My transplant-ready workbook

A workbook for your kidney transplant journey

This workbook belongs to:

Missouri Kidney Program
University of Missouri
Dedication

My Transplant-Ready Workbook was made possible with the financial support of the Gloria Hartman family. We dedicate this workbook to the Hartman family for their generosity and compassion on behalf of the Missouri Kidney Program and everyone pursuing a kidney transplant.
About this workbook

Transplant is a journey

My Transplant-Ready Workbook will walk you through the transplant process and support the choices you make along the way – from the day you decide you want a transplant to preparing for surgery.

Who is this workbook for?

My Transplant-Ready Workbook was created specifically for patients who have made the decision to get a kidney transplant and those who support them.

Who developed this workbook?

This was developed by the Missouri Kidney Collaborative (MKC). The MKC is a group of government-funded and non-profit organizations who have an interest in improving the health of Missourians with kidney disease, including: Missouri Kidney Program, The Missouri Department of Health and Senior Services – Organ and Tissue Donor Program, Qsource ESRD Network 12, and Health Literacy Media (HLM).

We used our combined expertise, experience, and resources to develop this workbook. The My Transplant-Ready Workbook is intended to supplement, organize, and build upon the information provided by medical professionals.

Missouri Kidney Program
University of Missouri
How to use this workbook

1. Read through **What is in this workbook** on the next page to better understand the transplant journey and start with the section that matches where you are in the process.

2. Fill out the worksheets to keep important information in one place.

3. Use the to-do lists on the section pages to mark off the tasks you’ve finished.

4. Read the green Q&A “call-outs” for commonly asked questions and answers.

5. Write down important dates and appointments in the orange calendar “call-outs.”

6. Read the blue info “call-outs” for helpful tips.

7. Use the dark grey “call-outs” to find additional information on the topic – this could be a website or another page in this workbook. If you have a digital copy of this workbook, click the “call-out” for a direct link.

8. Make copies of the extra worksheets in the resources section before you fill them out so you can use one each time you have a call or appointment, or need to list medicines or take notes.

9. Take this workbook to your medical appointments and to dialysis. Use it to update your team, ask questions, write down anything you want to remember, and share it with those who help you make important health decisions.
What is in this workbook

Use these links and page numbers to quickly get to different sections of this workbook.

- Getting started with a transplant  
  Page 7

- Transplant referral process  
  Page 17

- Transplant evaluation  
  Page 23

- Transplant listing  
  Page 37

- Transplant surgery  
  Page 47

- Transplant resources  
  Page 53
Getting started with a transplant

In this section, you’ll write down important information you’ll need throughout the process, review transplant treatment options, and choose a transplant center.

To-do:

- Fill out “my why” (page 8)
- Fill out “my-pick-me-up” (page 8)
- Fill out “my people” (page 9)
- Fill out “my healthcare team” (page 10)
- Review “my transplant decisions” (page 11)
- Choose a transplant center (page 14)

*You may not be able to complete all of these worksheets right now, and that’s okay.*
Transplant is a journey

Everyone’s transplant journey is a little different. This is your journey and your workbook, so start by filling out these first few pages with things about you!

My why

People choose to get a kidney transplant for many reasons. When the journey gets tough, it’s helpful to remember those reasons. This is your “why,” your motivation.

My reasons for wanting a kidney

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My pick-me-up

Everyone gets discouraged at some point, but keep going! Sometimes it’s helpful to have a list of things you can do to help you feel better, such as talking with someone who has been through a transplant, talking with your social worker, taking a walk, or watching inspiring stories. Check out the Finding a kidney transplant mentor or Connecting with others about transplant resources. page 66 page 67

Things I can do to feel better

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My transplant-ready workbook | 8
It’s important that you have support on this journey, so think about your trusted family and friends who will support you and how they will help. For example, you may have one person who drives you to appointments and another person who helps you at home after your transplant.

Most transplant centers require each patient to have a primary support person with them before, during, and after transplant. Think about who that person would be for you.

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What if I want to talk to someone who has been through this process? Check out the Find a kidney transplant mentor resources for organizations that can help you find a kidney transplant mentor.
**My healthcare team**

You are the most important part of your healthcare team. Remember, you are an important part of your healthcare team. Make sure you understand your medical care - and ask questions.

Stay active by making all of your visits and communicating with your team.

As you meet members of the team during your journey, write their names and phone numbers here!

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Dialysis center: __________________________________________

Name

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Address

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Phone number                 Fax number                 Other

Pharmacy: __________________________________________

Name

____________________________________

Address

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Phone number                 Fax number                 Other
transplant decisions

You will have a lot of decisions to make. You’ve already taken the first step by deciding to get a kidney transplant! The next step is to decide whether or not you want to get a kidney from a living or a deceased donor.

If you have started dialysis:

**Living donor kidney transplant**

During surgery, surgeons will put a kidney into you from a living person.

**There are many benefits to a living donor kidney:**

- Living donors can be a family member, friend, co-worker, or even a complete stranger
- Transplant can happen sooner and be scheduled
- These kidneys usually last longer than deceased donor kidneys

Think about people you could talk with about your interest in living donation and write their names and phone numbers below:

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If you already have a living donor, or someone who wants to be a living donor, write their name and phone number below:

________________________________________________________________________
If you have a living donor but their kidney is not compatible, there are other options for you and your donor, such as:

Paired donation (or kidney swaps): Takes place when 2 kidney patients have donors who aren't good matches for them. The 2 patients swap donors so each can get a kidney that's a good match for them.

Donor chains: A chain helps a group of kidney patients who have donors who are healthy but aren't matches. Swapping donors helps a whole group or chain of kidney patients get a living donor transplant.

To learn more about living donation options, check out the Living donation and donor exchange programs resources.

Deceased donor kidney transplant

During surgery, your surgeon will put a kidney into you from someone who has died. To get a deceased donor kidney, you must be on a waitlist until a suitable kidney becomes available.

There are benefits to a deceased donor kidney:

Deceased donor kidneys can come from people of all ages who have chosen to donate their organs

Deceased donor kidneys generally last for 10-15 years

How long will I wait for a deceased donor kidney?
Wait times may vary. In Missouri, the average wait time is 3-5 years.

If you or a loved one wants to be a donor, after death, register as an organ, eye and tissue donor at DonateLifeMissouri.org or OrganDonor.gov.
You can also consider accepting a **Public Health Service (PHS) increased risk kidney** (also called expanded criteria kidney).

- These are kidneys from a donor who may have had an increased risk for transmission of Hepatitis B, C, or HIV
- Doctors check every kidney for infection before a transplant
- You do not have to accept this type of kidney, but if you are willing to, you may be able to get a transplant sooner
- These kidneys last on average for 10-15 years

**Can I be on the waitlist and still search for a living donor?**

Yes! You are encouraged to continue to search for a living donor while you are on the waitlist for a deceased donor kidney.

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**If you have not started dialysis:**

### Pre-emptive kidney transplant

During surgery, surgeons will put a kidney into you from either a living or deceased donor before you have to go on dialysis. Most pre-emptive kidney transplants are from living donors.

**There are many benefits to a pre-emptive kidney transplant:**

- You can get a kidney transplant before you have to start dialysis
- Pre-emptive kidney transplants have the best health outcomes
- These transplants can be more cost-effective

**What if I want to know more about a pre-emptive kidney transplant?**

Talk to your nephrologist.
Choosing a transplant center

Talk to your healthcare team and support network about how to choose a center that’s right for you.

For a list of transplant centers in Missouri, Iowa, Nebraska, or Kansas, check out the Find a transplant center resources.

When choosing a transplant center, you may want to ask:

- How long will my evaluation take?
- Does the transplant center take my insurance?
- How far is the transplant center from where I live or will stay after surgery?
- What type of financial assistance does the transplant center offer?
- Does the transplant center participate in a pairs program?
- What are the transplant center’s requirements after surgery?
- What are the transplant center’s success rates?

What if I want to talk to someone who has been through this process? Check out the Living donation and donor exchange program resources for organizations that can help you find a kidney transplant mentor.
### Transplant centers I want to call

Identify 1 to 3 transplant centers. Write down the names of the transplant centers and any important information about them.

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Transplant referral process

In this section, you’ll learn about the transplant referral process and the next steps you must take to be considered for a transplant.

To-do:

- Call your transplant center (page 18)
- Review your referral packet (page 19)
- Fill out your forms (page 19)
- Send in your forms (page 20)
- Talk with your transplant center (page 21)

You do not need a written referral from your physician to get started with transplant evaluation.
# Call your transplant center

Call the transplant center and ask them for a referral packet. Referral packets contain a lot of important information about the transplant evaluation process and forms.

Fill in the blanks as you talk with someone from the transplant center.

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<th>What if I need help calling?</th>
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<tr>
<td>Someone from your healthcare team or support network can help.</td>
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<th>Transplant center</th>
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<th>Date and time I called</th>
<th>Person I spoke with</th>
<th>Notes</th>
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<th>What if I don’t hear back from the transplant center right away?</th>
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<td>The transplant coordinators have a lot to do when they get your referral forms. You are welcome to call and check on the status of your referral.</td>
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If you call more than 1 transplant center, use the extra Call your transplant center worksheet in the resources section.
Review your referral packet

Referral packet will most likely include:

- **Medical release forms** to obtain necessary information from your healthcare providers
- **Personal forms** asking about your insurance, background, and health history

Fill out your referral forms

Take your time going through your packet and complete it all. Make a list of information you may need to go find, using the lines below.

- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________
- ____________________________________________  ____________________________________________

What if I need help filling out my packet?
Ask a family member, friend, or the social worker or nurse at your dialysis center to help you fill out the forms.

Person who helped me  ____________________________________________
Send in your referral forms

Once you complete the forms, make a copy for yourself, and then send the originals to the transplant center. You can mail your forms or ask your dialysis center to send them in for you.

I (or my dialysis center) sent my forms on: ____________________

After you send in your forms, call the center to make sure they received your packet and ask how long it will take them to review the forms and get back with you.

The transplant center received my forms on: ________________

If you don’t hear back, check with your dialysis center or provider to make sure the transplant center has what they need.

I should hear back by: ____________________

If you don’t hear back by the date you wrote above, call the center back.

What to expect

After you send in your forms, your transplant center will:

Review the forms that you completed and sent in
Request your medical records from your other doctors
Contact your insurance company to make sure they accept your insurance plan

It may take the center a few weeks or longer to get back to you.
Talk with your transplant center

After the center reviews your referral forms, they will decide if you can move forward with a transplant evaluation at their center. You will get a letter or call from the center with next steps.

Share the letter or information from the call with your healthcare team and support network.

What if I can’t move forward at this transplant center?
Go back to the Transplant centers I want to call worksheet and call the next center on your list.

My notes
Transplant evaluation

In this section, you’ll learn about the transplant evaluation process and track your progress.

To-do:

- Understand the evaluation process (page 24)
- Learn what to expect at your class (page 24)
- Learn what to expect at your evaluation (page 25)
- Prepare for your class and evaluation (page 26)
- Fill out “my transplant team” (page 31)
- Prepare to meet your transplant team (page 32)
- Get a call from your coordinator (page 35)

Make sure you ask for a copy of your evaluation results.
Understand the evaluation process

If the center decides that you can move forward with transplant evaluation, you will go to a transplant education class, have your medical evaluation and additional testing, and meet members of your team along the way.

Every transplant center is different. Your education class, evaluation, and meeting with your transplant team may all happen on the same day or over the course of a few days or weeks.

Learn what to expect at your class

At your transplant education class, session, or appointment, you will learn about the overall transplant experience and the specifics of the process at that transplant center. Most transplant centers require you to attend a transplant education class. This may be in a group setting or 1 on 1, depending on your needs.

Add the date and time of the class to your calendar.

You will learn about:

- General kidney transplant information, such as the risks and benefits of a transplant
- Transplant surgery and follow-up care at that specific transplant center
- Financial counseling, including what your insurance plan will or will not cover

What if I don’t want to talk about finances with other people around? Ask the financial counselor if you can talk in a private room.
Learn what to expect at your evaluation

Most of your medical evaluation tests will take place at your transplant center and may all be in one day, over a few days, or even longer. You must complete the full evaluation process.

What if my evaluation happens over multiple days and times? Add the dates and times of your evaluation tests in your calendar.

You will be scheduled for a number of medical tests, including:

- **Blood tests** to help find a match and test your immune system
- **Other testing** such as a colonoscopy or a dental evaluation
- **X-rays and screenings** to look for any other health problems
- **Mental health and social support assessment**

After your evaluation, ask for a copy of your test results.
Prepare for your class and evaluation

Here are some ways to prepare:

- **Think about who you want to come with you**
  It’s important to have people with you on your transplant journey. Some transplant centers even consider a patient’s support system when deciding whether that patient is transplant ready.
  
  **Who will come with me to the class:**
  
  **Who will come with me to the evaluation:**

- **What if I don’t have anyone to go with me?**
  You should still go to the class to learn all you can, but go back to **My people** and think about who will support you throughout this process.

- **Think about how you will get there**
  If your class is not the same day as your evaluation you can drive yourself, take public transportation, or take a car service such as a taxi or rideshare. If your class and evaluation are on the same day, you should have someone you trust drive you there and back because you may be too tired.

  **How I will get to the class:**
  
  **How I will get to the evaluation:**

- **Reschedule dialysis**
  If your class or evaluation falls on a day that you have dialysis, you will need to reschedule dialysis around your class. Contact your dialysis center.

- **Wear comfy clothes and pack kidney-friendly snacks**

- **Bring your photo ID, all of your insurance cards, and a list of your medicines with you**
Think about the questions you want to ask
Your transplant education class is a great time to ask questions. Here are some questions that you might want to ask:

What is the testing like? __________________________________________

What if I don’t have someone to come with me? _______________________

How does the waitlist work? _________________________________________

What if I have a living donor? _______________________________________

Where can I stay nearby after my transplant? ___________________________

Is there anyone I can talk to who has been through the process? __________

What if I have more questions?
Use My notes on the next page to write down more questions and answers.
Meet your transplant team

Your team will provide medical care, advice, and support for you and your family throughout the transplant process.

It’s important (and helpful!) to stay in contact with your transplant team, so make sure to write down their names and contact information on the My transplant team includes page.  

Here are some of the people you may meet:

**Transplant Coordinator**

Transplant coordinators are usually licensed registered nurses (RN) and will help care for you before and after your transplant. After your transplant, your coordinator will prepare you for discharge and follow up with you when you leave the transplant center. They may also refer you to other providers or services to help you adapt to life after your transplant.

**Nurse Practitioner (NP) or Physician Assistant (PA)**

Nurse practitioners are registered nurses who have completed advanced education and training in diagnosing and treating common conditions and chronic illnesses. Physician assistants are non-physicians who give some of the same care as a doctor while working closely with a supervising doctor. At a transplant center, they might manage your daily medical care when you’re in the hospital or may follow your progress in the outpatient clinic.

**Clinical Nurse Specialist (CNS)**

Clinical nurse specialists are registered nurses with an advanced practice degree in a nursing specialty. They’re usually involved in the transplant evaluation as well as care in the hospital and after the transplant.

**Transplant Nephrologist**

Nephrologists are medical doctors who specialize in medical problems of the kidney. Most patients with kidney disease have a nephrologist who manages their medical care before a transplant. You may have another transplant nephrologist for during and after your transplant.
Transplant Surgeon
Transplant surgeons are medical doctors who specialize in kidney surgery and transplant. Your surgeon will perform the operation and will be involved in your care as you recover from surgery.

Social Worker
Transplant social workers are specially trained in the unique financial, educational, and support needs of patients before, during, and after their transplant. They can provide patients and their families with resources about housing, finances, community and support services, and vocational rehabilitation.

Financial Counselor
Financial counselors help you figure out the costs of your transplant, what your insurance will cover, and how you can afford any costs your insurance doesn’t cover.

Dietitian / Nutritionist
Dietitians / nutritionists help make sure you’re getting the nutrition you need before and after the transplant. The dietitian may also work with you on any special diets for health problems such as diabetes, high blood pressure, or high potassium levels.

Use the next page to write down the names and contact information for members of your transplant team.
My transplant team includes:

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My notes

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Prepare to meet your transplant team

When you meet members of your transplant team, ask them any questions you may have about transplant. Remember, they are there to help and support you throughout your journey.

Here are some questions that you might want to ask:

- **What will surgery be like?**

- **How long will surgery be?**

- **Will you remove my kidneys during the surgery?**

- **What will my incision look like?**

- **Where will my incision be?**

- **What will the pain be like? And what will I take for the pain?**
How long will I be in the hospital?

How long will recovery be?

What will I need to do after my transplant?

Will I need dialysis again?

What if I have more questions?
Use My notes on the next page to write down more questions and answers.
Get a call from your coordinator
Once your evaluation is complete, your transplant team will meet to determine if you’re suitable for a kidney transplant. It may take a few weeks.

You will get a call and a letter from the transplant team letting you know whether or not you will be listed for a deceased donor kidney transplant.

Being put on the waitlist

If you’re approved:
Your transplant wait time began the day you started dialysis. If you haven’t started dialysis, your wait time begins when you’re approved for a transplant.

If you’re not approved:
If the center decides you’re not a good candidate to get a transplant, they will explain the reasons. Some of the reasons may be:
- Advanced heart disease
- Active cancer
- Lack of social support
- Lack of financial support
- Certain behaviors such as smoking, chewing tobacco, illegal drug use, alcohol abuse, or not following medical instructions
- Mental illness that limits your ability to care for your new kidney

There may be things you can do to be approved. Talk to your coordinator and ask what you can do to be approved.

You may want to consider calling one of the other transplant centers on your Transplant centers I want to call worksheet.

If I am not approved at one center, can I be approved at another?
Yes, each center is different. One transplant center may turn a patient down and another center may approve them.
In this section, you’ll learn about what to do while you wait for your deceased or living donor transplant.

To-do:

- Understand waitlist status (page 38)
- Learn how to keep your status “active” (page 38)
- Learn how to stay healthy while you wait (page 40)
- Learn how to stay connected while you wait (page 44)
- Learn how to stay encouraged while you wait (page 44)
- Consider ways to get a kidney sooner (page 45)
“Active” vs “inactive” waitlist status

Once a person is placed on the kidney transplant waitlist, they are assigned a status – “active” or “inactive.”

If you are active on the list, then you are in line for a kidney and can receive a call for one at any time. If you are inactive or on hold, then you are still on the waitlist, but will not receive a call for a kidney until you address the transplant center’s specific concern, such as getting dental work, losing weight, recovering from an infection, or updating insurance information.

During the time you are waiting for a kidney, your status may change back and forth. If your status changes to inactive, contact your transplant center and find out what you need to do to become active again.

Keep your waitlist status “active”

Some things that make you inactive are out of your control, but here are some things to help keep your status active:

**Stay in contact with your transplant center**

Call them if your situation changes, such as when:

- Your health insurance or medication coverage changes
- Your contact information (phone number or address) changes
- You change dialysis centers or start seeing a new nephrologist
- You found someone who wants to donate a kidney to you
- You start or stop taking any medicines
- You get sick or go to the hospital
Repeat your evaluation testing
Your transplant coordinator will help you schedule this when the time is right. Usually you will get testing done every year.

Continue to get other testing or treatments
It’s important to keep up with your medical testing and treatments such as monthly blood draws and continuing with dialysis if you are already on it.

Check your status on the waitlist
Call your coordinator every few months or when you are not sure what your status is to make sure your waitlist status is “active.” If your status is “inactive,” ask what you can do to become “active” again.

Use the chart below to record when you call, what your status is, and if you need to do anything.

My waitlist status
Keep track of your calls, status, and anything you may need to do:

<table>
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<tr>
<th>Date I called:</th>
<th>Am I still active?</th>
<th>If I’m inactive, what can I do?</th>
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If you need more room, use the extra My waitlist status worksheet in the resources section.
Stay healthy while you wait

Staying healthy while you wait can help you have a more successful transplant and possibly get one sooner. If you are not healthy enough when you get the call that a kidney is available, you may not get that kidney. It will go to the next person on the list who is healthier.

Here are some tips to stay healthy while you wait:

**Stay physically active**
Ask your doctor how long and how many days each week you should exercise and write it below:

<table>
<thead>
<tr>
<th>My doctor says I should exercise</th>
<th>How often and how long</th>
</tr>
</thead>
</table>

**Some exercises my doctors said I should do**

**Stay at a healthy weight for you**
Ask your doctor what a good weight is for you and write it below:

<table>
<thead>
<tr>
<th>My doctor says I should stay around</th>
<th>lbs (pounds)</th>
</tr>
</thead>
</table>

**Take your medicines**
It’s important to take medicines as prescribed by your healthcare team and keep track of what you are taking.

Should I make a list of medicines?
Yes, keep a list of medicines to take to your medical appointments and tests. Use the My medicines chart on the next page.
**My medicines**

Use this medicine chart to write down the:

- **Name of the medicines you are taking**
- **Dose (how much you take and when you take it)**
- **Doctor who prescribed it (who wrote the prescription)**

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<tr>
<th>Medicine</th>
<th>Dose</th>
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If you have more medicine use the extra *My medicines* chart in the resources section.
Here are some more tips to stay healthy while you wait:

**Eat healthy foods**

Eating right can help you stay healthy and feel good. Ask your doctor what you should and shouldn’t eat and write it below:

<table>
<thead>
<tr>
<th>I should eat more</th>
<th>I should eat less</th>
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Keep your blood pressure at a healthy level

Eating well, being active, and taking your medicines can all help. Ask your doctor what numbers are right for you and write them below:

- **My blood pressure should be:**
  - __________ __________
- **I should call my doctor if it is:**
  - __________ / __________ or higher or __________ / __________ or lower

Keep your blood sugar at a healthy level for you

Keeping your blood sugar at a healthy level for you is especially important if you’re diabetic. Ask your doctor what numbers are right for you and write them in the lines below:

- **My blood sugar should be:**
  - __________
- **I should call my doctor if it is:**
  - ________ or higher or ________ or lower
Do not smoke, chew tobacco, or abuse alcohol
Tobacco and alcohol can cause health problems and some transplant centers may not list you if you smoke or abuse alcohol.

Attend and complete all dialysis treatments
Your transplant team may ask your dialysis center if you miss or skip any dialysis treatments.

Continue to get annual evaluation testing
Even though you are already on the waitlist, you still need to go through some evaluation tests every year to make sure you are still healthy enough for a kidney transplant.
Stay connected while you wait

When a donor kidney becomes available, the transplant coordinator will call you to get ready. The call could come at any time of the day or night. When you get the call, everything may seem like a blur. The coordinator will tell you when to go to the transplant center. Do not delay! There is a time limit once a kidney becomes available.

Tips to stay connected with your transplant team:

- Double check that your transplant team has your cell phone number and home phone number
- Always tell your transplant team if the numbers change
- Give your team the phone numbers of friends and family too, so that when your kidney is available they can find you if you’re not answering your phone. Remember to tell your family and friends if you gave the transplant center their contact information so they know.
- Remember, if your health insurance changes, tell your transplant team

Stay encouraged while you wait

You may be waiting for a long time and it’s easy to get discouraged. Here are some things to consider if you find yourself discouraged:

- Re-read your My why and do something from your My pick-me-up list
- Talk to someone who has been through a successful transplant. Check out the Finding a kidney transplant mentor resources.
- Check out the Kidney disease and treatment options resources at the end of this workbook to learn more
Consider ways to get a kidney sooner

On average, patients are on the waitlist for 2-4 years before they get a kidney, but it could be much longer depending on where you live. In some cases, you can get a kidney sooner if you do one of the things below:

**Consider a living donor kidney**

One of the benefits of getting a living donor kidney is that the transplant can happen sooner, when you and the donor are healthy and ready. Review the Living donation and donor exchange programs resources to learn more about living donation. ➔ page 67

What if I find a living donor while I’m on the waitlist?
Talk to your transplant center as soon as possible.

**Get multi-listed**

Multi-listed means that you are listed at more than one transplant center. In order to be multi-listed, you will need to contact another transplant center and you need to have the ability to quickly get to that transplant center if you were to get a call that a kidney is available.

What if I want to know more about being multi-listed?
Talk to the transplant centers on your list to see if this an option for you.
Transplant surgery

In this section, you’ll learn how to get ready and what will happen when it’s time for your transplant.

To-do:

- Get ready (page 48)
- What to expect (page 49)
Get ready

Make sure the transplant center has your correct contact information. If you change phone numbers, let your transplant coordinator know.

Pack your kidney transplant go-bag.
You may want to include:
- This workbook
- Extra clothes
- Toiletries
- Your medications
- Cell phone charger
- Entertainment (such as music, books, a tablet, or downloaded tv shows or movies)
- Headphones

Have a plan in place for how you will get to the transplant center and who will go with you

How will I get to the transplant center? ____________________________
______________________________________________________________

Who will go with me? ____________________________
______________________________________________________________

Who will look after my dependents, such as kids, parents, or pets?
______________________________________________________________
______________________________________________________________

Other: ____________________________
______________________________________________________________
______________________________________________________________

Have a plan if you will be traveling away from home while on the waitlist.
What to expect

When you get the call for a deceased donor kidney
When a deceased donor kidney is available, the transplant coordinator will call you. The call can come at any time.

There is a time limit once a kidney becomes available. The coordinator will tell you when to go to the transplant center and where specifically to go. Do not delay!

It is common that more than 1 patient is called when a kidney becomes available, but the kidney is offered to the patient who is the best match first. The United Network for Organ Sharing (UNOS) will decide who is the best match based on factors like medical condition, where the patient lives, and how long the patient has been on dialysis and the waitlist.

What if someone else is a better match for the kidney?
The other patient will get that kidney, and you may be close to getting a kidney, so do not get discouraged!

No one has to accept a kidney that is offered to them. If someone is a better match for a kidney but that patient doesn’t accept the kidney for any reason, it will be offered to the patient who is the next best match.

When you schedule surgery with a living donor kidney
If you have a living donor, or are participating in a paired donation, your center will schedule a date for surgery that is best for you and your donor. To learn more, check out the Living donation and donor exchange programs resources, in the back of this workbook. page 67

After surgery
Before you leave the transplant center, someone from your transplant team will talk to you about what medicines to take and how to take them. Remember, if you have questions, ask them!

What if I have questions about getting help paying for medicines?
Contact the Missouri Kidney Program (MoKP) at https://mokp.org.
Congratulations

Good job making it to the end of this workbook!

We know the journey doesn’t end here, so continue to use the resources in this workbook as you need them.

A few last things:

○ Make a list of at least three things you are grateful for. They can be big or small, anything that has helped you in your journey. Take into account the people who have supported you along the way.

**Things I’m grateful for**

__________________________________________

__________________________________________

__________________________________________

The donor family may want to contact you after the transplant. Think about whether you want to meet them. The decision to talk to them is yours.

Finally, **take a moment to go back** to the beginning of this workbook to your My why, My pick-me-ups, and My people. Remember what got you here, and what matters most to you. ![Link to page 8]

We wish you good luck and good health as you take your next steps.
Transplant resources

In this section, you’ll find extra resources to help you in your transplant journey such as:

- Extra worksheets (page 54)
- Transplant centers in MO, IA, KS, and NE (page 62)
- Learn more about transplant (page 66)

Remember to make copies of your blank extra worksheets so you can use one each time you need to.
My notes

Use this page to write down notes and things you don’t want to forget.

Date

- Phone call
- Meeting
- Appointment
- Class

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Call your transplant center

Use this worksheet if you decide to call more than one transplant center. Fill in the blanks as you talk with someone from the transplant center.

What if I need help calling?
Someone from your healthcare team or support network can help.

Transplant center

Phone number

Fax number

Date and time I called

Person I spoke with

Notes

The transplant coordinators have a lot to do when they get your referral forms. You are welcome to call and check on the status of your referral.
### My Waitlist Status

Keep track of your calls, status, and anything you may need to do:

<table>
<thead>
<tr>
<th>Date I called</th>
<th>Am I still active?</th>
<th>If I’m inactive, what can I do?</th>
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*My transplant-ready workbook* | 56
**My medicines**

Use this medicine chart to write down the:

- **Name of the medicines you are taking**
- **Dose** (how much you take and when you take it)
- **Doctor who prescribed it** (who wrote the prescription)

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Dose</th>
<th>Prescribed by</th>
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My phone call

Use this notes page when you make calls. Remember, if you don’t understand something, it’s ok to ask questions! To make sure you understand, repeat the information back to the person you are talking to.

**Before my call**

- Who am I calling? ________________________________
- Why am I calling? ________________________________
- What do I need to have with me, like my health insurance card, bill, or medicine?
- What questions do I have? (Write them in the lines below.)

**During my call**

- Who am I talking to? ________________________________
- What answers did I get from the questions I had? (Write them in the lines below.)

Questions and answers

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**After my call**

- Note to self: Put all the information from my calls in one place that is easy to get to.
My appointment

Use this notes page when you have medical appointments.

What | When
---|---
Who | Why

Questions and answers

What I need to know or do next
My journal

Use this page to reflect on something that has happened, how you are feeling, successes, and challenges.

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Date
My transplant-ready workbook

Calendar

Keep track of appointments, tests, and important events.

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(month and year)
Find a transplant center in:
Missouri (MO)

Barnes Jewish Hospital
1 Barnes Jewish Hospital Plaza
Saint Louis, MO 63110
Phone: (314) 362-5365 or toll-free (800) 633-9906
https://www.barnesjewish.org/medical-services/transplant/kidney-transplant

Children’s Mercy Hospital
2401 Gillham Rd
Kansas City, MO 64108
Phone: (816) 302-3088
https://childrensmercy.org/the-transplant-center-at-childrens-mercy

Research Medical Center
2340 East Meyer Boulevard
Building 2, Suite 646
Kansas City, MO 64132
Phone: (816) 822-8257
https://researchmedicalcenter.com/service/transplant-institute

Saint Louis Children’s Hospital
1 Children’s Place
Saint Louis, MO 63110
Phone: (800) 678 5437
https://www.stlouischildrens.org/conditions-treatments/transplant-services
Saint Luke’s Hospital
4320 Wornall Rd, Suite 304
Kansas City, MO 64111
Phone: (816) 932-3550
https://saintlukeskc.org/kidney-transplant

SSM Cardinal Glennon Children’s Hospital
1465 S Grand Blvd
St. Louis, MO 63104
Phone: (314) 577-5351
https://www.ssmhealth.com/cardinal-glenndon/pediatric-transplant

SSM Saint Louis University Hospital
3635 Vista Ave
St. Louis, MO 63110
Phone: (314) 577-8867
https://www.ssmhealth.com/transplant-services/kidney

University of Missouri Hospital
1 Hospital Drive
Columbia, MO 65212
Phone: (573) 882-8763
https://muhealth.org/conditions-treatments/urology/kidney-transplant
Kansas (KS)

University of Kansas Hospital
4000 Cambridge St.
Kansas City, KS 66160
Phone: (913) 588-1227

https://www.kansashealthsystem.com/care/centers/transplantation-center

Nebraska (NE)

University of Nebraska Medical Center
4315 Emile Street
Omaha, NE 68105
Phone: (402) 559-5000 or toll-free (800) 401-4444

https://www.nebraskamed.com/transplant/kidney

Iowa (IA)

Iowa Methodist Medical Center
1215 Pleasant Street, Suite 506
Des Moines, IA 50309
Phone: (515) 241-4044

https://unitypoint.org/desmoines/services-transplant-center.aspx
University of Iowa Hospital & Clinics Dialysis
200 Hawkins Drive
Iowa City, IA 52242
Phone: (877) 386-9108
https://uihc.org/kidney-and-pancreas-transplant

VA Iowa City Health Care System
601 Highway 6 West
Iowa City, IA 52246
Phone: (319) 887-4989
https://www.iowacity.va.gov/transplant/
Learn more about:
Kidney disease and treatment options

American Association of Kidney Patients  
https://aakp.org

Explore Transplant  
https://exploretransplant.org

QSource ESRD Network 12  
http://esrdnetwork12.org

Kidney School  
https://kidneyschool.org

Missouri Department of Health & Senior Services  
https://health.mo.gov

Missouri Kidney Program (MoKP)  
https://mokp.org

My Transplant Coach  
https://mytransplantcoach.org

National Kidney Foundation  
https://kidney.org

PKD Foundation  
https://pkdcure.org

Renal Support Network  
https://rsnhope.org

Renewal  
https://www.renewal.org

Transplant Recipients International Organization (TRIO)  
https://trioweb.org
Living donation and donor exchange programs

Alliance for Paired Donation  https://paireddonation.org

Explore Living Donation  https://expolrelivingdonation.org

Living Donors Online  http://livingdonorsonline.org

National Kidney Registry  https://kidneyregistry.org/index.php


Finding a kidney transplant mentor

American Transplant Foundation: 1+1=Life Mentorship Program  https://americantransplantfoundation.org/programs/mentorship-program-2

Gift of Life: Transplant Mentors  https://giftdonor.org/programs/transplant-mentors


Transplant Mentor Program at Barnes Jewish Hospital  https://www.barnesjewish.org/Medical-Services/Transplant/Transplant-Support-Resources/Transplant-Mentor-Program
Connecting with others about transplant

Explore Transplant: Recipient stories

https://exploretransplant.org/basics-of-kidney-disease/recipient-stories/

Mid-America Transplant

https://www.midamericatransplant.org/stories

Midwest Transplant Network

https://www.mwtn.org/recipients/recipient-stories/

UNOS: Stories of Hope


UNOS: Support groups

https://transplantliving.org/community/support-groups/

Getting help paying for a kidney transplant

American Kidney Fund

https://www.kidneyfund.org

American Transplant Foundation

https://americantransplantfoundation.org

Medicare Coverage

https://medicare.gov/Pubs/pdf/10128-medicare-coverage-esrd.pdf

National Living Donor Assistance Center

https://livingdonorassistance.org
Acknowledgments

Many have contributed to the writing and development of the My Transplant-Ready Workbook. We are especially grateful for Laurie Hines, Director of the Missouri Kidney Program (MoKP), for her passion for life, her empathy for others, and her consistent advocacy for kidney patients and organ donation. Her leadership, direction, encouragement, and drive empowered the Missouri Kidney Collaborative to create this workbook.

We would also like to thank Christina Goalby, Manager of Transplant Initiatives and Lead Trainer at Health Literacy Media (HLM), for her insight as she facilitated the creation of this book. She patiently guided the team through the process of developing a workbook that provides the information patients need while being easy to use, read, and understand. Her dedication to and leadership of the HLM team helped ensure that the workbook meets health literacy standards.

We thank Virginia Beatty, Manager of the Missouri Organ and Tissue Donor Program and Donate Life Missouri registry with the Department of Health and Senior Services (DHSS). Virginia embraced this project from its inception. She has been the team’s most steady, smart, and focused contributor, editor, and motivator. Her standards of perfection for language and style were relentless. We also thank DHSS for supporting her participation in this project and their financial commitment to production.

We sincerely thank Heather Lawyer, nephrology social worker, for keeping us grounded in what matters to the patient and the reality of dialysis.

We are grateful for the expertise and insight of QSource Network 12 staff: Shane Perry, Stephanie Huskey, and Stephanie Smith.

We appreciate Candra Johnson, graphic designer at HLM, for beautifully designing this workbook (even through multiple adaptations) and for her infectious positivity.

We thank Sara Ashbaugh, our MoKP Research Specialist, for compiling feedback from experts and patients and calmly keeping this team organized. Sara reflects the best of the coming generation of smart, disciplined, passionate professionals.

And, finally, we are grateful for the input of transplant experts (medical and non-medical) and the dialysis patients who answered questions, read through workbook drafts, and provided constructive and vital feedback.