>
<th>Ochsner</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 MONTH</td>
<td>98.6%</td>
<td>97.2%</td>
</tr>
<tr>
<td>1 YEAR</td>
<td>93.8%</td>
<td>90.9%</td>
</tr>
<tr>
<td>3 YEARS</td>
<td>84.6%</td>
<td>81.5%</td>
</tr>
</tbody>
</table>

**2014 LIVER TRANSPLANT WAIT TIMES**

<table>
<thead>
<tr>
<th>Wait Time</th>
<th>National</th>
<th>Ochsner</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 MONTHS</td>
<td>15.6</td>
<td></td>
</tr>
<tr>
<td>12 MONTHS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 MONTHS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 MONTHS</td>
<td></td>
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</tr>
<tr>
<td>3 MONTHS</td>
<td></td>
<td>2.1</td>
</tr>
</tbody>
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1 CareChex®
2 United Network for Organ Sharing (UNOS)
3 Scientific Registry of Transplant Recipients (SRTR), June 2015
WE WANT EVERY PATIENT TO EXPERIENCE:
• Total well-being
• Excellent medical care

Simply put, we care deeply about our patients.

The Patient-Transplant Team Covenant is a reminder of the important relationship between patients and those who provide healthcare. Respect, trust and partnership between patients and healthcare team members set the foundation for healing.

The partnership between you and your transplant team starts with your first visit. It continues over many years, both in the clinic and hospital.

TOTAL WELL-BEING

“Because transplant care is so complex and because we work so intensely with our patients, we need to trust and respect each other. The Patient-Transplant Team Covenant helps us develop those essential qualities that can influence a patient’s outcomes.”

— Ochsner Transplant Surgeon Trevor Reichman, MD, PhD
Patient-Transplant Team COVENANT

As the Transplant Team and partner in your healthcare, we commit to always:

VALUE YOU AS A PERSON
- Recognize you as a whole person.
- Respect your dignity, values and beliefs.
- Keep your information private unless you give us permission to share.
- Carefully listen to what you have to say.

VALUE YOU AS PEOPLE
- Recognize you as people committed to my well-being.
- Respect your expertise and experience.
- Be very clear about what information is okay to share with others.
- Carefully listen to what you have to say.

TELL YOU THE TRUTH WITH COMPASSION
- Help you feel comfortable sharing your doubts and fears.
- Be honest about your health conditions and how you respond to treatment.
- Tell you about your medical condition in a timely manner.

TELL YOU THE TRUTH WITH CONFIDENCE
- Be able to talk about my doubts and fears with you.
- Be truthful about my health, treatments and how I am following your instructions.
- Tell you all I can about my health in a timely manner.

INCLUDE YOU AS AN ACTIVE TRANSPLANT TEAM MEMBER
- Partner with you to agree on your best healthcare plan.
- Coordinate with all who provide you with healthcare.
- Answer your questions as best we can.
- Include your caregivers as part of your transplant team.

BE AN ACTIVE MEMBER OF MY TRANSPLANT TEAM
- Partner with you on the healthcare plan I agree to follow.
- Tell you about everyone who provides me with healthcare.
- Ask you right away when anything is not clear to me.
- Include my caregivers as part of my transplant team. Bring a caregiver to all my visits.
HOME AWAY FROM HOME

Leaving home for a transplant can be tough. We want you to be as comfortable as possible while here.

WE OFFER OPTIONS TO HELP:

- Our Brent House hotel is a select-service hotel. It is conveniently located on Ochsner’s campus.
- Affordable nearby apartments may be an option for longer stays after transplant.
FOR MORE INFORMATION

You may want to read more about Ochsner’s Multi-Organ Transplant Institute.

The Ochsner team has designed a more detailed guide to help you along your transplant journey. Visit ochsner.org/liverguide to view or download your copy of My Transplant Guide: Empowering Myself throughout the Journey.

You may want to read more about Ochsner’s Multi-Organ Transplant Institute. Visit ochsner.org/ochsneroutcomes to view or download the latest edition of our Ochsner Multi-Organ Transplant Institute 2014 Ochsner Outcomes book.

YOU CAN CONTACT US ANYTIME:

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