

A photograph of a dirt path in a forest, with a hammock strung between two trees on the left. The right side of the image is a light gray overlay containing text and graphics. Abstract white lines and circles are drawn across the gray area.

Continuing My Journey:

*Staying on the Right
Path as I Wait for My
Kidney/Kidney-Pancreas
Transplant*

“A journey of a thousand miles
begins with a single step.”

– Lau Tzu

CONTINUING MY JOURNEY

This guide is for you now that you are listed for transplant. Inside are important reminders to help you stay on the right path as you wait for your transplant.

You are the most valuable player (MVP) of your healthcare team. What does it mean to be MVP? It means always being:

- At the center of your healthcare
- The best champion for your care

We do our best to make sure that you have a successful transplant. You can help meet this goal as MVP:

- Review the information in this guide
- Take the best possible care of yourself
- Be prepared for the lifetime commitments that come with a new organ(s)

***Thank you for choosing us as your transplant center.
We are committed to providing you with excellent care.
We want the best for you!***

“The sidelines are not where you want to live your life. The world needs you in the arena.”

– Tim Cook

USING YOUR GUIDE

You now have this guide and the one you received when you began your transplant journey with us.

Share your guides with those close to you. Review your guides often.

Key phrases used in this guide:

Yes I Can!

- Reminders of important actions you can take as the most valuable player (MVP) of your healthcare team
- Helpful checklists for you to complete during your transplant journey

Say What?

- Definitions of words or phrases often used in transplant

Ask Myself *

- Three simple questions and a place to write your answers as a review at the end of each chapter:
 1. What do I need to do?
 2. What do I need to remember?
 3. Why is it important?

*Adapted from AskMe 3™

NOTES

Blank pages for you to write more notes at the end of this guide

*Many transplant staff members helped put together this guide.
Our transplant patients and their caregivers also gave us great ideas.
May you benefit from the wisdom and compassion of everyone who contributed.*

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PATIENT – TRANSPLANT TEAM COVENANT

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. The Patient-Transplant Team Covenant reminds us of this partnership's key guidelines.

Patient-Transplant Team COVENANT

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

As a **Patient** and partner in my
healthcare, I 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.



RESPECT

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.



TRUST

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.



PARTNERSHIP

YOUR TRANSPLANT TEAM

*There are **2** key members of your transplant team*

1 YOU – Most Valuable Player (MVP)!

Why are you the MVP (Most Valuable Player) 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 plan are the patients who usually feel and do better.

2 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.



I am my transplant team's
MVP
(Most Valuable Player)

MVP:

(YOUR NAME HERE)

MY ROLE AS MVP

IN CAN I SEE

WHAT I ALWAYS WANT TO REMEMBER

- ☐ Do my part as my transplant team's MVP(Most Valuable Player).
- ☐ Follow the healthcare plan that my transplant team and I agree is best for me.
- ☐ Include my primary caregivers in all aspects of my care.
- ☐ Learn all I can about my illness and transplant.
- ☐ Keep a transplant notebook with all my information.
- ☐ Keep a calendar with all my transplant-related appointments.

WHAT MY TRANSPLANT TEAM NEEDS FROM ME SO THEY CAN DO THEIR PART

- ☐ Share all I can about my health in a timely manner.
- ☐ Show up for all my appointments, labs and tests.
- ☐ Bring my caregivers to my appointments – two (or more) heads are better than one!
- ☐ Take my medicines exactly as instructed.
- ☐ Never let my medicines run out! Refill my medicines on time, every time.
- ☐ Ask questions when I am not sure.

OTHER ACTIONS I CAN TAKE TO HELP MYSELF

- ☐ Talk openly about any fears or doubts I have.
- ☐ Take it one day at a time, one visit at a time.
- ☐ Keep in mind that this can be an emotional time.
- ☐ Stay connected to others.
- ☐ Stay as active and healthy as possible.
- ☐ Be honest with my transplant team. The more honest I am, the better they can help me.

HOW KIDNEYS ARE MATCHED

Two scores are used in matching kidneys. These are the KDPI score and EPTS score.

Let us take a closer look at how these scores are used.

	KDPI Score	EPTS Score
STANDS FOR	Kidney Donor Profile Index	Estimated Post-Transplant Survival
USED FOR	Deceased donor kidney	Patient needing a kidney
MEASURES	How long the kidney is expected to work	How long the patient is expected to need a working kidney transplant
SHOWN AS	Percentage that can be from 0 to 100 percent	Percentage that can be from 0 to 100 percent
LOOKS AT	Deceased donor <ul style="list-style-type: none"> • Height • Weight • Ethnicity • Brain or heart death • Stroke as cause of death • High blood pressure • Diabetes • Hepatitis C virus • Serum creatinine (measure of how kidney is working) • Age 	Patient <ul style="list-style-type: none"> • Time on dialysis • Previous transplants (any organ) • Diabetes when listed for a transplant • Age

MATCHING PRIORITY

Kidney with KDPI equal to 20% or less \longleftrightarrow Patient with EPTS equal to 20% or less
 Kidney with KDPI greater than 20% \longleftrightarrow Patient with EPTS greater than 20%

LIVING DONOR KIDNEY TRANSPLANT

Living donor kidney transplant is a transplant using a living person's kidney. There are not enough deceased donor kidneys available on the national waiting list for the people who need them. One option for people is a transplant that uses a kidney from someone who is still alive.

Most people are born with two kidneys. This means one of the two kidneys can be taken out and put into another person's body. The donor's kidney adapts to make up for having one kidney.

Living kidney donation is safe. Donating a kidney does not affect how long a donor lives. A donor is at no greater risk for kidney failure than an average person. Adult family and friends can be considered as living donors.

People **can** donate if

- They are at least 18 years old
- They are in overall good health
- Their blood type is the right type for the person needing a new kidney
- Donating their kidney is something they really want to do

People **cannot** donate if they

- Are severely overweight (BMI over 33)
- Have cancer
- Use illegal drugs or abuse drugs
- Have diabetes
- Have active infections
- Are pregnant

People **may** be able to donate if they have

- High blood pressure that is well controlled
- Kidney stones

ADVANTAGES OF A LIVING DONOR KIDNEY TRANSPLANT

1. HIGH QUALITY NEW KIDNEY

We know more about a living donor's past and present health. This means we are better able to make sure the donor's kidney works well for you. Kidneys from living donors usually work better for a longer time.

2. TIMELY TRANSPLANT FOR PATIENTS NOT ON DIALYSIS

Your living donor transplant can be done before you get sicker or before you begin dialysis. This means you can have the transplant done at the best time for you.

3. SHORTER WAIT TIME

You do not have to wait for three to five years on a list when you have a living donor. This means you may be 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 the person needing a new kidney.

STEPS TO BE A LIVING DONOR

1. INTERVIEW

- Donor must call to begin the process.
- Donor's information is taken over the phone. This includes getting the donor's medical history.

2. EVALUATION

- Blood tests are done to know if the donor's kidney is a match for you. This can be done in the donor's hometown.
- Tests are done to make sure the donor is healthy and that their kidneys work well. This must be done at Ochsner's transplant center in New Orleans, LA.
- Test results are reviewed. It is decided if the person can donate.

3. SURGERY

- Surgery is scheduled after the donor is approved.
- Surgery is done laparoscopically. It is minimally invasive. This lets the donor heal more quickly.
- Surgery lasts about three to four hours.
- Donor stays in the hospital for 24 hours.
- Donors can restart most regular activities within two to four weeks.

The insurance of the person needing the kidney pays for the donor's:

- Testing
- Surgery
- Hospital stay
- Medical visits for the first month after surgery

NOTE: *Travel and time off from work are not paid for by insurance.*

KIDNEY PAIRED DONATION (KPD)

KPD is a national kidney swap program. This is an option if your donor:

- Is not a match for you
- Has a different blood type than you need

HOW KIDNEY PAIRED DONATION WORKS

- Your donor offers a kidney to someone in the country waiting for a kidney transplant. In return, you get a kidney that matches with you.
- Your donor's evaluation and surgery are done at Ochsner.
(See Steps to Be a Living Donor.)
- Your donor's kidney is sent to the transplant center where the person getting that kidney is being transplanted.
- The kidney that matches with you is shipped to Ochsner for your transplant.

***Anyone interested in being tested
as a living kidney donor:***

Call 504-842-3925.

Ask to speak with the Living Donor Kidney Coordinator.

COMMON MYTHS ABOUT DONATION

1. DONATING IS DANGEROUS/PAINFUL.

FACT Donors are carefully evaluated and are typically much healthier than most people.

FACT Complications are very rare for donors, who can usually return to work in two to four weeks.

FACT It is extremely rare for donors to die or need dialysis.

2. DONORS WILL HAVE TO CHANGE THEIR LIFESTYLE.

FACT Donors can take up all regular activity after they have recovered from the surgery.

FACT Women can have children after they donate.

3. MEDICAL BILLS AND TIME OFF FROM WORK WILL CAUSE FINANCIAL PROBLEMS FOR DONORS.

FACT The insurance of the person needing the kidney pays for the donor's testing, surgery, hospital stay and medical visits for the first month after surgery.

FACT Donors who have sick leave can use it for the surgery.

FACT Donors who qualify may be able to get help with travel costs through the National Living Donor Assistance Program.

FACT Some states offer tax deductions for kidney donation.

4. ONLY FAMILY MEMBERS CAN DONATE

FACT Anyone who is 18 years or older, matches with you and is healthy can donate.



HOW DO I ASK?

Learn all you can

- You can explain it to your family and friends.
- You can answer questions.

Start a conversation

- Begin your talk with others about donating.
- People cannot offer if they do not know you are in need.

Share your story

- Why you need a transplant
- How you are doing right now
- What it is like to live with kidney disease
- Why a transplant will help you

Start with those closest

- Start with your closest family and friends.
- Then widen your search.

Use technology

- Email all your contacts.
- Use social media.

Give it in writing

- Provide written information or websites.
- Gives others something to read more carefully later.

Ask for help

- Have a family member or friend be your “hero” who talks to others on your behalf.
- You may find it easier for someone else to talk to others about donating you a kidney.

Stay positive

- Donating may not be the right decision for some people you ask.
- It may not be the right time to donate for some people you ask.
- Focus on finding someone who is ready and able to be your donor.
- Remain hopeful and upbeat.

{ “The activity you’re most avoiding
contains your biggest opportunity.” }

– Robin Sharma

We understand that is not always easy to approach others about donating a kidney. Know that our team is here to support

- You as you talk with others about kidney donation
- Anyone who has questions about donating a kidney



PLAN AHEAD

1. American Kidney Fund (AKF) insurance premium assistance ends at the time of transplant. Be prepared to pay for your insurance coverage after transplant.
2. If you get Medicare because of permanent kidney failure alone:
 - Your Medicare ends 36 months (three years) after the month you have a kidney transplant *unless* you have another qualifying disability.
 - Know exactly when your Medicare ends.
 - Plan ahead for how you will cover your transplant and other medical costs if your Medicare does end.

FUNDRAISING

Fundraising can be a useful way to help with transplant costs. Money from fundraising helps you have what you need for all expected and unexpected transplant costs before and after transplant.

Fundraising is often a major effort that requires help from your family, friends and even your community. It may be best to have a committee of volunteers to help you.

OTHER GROUPS THAT MAY BE ABLE TO HELP INCLUDE:

- Your church or religious organization
- Your job
- Groups you belong to
- Non-profit groups
- Local businesses
- Media (newspaper, radio, TV, social media)

YOU CAN RAISE FUNDS IN MANY WAYS. SOME IDEAS INCLUDE:

- Dinners
- Bake sales
- Raffles
- Car washes
- Garage sales
- Online social networking sites

**These are just a few fundraising ideas.
There are many other ways to raise money. Ask others for ideas.
Be creative. Use your imagination!**

REMEMBER

Talk to your:

- Transplant social worker or financial coordinator before you do any fundraising.
- CPA or accountant for specific advice.
- Bank about setting up a fundraising account. Show your bank the letter that says you are “listed for transplant.”

RESOURCES TO HELP YOU FUNDRAISE

We understand that it can be difficult to know where to start with your fundraising. A few points to keep in mind:

- National agencies are available to help guide you as you fundraise.
- These agencies may also sponsor your efforts with short-term financial help.

There are many resources to help you fundraise.

Below is a list of some of the many resources available to help you:

American Kidney Fund

(800) 638-8299

www.kidneyfund.org

The Transplant Foundation

(800) 533-3172

www.transplantfoundation.org

Children's Organ Transplant Association (Childhood disease onset)

(800) 366-2682

www.cota.org

National Kidney Foundation

(212) 889-2210

www.kidney.org

National Foundation for Transplants

(800) 489-3863

www.transplants.org

National Transplant Assistance Fund

(800) 642-8399

www.transplantfund.org

Nielson Organ Transplant Foundation

(904) 798-8999 (Florida only)

www.notf.org

WHY EACH PERSON'S WAIT TIME IS DIFFERENT

***“How long will I have to wait before
I get my new kidney and/or pancreas?”***

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.

The current average wait time for a deceased donor kidney in Louisiana is three to five years. The current average wait time in Louisiana for a deceased donor kidney-pancreas is one year. Your wait for a new kidney and/or pancreas may be as short as a few days or as long as several years.

Factors that *can* affect a person's wait time include:

- Blood type
- Tissue type
- Height and weight of the person
- Size of the donated organ(s)
- Antibody levels
- Crossmatch results
- Time on the waiting list
- Time on dialysis

Factors that *do not* affect a person's wait time:

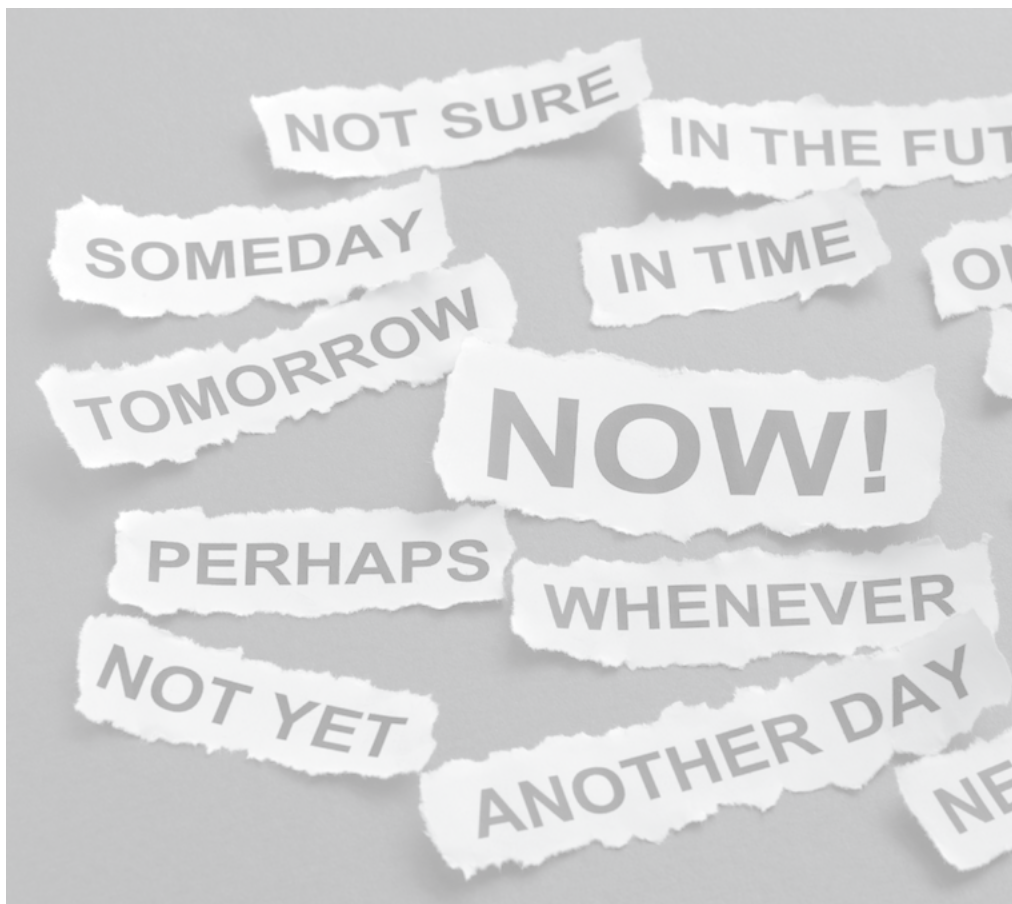
- Gender
- Race
- Religion
- Celebrity
- Financial status

A donated kidney and/or pancreas may look like a good match for you on paper. Your transplant surgeons do not know for sure until:

- Blood testing is completed
- They examine the organ(s) in person

You may not be transplanted if the surgeons decide this kidney and/or pancreas is not the best for you once they actually see the organ(s).

Unfortunately, there are more people on the transplant waiting list than there are available organs. This means it is impossible to know exactly how long you wait for the organ(s) that are the right match for you.



PRA (PANEL REACTIVE ANTIBODY)

PRA is a blood test that measures your body's immune system activity from 0-100%. The PRA percentage is higher when your body is making more antibodies. This means your immune system activity is higher.

Your immune system activity may be higher if you are exposed to tissues of another person. Some examples of when this can happen include:

- Blood transfusion
- Pregnancy
- Previous transplant

SAY *what?*

Antibody is a protein your body makes to fight disease. Antibodies can affect your transplanted organ(s).

PRA IMPACT ON GETTING A TRANSPLANT

A patient with a high PRA:

- Has a highly active immune system
- Makes antibodies that may attack and damage the transplanted kidney

This means that for this patient:

- Fewer kidneys are a match
- Wait is much longer than for patients with low PRAs

A crossmatch test is done before every transplant. This test shows if the donor's organ(s) can work for you. This test may need to be done more often before a match is found if your PRA level is high.



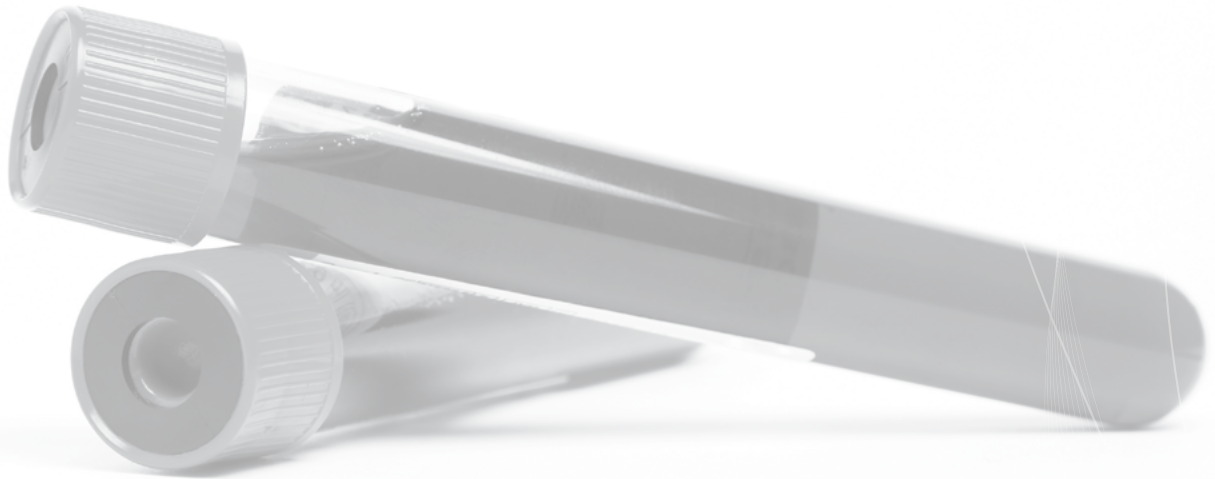
PRIORITY FOR PATIENTS WITH HIGH PRAS

Patients with high PRAs have a highly active immune system. This means they produce antibodies that may cause them to reject a kidney transplant. These patients are also called *highly sensitized* patients.

Fewer kidneys are a good match for highly sensitized patients. Highly sensitized patients get more priority for kidneys that are a good match for them. This boosts their chances of getting kidney offers.

Your transplant team tells you:

- If you are highly sensitized
- Extra priority you get for matching kidneys if you are highly sensitized



SAY *what?*

Crossmatch test is a test where blood from you and the donor are mixed. This test shows if there is a reaction:

- No reaction: The donor's organ(s) can work for you.
You are compatible with that donor.
- Reaction: The donor's organ(s) will not work for you.
You are not compatible with that donor.

It takes about four to six hours to get crossmatch results. Your transplant coordinator tells you if you will wait for the results at home or at the hospital. Your transplant coordinator lets you know when to come to the hospital.

INACTIVE STATUS (STATUS 7)

You may be told that you are on *inactive status (status 7)* during your wait for a transplant. It is in your best interest to not get a transplant during this time. Let us look more closely at what inactive status means for you.

A person on the transplant wait list can be listed as either:

1. ACTIVE	2. INACTIVE
• Person builds up wait time	• Person builds up wait time
• Person <i>can</i> be offered an organ(s)	• Person <i>cannot</i> be offered an organ(s)
• Known as status 1	• Known as status 7

Note: Inactive status is only for a certain amount of time. It is not permanent.

REASONS FOR INACTIVE LISTING INCLUDE:

- Not following advised treatment
- Major surgery
- Heart issues
- Peripheral vascular disease (PVD)
- Stroke
- Cancer
- Weight gain above maximum allowed
- Changes in financial situation and/or insurance coverage

People are listed as inactive when they:

- Have a medical or other situation that could hurt the new organ(s)
- Will not benefit from a transplant in their current situation
- Will benefit from waiting until their medical or other situation improves

{ “Life is about timing.” – Carl Lewis }

IMPORTANT FOLLOW-UP DURING YOUR WAIT

Make sure you keep up with needed care while you wait for a new organ(s):

1. All medical visits with your
 - a. Ochsner transplant team (yearly or semi-yearly)
 - b. Other doctors
2. Monthly blood samples

MONTHLY BLOOD SAMPLES

You send us one tube of blood each month while you are on the waiting list.

You can have your blood drawn by:

- Your dialysis unit if you are on dialysis
OR
- An Ochsner facility
OR
- Your local lab using tubes we mail to your home

We get monthly blood samples from you to:

- Check antibody levels in your blood
- Match your blood with a kidney and/or pancreas that may be right for you

You must come in to give us a blood sample if we do not have a recent sample. This can be at any time of the day or night.

Make sure you send us blood samples every month.

Sending us a monthly blood sample helps you:

- We can quickly test your blood when you are called.
- You save yourself a drive to Ochsner to give us a blood sample.
- You can usually wait at home while we test your blood.

YEARLY OR SEMI-YEARLY TRANSPLANT UPDATES

You come back to see us every six months to a year for updates:

- Transplant nephrologist or advanced practice provider to update your:
 - Medical history
 - Tests as needed
- Social worker to update your:
 - Personal history
 - Caregiver information

We send you a letter when it is time to make an appointment. Please call to make your appointment with us as soon as you receive this letter.



It is very important that you come back for these updates. You may not be able to be transplanted if your information is not up-to-date when you are called for a transplant.



We want to know about changes in your life while you wait for your new organ(s). Always let us know if you have:

- A new address and/or phone number
- Any changes in your support system
- A new doctor and/or dialysis unit
- Started or stopped dialysis
- Been hospitalized or had surgery
- Had an infection
- Had a blood transfusion
- Been offered a kidney by someone
- Any insurance changes

It is especially important for you to stay in touch with us now that you are on the waiting list. Please make sure we know how to reach you at *all times*.

REMEMBER

We cannot transplant you if we cannot get in touch with you!



EMOTIONAL SIDE OF WAITING

Being put on the transplant waiting list can comfort you and those close to you. You may feel more hopeful now that you are one important step closer to getting transplanted.

Waiting for your transplant can also be a difficult time. You may wonder why others get transplanted before you. Being called for a transplant and then not being transplanted can be tough for you and those close to you.

You may get frustrated while you wait. You may even feel depressed, anxious or helpless. It may help to talk openly with those around you about how all of you are feeling as you wait for your transplant.

Talk with your transplant team about any challenges you have while waiting for your transplant. We are here to support you and your caregivers during this time!

{ “Everything comes gradually and at its appointed hour.”
– *Ovid* }

MULTIPLE LISTING

Multiple listing is being registered at more than one transplant center at the same time. Patients from transplant centers closer to the available deceased donor are usually considered before patients from more distant centers.

This means multiple listing may:

- Increase your chances of getting a local offer
- Decrease your wait time by several months

In the state of Louisiana, you can only be on one transplant center's list. To be listed with other transplant centers outside of Louisiana, you must:

1. Contact each transplant center where you want to be evaluated
2. Be evaluated by the transplant center
3. Be accepted by the transplant center before you are registered on the UNOS list with this center

A few other points about multiple listing:

- Know the specifics about multiple listing if you decide to pursue this option.
- You may have other costs.
- Know your options for care after transplant.
- You can transfer your waiting time if you choose a different transplant center.

You are encouraged to call UNOS with any questions about multiple listing:

1-888-894-6361

www.unos.org



THE CALL

Time to go to the hospital

WHAT HAPPENS

- The transplant surgeon is offered a kidney and/or pancreas that looks right for you.
 - The transplant nurse coordinator calls you to:
 - Let you know an organ(s) is available for you
 - Make sure you do not have any unknown medical problems
 - If you have no medical problems:
 - We do a crossmatch test using your monthly blood sample and the donor's blood.
- OR
- You drive to Ochsner to give us a blood sample if we do not have a current sample. We do a crossmatch test with this sample.



***We turn down the organ(s)
if we cannot reach you by phone
after 60 minutes (1 hour).
This is a national rule.***

8 WHILE I WAIT:

***8 Things
I Do While
I Wait For
My Transplant***

8 WHILE I WAIT:

8 Things I Do While I Wait For My Transplant

IN CAN I SEE

1. KEEP MYSELF HEALTHY

I follow the care plan that my healthcare team and I agree is best for me:

- I watch my fluid intake.
- I follow my diet.
- I take my medicines.
- I make all my dialysis treatments. I stay on dialysis for the entire time for each treatment.

2. TURN IN MY MONTHLY BLOOD SAMPLES

I make sure my transplant team gets my monthly blood samples, *on time, every time*. Blood samples must be updated because:

- It is the only way to know if new antibodies have formed.
- Only fresh blood samples can be used to test if an organ(s) is the right match for me.

NOTE: *Fresh blood samples are samples that are less than 40 days old.*

I understand that:

- I am the one who needs to make sure that my blood samples are sent to Ochsner every month – even if they are being sent by my dialysis unit, other Ochsner facility or local lab.
- My up-to-date blood sample is needed for the crossmatch test when an organ(s) offer comes.
- I may not be able to accept an organ(s) offer if my blood sample is not up-to-date. This is even more important the farther away I live from Ochsner's transplant center.

3. SHOW UP

I show up for all of my:

- Yearly or semi-yearly visits with my transplant team
- Medical visits with other doctors
- Visits with other healthcare team members
- Labs
- Tests

When I cannot make it to my visits, labs or tests, I make sure to:

- Cancel as soon I know
- Reschedule any missed visit, lab or test

4. TELL YOU ABOUT IMPORTANT CHANGES IN MY LIFE

I always let you know if I have:

- A new address and/or phone number
- Any changes in my support system
- A new doctor and/or dialysis unit
- Started or stopped dialysis
- Been hospitalized or had surgery
- Had an infection
- Had a blood transfusion
- Been offered a kidney by someone
- Any insurance changes

5. ANSWER MY CHARGED PHONE

I make every effort to answer my phone. I understand your call may appear as “private” or “unknown.” My cell phone is always:

- Turned on
- Easily heard
- Fully charged

If I miss the call, I:

- Quickly listen to your voice message
- Call back right away

I understand:

- You turn down the organ if you cannot reach me by phone after 60 minutes (1 hour).
- You need to be able to reach me to transplant me!

6. AM READY FOR “THE CALL”

I always have a plan in place for:

- A ride to take me to the hospital for my transplant
- A caregiver to care for me as needed
- What I will bring to the hospital
- All needed arrangements related to my transplant

I am prepared at all times:

- I fundraise: It is best to fundraise now rather than wait until after my transplant.
- I have a financial plan: I always know what transplant costs I need to pay and have a plan in place to meet my financial needs.

I understand that the call can come at anytime – usually when it is least convenient!

7. LIVE A FULL LIFE

I do all I can to enjoy my life while I wait for my transplant.

I know that my transplant coordinator calls me when 1) it is time to schedule my transplant follow-up visits or 2) there is an organ(s) offer for me. I can be confident that it is okay to not hear from my coordinator otherwise.

I understand that the way the transplant wait list works means:

- The order of people on the transplant wait list is always changing.
- It is impossible to know how long I have to wait before my transplant.
- Inactive status (status 7) is temporary.

8. ACT AS MY OWN MVP

I do my part as MVP of my healthcare team. I understand that I am the best champion for my care. I always ask when I have any doubts or questions.



**An organ offer is a precious gift.
We do our best to make sure that you have a successful transplant.
We need **you** to help us meet that goal!**

**Good luck.
Always remain hopeful.
Your call can truly come at any time.**

{ Never talk defeat. Use words like hope, belief, faith, victory."
– *Norman Vincent Peale* }

HELPFUL CHECKLISTS

A large, stylized orange checkmark graphic is positioned diagonally across the page, starting from the bottom left and extending towards the top right. The background is a solid blue color.

MY AFTER-TRANSPLANT PLAN

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PRIMARY CAREGIVERS

Who will care for me after I leave the hospital?

- ☐ Family member
- ☐ Friend
- ☐ Other

My caregivers _____

PLACE TO STAY

Where will I stay after I leave the hospital?

- ☐ Short-term housing
 - ☐ Family
 - ☐ Friends
 - ☐ Hotel
 - ☐ Apartment
- ☐ Long-term housing
 - ☐ Your home
 - ☐ Family
 - ☐ Friends
 - ☐ Other

My place to stay _____

{ “The person who removes a mountain begins by carrying
away small stones.”
– *Anonymous* }

WAY TO PAY FOR MEDICINES

How and where will I buy my medicines after I leave the hospital?

☐ How: Financial plan

☐ Insurance (private insurance, Medicare, Medicaid)

☐ Cash

☐ Full-time or part-time work

☐ Fundraising

☐ Other

☐ Where: Pharmacy (name and phone number)

My medicine information _____

FUNDS

How will I pay for all my transplant-related expenses after I leave the hospital?

☐ Insurance (private insurance, Medicare, Medicaid)

☐ Cash

☐ Full-time or part-time work

☐ Fundraising

☐ Other

My funds _____

TRANSPORTATION

How will I get around after I leave the hospital?

☐ Family member's car

☐ Friend's car

☐ Taxi

☐ Bus

☐ Other

My transportation _____

MY HOSPITAL CALL CHECKLIST

IN
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CONTACT INFORMATION

- ☐ My transplant team knows how to reach me at all times. I gave them all phone numbers to contact me right away when a kidney and/or pancreas become available.
- ☐ My transplant team knows when any of these phone numbers change.
- ☐ My cell phone is turned on, can be heard and is fully charged at all times.
- ☐ My transplant team's phone numbers are always with me.

PERSONAL/HOME ARRANGEMENTS

I have reliable people to:

- ☐ Care for my children and/or parents
- ☐ Watch my home
- ☐ Look after my pets
- ☐ Water my plants
- ☐ Pick up my mail (unless I have my mail held at the post office)
- ☐ Pay my bills (unless I choose to set up automatic bill payments)

RIDE TO THE HOSPITAL

- ☐ I have a primary driver who takes me to the hospital. My driver knows I have to leave for the hospital when the nurse coordinator tells me.
- ☐ I have a back-up driver in case my primary driver cannot drive me.
- ☐ My caregiver knows to travel with me to the hospital.

POINT PERSON

- ☐ I have someone to let others know how I am doing so I can get the rest I need while I am in the hospital.

PACKED BAGS

- ☐ For anyone staying with me in the hospital
- ☐ For myself

THINGS I WILL NEED IN THE HOSPITAL

INCREASE

- ☐ Medicines (prescription, over-the-counter medicines; injections if used)
- ☐ Medical equipment I use often
- ☐ Peritoneal dialysis (PD) supplies (if on PD)
- ☐ Eyeglasses (distance and reading)
- ☐ Underclothes
- ☐ Robe
- ☐ Slippers
- ☐ Socks
- ☐ Change of clothes
- ☐ Dental care items (toothbrush, toothpaste, dental floss; dentures if used)
- ☐ Hair care items (shampoo, comb, hairbrush)
- ☐ Deodorant
- ☐ Other personal care items
- ☐ Important phone numbers
- ☐ Personal transplant notebook
- ☐ Cell phone and charger*
- ☐ Identification*
- ☐ Cash *
- ☐ Credit card*
- ☐ Insurance cards*
 - ☐ Medicare card
 - ☐ Medicaid card
 - ☐ Private insurance card
- ☐ PAP application information* (if applicable)

****Ask your caregivers to keep any valuable items for you so these do not get misplaced.***

THINGS I MIGHT WANT TO HAVE TO BE MORE COMFORTABLE

- ☐ My own pillow, blanket
- ☐ Loose, comfortable clothing
- ☐ Reading material
- ☐ Crossword/jigsaw puzzles
- ☐ Laptop and charger
- ☐ Photos
- ☐ Paper and pen

DO NOT BRING

- ☐ Jewelry
- ☐ Other valuables that can be left at home



I HAVE FINISHED TALKING TO THE NURSE COORDINATOR ABOUT COMING INTO THE HOSPITAL.

Now I make sure I:

- ☐ Leave for the hospital when the nurse coordinator tells me.
Note: For peritoneal dialysis (PD) patients: Drain my PD fluid as my coordinator instructs me to drain. Bring enough PD supplies for three to four exchanges.
- ☐ Have my caregiver with me when I travel to the hospital
- ☐ Ask my coordinator what I can eat or drink
- ☐ Have everything I need to take with me to the hospital
- ☐ Have taken care of anything that needs to be handled for me while I am in the hospital
- ☐ Park in Ochsner's parking garage – the same garage where I park for my medical visits before transplant
- ☐ Have my caregiver with me in the hospital
- ☐ Go straight to the Admit Office on the first floor (Monday-Friday, 8am-5pm)
OR
Go straight to the Emergency Room (Monday-Friday, 5pm-8am; weekends)

Once you get to the hospital, you will be told what to do next.

Hold up – Did I remember everything?

- ☐ Do I know where to go once I get to the hospital?
- ☐ Do I have my packed bags with me?
- ☐ Did I make all arrangements for while I am in the hospital?

What do I need to do?

What do I need to remember?

Why is it important?

[illegible]

ASK *myself*

1.

What do I need to do?

2.

What do I need to remember?

3.

Why is it important?

[illegible]



504.842.3925 or 800.643.1635
ochsner.org/transplant