

# 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.



# 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.



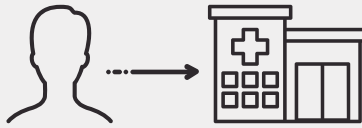
# What is in this workbook

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



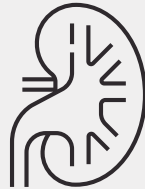
Transplant evaluation

➔ 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 people

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.

Name	How they might help me	Phone number
Primary person		

➔ page 67

➔ **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!

Name	Role	Phone number	Fax number

Dialysis center: \_\_\_\_\_

Name

\_\_\_\_\_

Address

\_\_\_\_\_

Phone number

Fax number

Other

Pharmacy: \_\_\_\_\_

Name

\_\_\_\_\_

Address

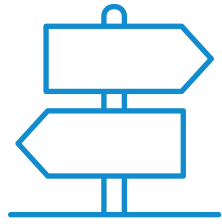
\_\_\_\_\_

Phone number

Fax number

Other

# My 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:

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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.

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## 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](https://www.DonateLifeMissouri.org) or [OrganDonor.gov](https://www.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.

## 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.

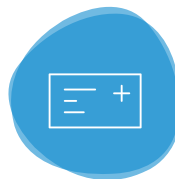
 For a list of transplant centers in Missouri, Iowa, Nebraska, or Kansas, check out the **Find a transplant center** resources.

 page 62

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



How long will **my evaluation** take?



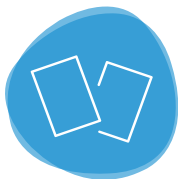
Does the transplant center take **my insurance**?



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.

 page 67

## 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.

Transplant center

Notes

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Transplant center

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Transplant center

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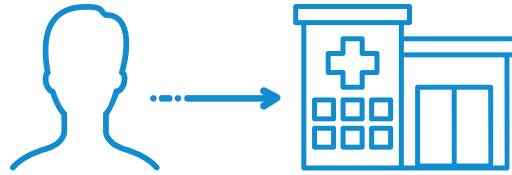
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# Transplant referral process



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 \(page 21\)](#)

**i** 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.

## → 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 \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## → What if I don't hear back from the transplant center right away?

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.

**i** If you call more than 1 transplant center, use the extra **Call your transplant center** worksheet in the resources section.

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# 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.

<input type="radio"/>	_____	<input type="radio"/>	_____
<input type="radio"/>	_____	<input type="radio"/>	_____
<input type="radio"/>	_____	<input type="radio"/>	_____
<input type="radio"/>	_____	<input type="radio"/>	_____
<input type="radio"/>	_____	<input type="radio"/>	_____
<input type="radio"/>	_____	<input type="radio"/>	_____

→ **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

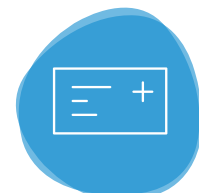
After you send in your forms, your transplant center will:



**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.

page 15

**→ 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

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# Transplant evaluation



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

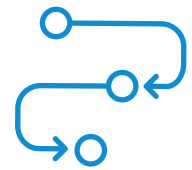
## To-do:

- [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 \(page 35\)](#)

[i](#) 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.



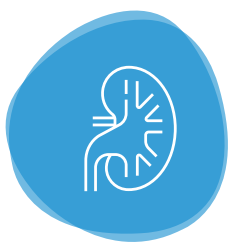
Every transplant center is different. Your education class, evaluation, and meeting with your transplant team may all happen on the same day or over the course of a few days or weeks.

## 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**

i 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:** \_\_\_\_\_

➡ page 9

- ➔ **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**



### Bring this workbook and a pen

Bring this workbook (or a notebook) and a pen or pencil. You will learn a lot of information in your class, and it may be hard to remember it all. Use **My notes** on the next page of this workbook or a notebook.  page 28



### 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?** \_\_\_\_\_  
\_\_\_\_\_

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### 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. [page 31](#)

**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.

 page 31

My transplant team includes:

Name	Role/Title	Phone number	Fax number

 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?

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How long will surgery be?

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Will you remove my kidneys during the surgery?

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What will my incision look like?

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Where will my incision be?

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What will the pain be like? And what will I take for the pain?

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How long will I be in the hospital?

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How long will recovery be?

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What will I need to do after my transplant?

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Will I need dialysis again?

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➡ page 34



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.

 Share the letter you get with your healthcare team.

## 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.  page 15

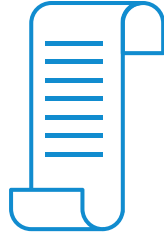


### If I am not approved at one center, can I be approved at another?

Yes, each center is different. One transplant center may turn a patient down and another center may approve them.



# Transplant listing

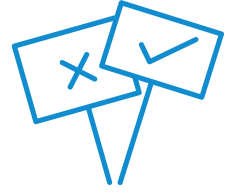


In this section, you'll learn about what to do while you wait for your deceased or living donor transplant.

## 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.

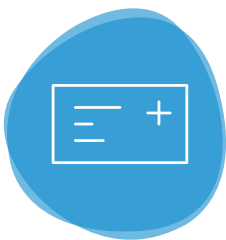
During the time you are waiting for a kidney, your status may change back and forth. If your status changes to inactive, contact your transplant center and find out what you need to do to become active again.

## 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:



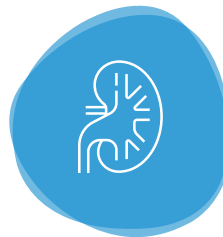
Your health insurance or medication coverage changes



Your contact information (phone number or address) changes



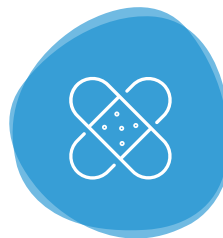
You change dialysis centers or start seeing a new nephrologist



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.

## waitlist status

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

Date I called:	Am I still active?	If I'm inactive, what can I do?
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	
	<input type="radio"/> Yes <input type="radio"/> No	

 page 56

 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:

My doctor says I should exercise \_\_\_\_\_

How often and how long

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:

My doctor says I should stay around \_\_\_\_\_

lbs (pounds)



### Take your medicines

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

➔ page 41

#### ➔ 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)

Medicine	Dose	Prescribed by

||> page 57

**i** 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:

I should eat more

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I should eat less

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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** 

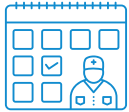
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 or lower



### **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.

## **notes**

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## 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 [page 8](#)



Talk to someone who has been through a successful transplant. Check out the **Finding a kidney transplant mentor** resources. [page 67](#)




Check out the **Kidney disease and treatment options** resources at the end of this workbook to learn more [page 66](#)

# 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.

## notes

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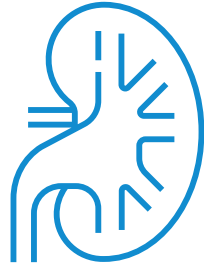
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# Transplant surgery



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)

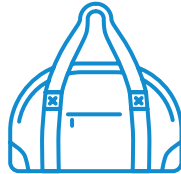
# Get ready

○ 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:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**i** 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

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- 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.

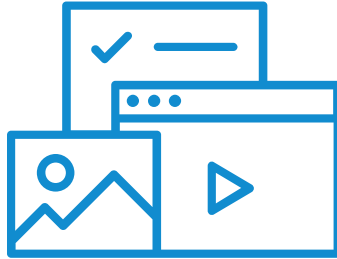
- Finally, take a moment to go back to the beginning of this workbook to your **My why**, **My pick-me-ups**, and **My people**. Remember what got you here, and what matters most to you.  page 8

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)

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



# 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 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.

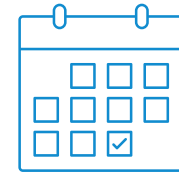




# My calendar

Keep track of appointments, tests, and important events.

(month and year)



SUN	MON	TUES	WED	THURS	FRI	SAT
●	●	●	●	●	●	●
●	●	●	●	●	●	●
●	●	●	●	●	●	●
●	●	●	●	●	●	●
●	●	●	●	●	●	●
●	●	●	●	●	●	●

# 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-glennon/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://explorelivingdonation.org>

Living Donors Online <http://livingdonorsonline.org>

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

United Network for Organ Sharing (UNOS)

<https://unos.org/donation/kidney-paired-donation>

## 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>

National Kidney Foundation: NKF Peers <https://kidney.org/patients/peers>

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

<https://transplantliving.org/community/stories-of-hope/kidney-transplants/>

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>

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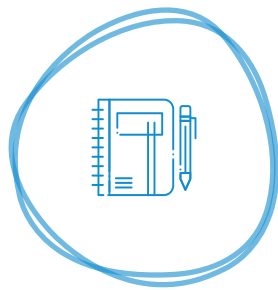
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[www.mokp.org](http://www.mokp.org)

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