My transplant-ready workbook

A workbook for your kidney transplant journey

About this workbook

What is this workbook?

The 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 the day of your surgery.

ⓘ The My transplant-ready workbook is meant to add to, organize, and build on the information provided by medical professionals.

Who is this workbook for?

The My transplant-ready workbook is for patients who have decided to get a kidney transplant and those who support them.

Who developed this workbook?

This workbook was developed by the Missouri Kidney Program, together with Missouri Department of Health and Senior Services - Organ and Tissue Donor Program, Health Literacy Media, and independent reviewers.

Missouri Kidney Program
University of Missouri

MISSOURI DEPARTMENT OF
HEALTH &
SENIOR SERVICES

HLM
Health Literacy Media

How to use this workbook:
Patients

Congratulations on taking the first step!

How to use this workbook:

- **Read through the list of chapters** on page 8 to get started. You can go through the workbook chapters at your own pace.

- **Use the lists** on the first page of each chapter to track your progress.

- **Fill out the worksheets** to keep important information in one place.
  - **Print or make copies of extra worksheets** so you can use one each time you need it. Find more worksheets in the back of this workbook or at: https://mokp.org/education/patient-education

- **Look for call-out boxes** with more information:

  The kidney-arrow call-out boxes have commonly asked questions or helpful tips.

  The info call-out boxes have more information that may be helpful as you move through this workbook and your transplant journey.

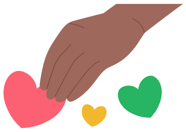
- **Use links (underlined text)** to point you to information on another page of the workbook or a website. If you have a digital copy of this workbook, you can click the link to go to that workbook page or website.

  Resources marked with the Missouri circle are Missouri-specific.

- **Use and share this workbook with others:**
  - Take this workbook with you to all medical appointments and to dialysis. Use it to update your medical team, ask questions, and write down things you want to remember.
  - Share this workbook with your care partner (close family member or friend who helps care for you) or other people who help you make important health decisions.

How to use this workbook:
Care partners

> **If you're a care partner helping someone complete this workbook, thank you!** You have a very important role. Think about how you can support the person you are caring for.



How to use this workbook:

- **Encourage them to use this workbook** throughout their journey:
  - **Print or make copies of extra worksheets** so they can use one each time they need it. Find more worksheets in the back of this workbook or at: https://mokp.org/education/patient-education
  - **Remind them to take the workbook to their medical and dialysis appointments** so they can update their medical team, ask questions, and write down anything they want to remember.

- Let them lead:
  - They can start with the chapter that matches where they are in the process, or that they are most interested in.
  - They do not have to complete the workbook all at once and can go at a pace that is most comfortable for them.

- **Look for call-out boxes** with more information:
  - The kidney-arrow call-out boxes have commonly asked questions or helpful tips.
  - ⓘ The info call-out boxes have more information that may be helpful as they move through this workbook and their transplant journey.

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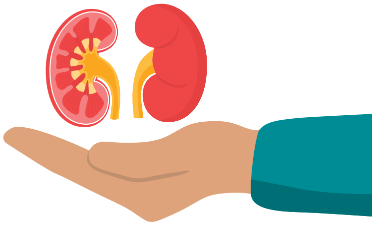
About transplants



Benefits of a kidney transplant

For people whose kidneys are failing, kidney transplants are a good treatment option. Kidney transplants can help people:

Feel better: A transplanted kidney can do 50-85% of a normal kidney's work. This gives you strength and energy to do what's important to you.

Live longer: On average, life expectancy increases by 15-20 years.

Enjoy more freedom: When you get a transplant, you can do more of your daily activities and enjoy a more active social life.

Feel less depression and anxiety: When you're healthier, you feel better emotionally too!

Eat and drink more foods and drinks: You don't have to restrict fluids and you have more food choices. Choose foods low in salt, low in sugar, and high in fiber.

What are some of the reasons you want to get a transplant?
Think about them now - we'll ask you to write them down later on page 11.

Things to consider

Going through the process of getting a transplant can be challenging for many people, **especially if...**

A person:

- Doesn't know much about kidney transplants
- Has other health issues, such as active cancer or advanced heart disease
- Has mental or cognitive challenges that may make it hard to regularly care for a new kidney after the transplant
- Has a lower income and cannot afford the care they need
- Has less social support (family or care partners to help throughout the process and after surgery)
- Does certain behaviors like smoking, vaping, chewing tobacco, or drug or alcohol misuse

If any of these describe me, can I still try to get a transplant?
Yes! The process may be challenging, but if a kidney transplant is your best treatment option, don't let that stop you.

Continued

Things to consider

Going through the process of getting a transplant can be challenging for many people, **especially if…**

A healthcare provider:

- Doesn't explain health information clearly
- Doesn't explain complex medical terms
- Doesn't understand the patient's culture
- Doesn't speak the same language as the patient or doesn't use an interpreter

Tip: If you don't understand what the provider is saying, don't be afraid to ask questions.

A healthcare system:

- Is complex and hard to navigate
- Has facilities that are not near the patient or are not easy to access
- Does not make quality care easy to access for people of certain races, cultures, or languages
- Gives people reasons to mistrust the provider or system

What is in this workbook

Use the links to go to another page of the workbook, or a website.

Getting started with a transplant

In this chapter, you will:

☐ Write down important information about your transplant journey
☐ Review transplant treatment options
☐ Choose your transplant programs

Worksheets and resources

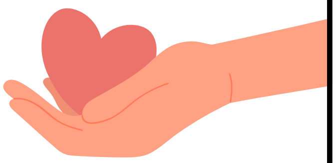
- **My why and my pick-me-up** on page 11
- **My people** on page 12
- **My healthcare team** on page 13
- **My health insurance** on page 14
- **My transplant decisions** on page 23
- **My transplant programs** on page 26
- **Resources to help you get started** on page 29

You may not be able to fill out all of these worksheets right now, and that's okay. Fill them out as you get the information.

My transplant journey

Getting a transplant is a journey, and everyone's transplant journey is a little different. This is **your journey** and **your workbook**. You may want to start by filling out these first few pages about you!

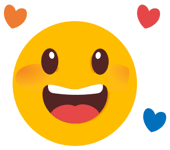
My why



What is your motivation to get a transplant? Write down your reasons so you can come back to them during your journey.

My reasons for wanting a kidney transplant

My pick-me-up



What are things you do to help you feel better? Write a list so you can come back to it when you feel stressed or discouraged. This may include talking with someone who has been through a transplant, talking with your healthcare team, taking a walk, or watching inspiring stories.

Things I can do to feel better

Social support

It is very important to have social support while on your journey. Transplant programs consider a person's support system when deciding if they are ready for a transplant.

You will need people to help you:

During the evaluation process: Bring your care partner to appointments so that they can learn about the transplant process and how they will help. They may ask questions you don't think of.

Throughout the transplant process: Most transplant programs require each person have a primary care partner with them before, during, and after a transplant. Consider your support system. Write down their names, how they will help, and their phone numbers.

My people

Think about your trusted family and friends who will support you and how they will help, then write their names, roles, and phone numbers in the table below.

Name	How they will help	Phone number
	Be my care partner	
	Take me to appointments	
	Help clean the house	
	Help me with the laundry	
	Help me meal prep	
	Get groceries	
	Pick up medicines	

Tip: Come back to this list of people whenever you need help from others.

My healthcare team

You are the most important person on your healthcare team. Write the names of the providers on your healthcare team, and their information below:

Name	Role / Title	Phone number	Fax or email
	Primary care doctor		
	Dialysis social worker		
	Dietitian		

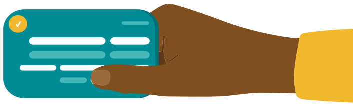
Dialysis center

Name	
Address	
Phone number	
Fax or email	

Pharmacy

Name	
Address	
Phone number	
Fax number	

Health insurance coverage



It’s important to understand how healthcare services and medicines will be covered during and after your transplant. Health insurance can be confusing. There are people trained to help you. Learn more on page 17.

Questions to ask your health insurance plan:

- Will my insurance cover me throughout the transplant process?
- Do I need to wait a certain period of time before I will be covered for a transplant?
- Do I need approval (pre-authorization) before I get evaluated for a transplant, have a transplant, or get the medicines I need after a transplant?

If you are on Social Security Disability for End Stage Renal Disease (ESRD), some time after your transplant you may be able to go back to work and will no longer be considered disabled, which means you may lose your disability payments and Medicare coverage for kidney disease.

My health insurance

My current health insurance is (check all that apply): ✓

Commercial or private health insurance is a plan through an employer, a private insurance agent, a spouse, or the Health Insurance Marketplace. ☐

If you have commercial or private insurance, go to page 15.

Medicaid (called MO HealthNet in Missouri) is a state-sponsored plan and is based on a person’s financial situation. Financial criteria for Medicaid vary from state-to-state. ☐

If you have Medicaid, go to page 15.

Original Medicare is a government-sponsored plan for people who are 65 years of age or older, disabled, have End Stage Renal Disease (ESRD), or who have had a kidney transplant. ☐

If you have Original Medicare, go to page 16.

Original Medicare is often the best choice for patients with ESRD.

Medicare Advantage is a plan offered by private companies that contract with Medicare. ☐

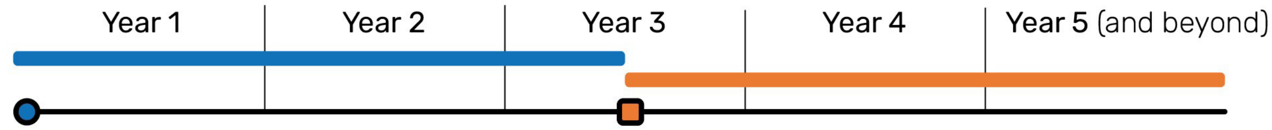
If you have Medicare Advantage, go to page 16.

Tip: Tell your transplant program and healthcare team anytime your insurance plans change.

If you checked Commercial or private health insurance

Most health insurance plans require you to enroll in Medicare after a certain time on your transplant journey. They work together with you to cover medical costs. It's called Coordination of Benefits, and it happens under a specific timeline.

Coordination of Benefits timeline:



In the first 2 and a half years of being eligible for Medicare:

Your commercial or private insurance pays first for your healthcare expenses. Medicare pays second.

After 2 and a half years of being eligible for Medicare:

Medicare pays first for your healthcare expenses. Your commercial or private insurance pays second.

I am, or will, be eligible for Medicare on:

________ / ________ / ________

Month Day Year

Enrollment in Medicare Part A before a transplant is highly recommended, even if you have commercial or private insurance.

Tip: If you are on dialysis, you can ask your dialysis social worker about your Coordination of Benefits timeline, and how and when you will need to apply for Medicare.

If you checked Medicaid and you only have Medicaid

Make sure that the transplant programs where you want to list accept Medicaid only. This will ensure you have enough insurance coverage for your transplant.

If you only have Medicaid, it is recommended that you also get Medicare (if you qualify), before you get evaluated for a transplant.

If you checked Original Medicare

Medicare covers most of the costs of kidney transplants (80%), including all the transplant-related costs for living donors. The remaining 20% will be covered by your Medicare Supplement Plan if you have one. Most transplant programs accept Original Medicare.

If you have Original Medicare (Medicare Parts A and B), you are covered for:

- Hospital insurance, also known as Medicare Part A.
- Medical insurance, also known as Medicare Part B.

After your transplant, you will be on medicines called Immunosuppressants, which help your body accept and protect your transplanted kidney. You will need to be on these medicines for the rest of your life. Medicare Part B will cover your immunosuppressant medicines if you had Medicare Part A at the time of your transplant and received a transplant in a Medicare-approved hospital.

You have the option of adding:

- Coverage for prescription medicines, also known as Medicare Part D. Medicare Part D plans are different, so shop to see which ones cover your medicines and pharmacy.
- A Medicare Supplement Plan (also called a Medigap Plan) covers the 20% not covered by Medicare Parts A and B.

Each state has different rules for who can sign up for a Medigap plan and when. Contact your state's SHIP (State Health Insurance Program) using the information on page 17.

If you checked Medicare Advantage

Your Medicare Advantage plan can change from year-to-year or even during the year, so it is important to check with your plan to make sure you are covered.

You will have 2 cards, a Medicare card and a commercial health insurance card.

Tip: Call your health plan every year between January 1st and March 31st to make sure that the transplant programs where you want to list are covered in your health plan's network.

You should also ask your plan if there are limits on:

- The number of transplant programs where you can list.
- The number of potential living donors who can be tested (if you're interested in a living donor transplant).

You can switch to original Medicare if your Medicare Advantage plan does not meet your needs for a transplant.

Get help understanding health insurance

Don't let health insurance challenges stop you. It's important to know who to ask for help and where to find it, when you need it.

Medicare Coverage of Dialysis and Kidney Transplant Services

The Center for Medicare & Medicaid Services (CMS) developed this official booklet that includes information about benefits, coverage, protections, and answers to frequently asked questions for people with Medicare. To view or download a PDF, visit: medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf

SHIP

For questions about Medicare, contact your State Health Insurance Program (SHIP). They offer free, unbiased, local health insurance counseling services about Medicare, and can help you make informed decisions about which plan is right for you. To find the SHIP contact information for any state, visit shiphelp.org or call 1-800-633-4227 and TTY users 1-877-486-2048.

In Missouri, the State Health Insurance Program is called Missouri SHIP. They can be reached at 1-800-390-3330. The Missouri Kidney Program has SHIP-trained counselors who can help. They can be reached at 1-800-733-7345.

Medicare Savings Programs

There are programs to help pay for Medicare premiums each month. To see if you are eligible for one of these programs, visit: medicare.gov/medicare-savings-programs

Tip: If you have trouble paying your premiums or out-of-pocket costs, you can find financial resources on page 31.

UNOS Transplant Living

The United Network for Organ Sharing (UNOS) has a list of frequently asked questions related to transplant insurance and finances. To read them, visit: https://transplantliving.org/financing-a-transplant/frequently-asked-questions

Transplant Financial Specialist or Coordinator

Once your transplant program assigns you a transplant financial specialist, or transplant financial coordinator, you can ask them questions about your insurance coverage.

Advance care planning

Throughout this process, you will be asked if you have a living will. You may also be asked if you have a durable power of attorney for healthcare decisions.

These important documents share your wishes around medical treatment and end-of-life care in case you ever cannot communicate. The hospital where you have transplant surgery will ask for a copy of your advance care planning documents before your surgery.

What is advance care planning?

Advance care planning is a process where you:

- Make decisions about your end-of-life care and how you want your healthcare team to carry out your decisions if/when you can't speak for yourself.
- Share your decisions in a written document so that your wishes are known by family and doctors.

What forms do I need for advance care planning?

Advance care planning includes completing and signing documents called advance directives. There are 2 basic types:

- **Living will:** A document that explains your decisions about what interventions and treatments, including end-of-life care, you want or do not want if you are severely ill or injured.
- **Durable power of attorney (POA) for healthcare:** Names a person (called an agent) to make your healthcare decisions if you are not able to make them.

ⓘ These are healthcare documents, not financial documents.

While advance directives are legal and valid throughout the United States, each state has its own laws on their use. It's important to create an advance directive that follows your state's laws.

Storing and sharing your advance directive

Keep your advance directives up-to-date and in a place that is easy for others to find. Make sure you review and update it before surgery. Give a copy of your signed advance directives to your hospital, POA, and loved ones.

How do I get started with advance care planning?

1. Once you make your decisions about your care, write your advance directive documents.
    - Download the Missouri advance healthcare directive form at https://www.caringinfo.org/planning/advance-directives/by-state/missouri/. Be sure to follow instructions about your signature for each document, such as if you need witnesses or a notary.

      You can find a link to search for notaries in Missouri on page 33.

    - Consider using this helpful toolkit: My End-of-Life Decisions: An Advance Planning Guide and Toolkit. This includes a Planning Checklist and a Values Worksheet that guides you through end-of-life planning, such as:
        - Questions to consider
        - How to think about what is important to you
        - How to decide on your wishes
        - How to talk with loved ones about end-of-life

      Download this toolkit for free at:
      https://www.compassionandchoices.org/resource/eoldgt

2. Talk with your family and friends about the importance of following your advance directive and your POA. If you can, tell them why you've made the decisions you have. If you choose a POA, discuss your wishes in detail to be sure they know what you want.

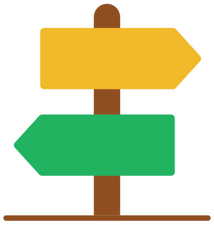
3. Make the documents easy to find – keep one for yourself, and make copies for your POA and your hospital. Review and update your decisions before any surgery.

If you already have a living will or a POA, review them every year to be sure they reflect your current wishes.

Tip: If you are on Medicare, ask your doctor about a visit to discuss advance care planning. Medicare pays doctors for a 30-minute visit to discuss advance care planning, before an illness progresses or during treatment.

Life is full of the unexpected. Knowing and telling others your wishes while you can communicate them is a gift you can give to yourself and your loved ones.

Types of transplants



You will have a lot of decisions to make about your transplant. You will need to consider the types of kidney transplants that may be available to you, such as:

- Living donor kidney transplant.
- Deceased donor kidney transplant.
- Kidney paired donation.

Can I get a transplant before I start dialysis?
Yes, you may be able to get a transplant before dialysis. This is called a pre-emptive transplant. Ask your kidney doctor about this type of transplant.

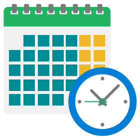
Living donor kidney transplant

During surgery, surgeons will put a kidney from a living person into you. You (the recipient) and the person who has agreed to donate their kidney (the donor), must be a match, which means your body will accept the kidney.

Benefits of a living donor kidney

Living donors can be a family member, friend, co-worker, or even a complete stranger.

You may be able to get a living donor transplant sooner than a deceased donor transplant.



Surgery can be scheduled at a day and time that works best for you and your donor.

Living donor kidneys usually last 15-20 years.

Considerations for living donors

Living donors can always change their mind. They should never be pressured into being a living donor. A living donor can let the transplant program know that they no longer wish to be a donor at anytime up until the time of surgery.

All living donor costs for transplant evaluation, surgery, and after surgery care are covered by the transplant recipient's insurance. Other costs, including travel or hotel stays, may be covered by financial assistance programs.

Ways to find a living donor

To find a living donor, you'll have to share your story! Sometimes talking with people about finding a living donor can be scary or uncomfortable, but you have to do it! Here are some steps you can take to share your story with others.

Your "My why" is on page 11.

How it works:

Talk with people closest to you. Let them know that you understand living donation may not be right for everyone. You can also tell them that your relationship will not change if they choose not to donate.

Find someone who will speak for you. This person can help share your story with others and explain how living donation works.

Share your story on social media. If you feel comfortable, write a post or record a short video and share it on social media platforms, such as Facebook or Instagram.

Tip: Watch videos from patients and donors, and learn how to tell your own story using the resources on page 29.

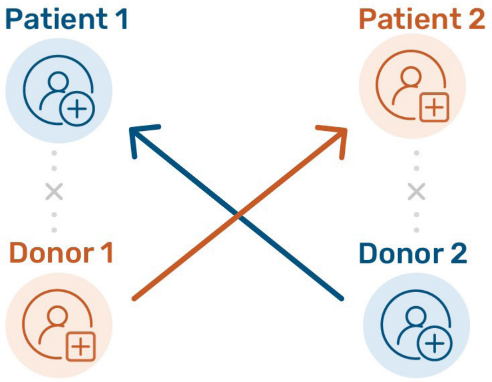
Share your story through a letter. Write a letter that you and others can share.

Tip: To get started, use the sample letter on page 81.

Options if your potential living donor is not a match:

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

- **Paired donation (or kidney swap):** This is when 2 kidney patients have living donors who are not a good match for them. The 2 patients swap donors so each can get a kidney that is a good match for them.



Patient 1 and **Donor 2** match ⊕

Patient 2 and **Donor 1** match ⊞

- **Donor chains:** A chain helps a group of patients who have donors but aren't matches. Donor chains are carefully managed by the transplant programs.

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 active on the transplant waiting list until a match becomes available. Deceased donor kidney transplants are the most common type of kidney transplant.

Deceased donor kidneys can:

- Offer a better quality of life compared to dialysis.
- Let you eat more of the foods you enjoy.
- Make it more likely that you will live longer.

Being listed at multiple transplant programs may shorten your wait time. Learn more about multi-listing on page 25.

Can I be on the waiting list for a deceased donor kidney and still search for a living donor?
Yes! You are encouraged to continue to search for a living donor.

Extended criteria donor kidneys:

Ask your transplant program if they offer extended criteria donor (ECD) kidneys, and if it may be an option for you. You may also hear these called high KDPI kidneys.

- These kidneys are from donors who have certain risk factors.
- Doctors check every kidney for infection before a transplant to lower the chance of transferring it to the patient.
- 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 may not last as long but may be better for you than being on dialysis.

Your blood type may affect how long you are on the waiting list. Recipients with blood type O can only receive a kidney from a donor with blood type O.

My transplant decisions

I am interested in a: (check all that apply)

☐ Living donor kidney
☐ Deceased donor kidney
☐ Paired kidney donation
☐ ECD kidney

If you are interested in a living donor transplant, write down the names and phone numbers of people you can ask about being a living donor in the table below.

People I can ask about being a living donor	Phone Number

Choosing your transplant programs

Talk to your healthcare team about how to choose a program that's right for you.

You can find a list of transplant pbrograms in Missouri, and links to lists of transplant programs in other states on pages 33-34.

When looking at transplant programs, ask these questions:

This won't be your only conversation, but asking these questions is a good start!
Write your answers on the worksheets on pages 27-28.

- How **soon** can I get an evaluation?
- How long will **my evaluation** take?
- Do you take **my health insurance?**
- What type of **financial help** do you offer?
- **How far is the hospital** from my home?
- What is the average **wait time to get a kidney?**
- If I want to list at more than one transplant program, will your program share **my evaluation results with other programs?**
- Does your program offer **living donation transplants?**
- Does your program offer **paired donation?**
- **How many living donors** can test to be a match for me?
- How many nights do I need to **stay after surgery?**
- What will I need to do **after my transplant?**
- How will my transplant team **communicate with me?**
- Does your program have a **patient portal** where I can see my transplant information?

Consider multi-listing

What is multi-listing?

Multiple listing or "multi-listing" means that you are listed at more than one transplant program.

Multi-listing can shorten your average wait time for a kidney transplant, but this doesn't mean that every person who multi-lists will have a shorter wait time.

Multi-listing is an option for everyone.

Tip: Read more about multi-listing using the resources on page 30.

How multi-listing works

To be multi-listed, you will need to:

- Contact all transplant programs where you are interested in listing.
- Be evaluated and approved for a transplant with each program.
- Be able to quickly get to each transplant hospital if a kidney becomes available.
- Attend multiple pre- and post-transplant visits that may require staying overnight.
- Have support from friends and family at each location.

Tip: Think about where the transplant hospital is located and if you will have help and support near each location.

Each transplant program is required to tell you and give you written information that explains if:

- You can list at multiple transplant hospitals.
- You can move your wait time to another transplant program.
- You can move your care to another transplant program without losing wait time.

Transplant programs are also required to tell you and give you written information on their specific policies for multi-listing, if:

- They do not accept patients who are multi-listed.
- They do not allow patients to move their wait time to that program.

Transplant programs can choose not to accept patients who are listed at other transplant programs.

Get help understanding multi-listing

It's important to understand multi-listing to decide if you want to be multi-listed.

Organ Procurement and Transplantation Network (OPTN)

The Organ Procurement and Transplantation Network (OPTN) has a webpage about multiple listing for organ transplant with frequently asked questions. To view, visit: https://optn.transplant.hrsa.gov/patients/about-transplantation/multiple-listing/

Transplant coordinator

You can ask a transplant coordinator how multi-listing works with that transplant program.

Transplant programs I want to call

Find and call a few transplant programs to learn more, and add the contact information to the table below. If you decide you will apply for a transplant there, add a check mark to the last column in the table.

Transplant programs	Phone number	Who I talked to	✓
			☐
			☐
			☐
			☐
			☐
			☐
			☐

Tip: To guide your conversation so you can get the information you need, use the worksheets starting on page 27.

My transplant programs

After calling different transplant programs, **I would like to be evaluated at:**
(Write down all transplant programs in the table below.)

Transplant programs	Phone number

Transplant program information sheet

Fill in the program contact information in the table below.

Name	
Address	
Website	
Phone number	
Email address	

Tip: Include your care partner on the call.

Questions to ask

Write down answers in the space below each question.

How **soon** can I get an evaluation?

How long will **my evaluation** take?

Do you take **my health insurance?**

What type of **financial help** do you offer?

How far is the hospital from my home?

What is the average **wait time to get a kidney?**

If I want to list at more than one transplant program, will your program share **my medical evaluation results with other programs?**

Does your program offer **living donation transplants?**

Does your program offer **paired donation?**

How many living donors can test to be a match for me?

How many nights do I need to **stay after surgery?**

What will I need to do **after my transplant?**

How will my transplant team **communicate with me?**

Does your program have a **patient portal** where I can see my transplant information?

My notes

Write any additional questions and answers, or notes in the lines below.

There are extra worksheets on pages 82-83.

Resources

Kidney transplant and living donation

Alliance for Paired Kidney Donation

pairedonation.org

DaVita Kidney Care: How to Find a Living Donor

youtu.be/0gGnRX0lrv8

Donate Life Missouri: Stories

donatelifemissouri.org/stories

Explore Transplant

exploretransplant.org

Explore Transplant: Beyond direct donation

exploretransplant.org/beyond-direct-donation-what-if-your-friends-and-family-dont-match

Health Resources & Services Administration (HRSA): Living Organ Donation

https://www.organdonor.gov/learn/process/living-donation

Kidney Transplant Decision Aid

srtr.org/tools/kidney-transplant-decision-aid

The Living Donation Storytelling Project

livingdonationstories.org

Living Donors Online

livingdonorsonline.org

Mayo Clinic: Tips on Finding a Living Donor

youtube.com/watch?v=0j69JGS4tog

My Transplant Coach

mytransplantcoach.org

National Kidney Foundation

kidney.org/transplantation/livingdonors/general-information-living-donation

National Kidney Registry

kidneyregistry.org

Check out the National Kidney Foundation's Kidney Learning Center at:

learningcenter.kidney.org

Organ Procurement and Transplantation Network (OPTN)

optn.transplant.hrsa.gov/patients/about-donation/living-donation/living-donation

Project Donor

projectdonor.org

United Network for Organ Sharing (UNOS)

unos.org/donation/kidney-paired-donation

Multi-listing

National Kidney Foundation

kidney.org/atoz/content/multiple-listing

Organ Procurement and Transplant Network (OPTN)

optn.transplant.hrsa.gov/patients/about-transplantation/multiple-listing

Kidney transplant mentors

American Transplant Foundation: 1+1=Life Mentorship Program

americantransplantfoundation.org/programs/mentorship-program-2

Gift of Life: Transplant Mentors

giftdonor.org/programs/transplant-mentors

National Kidney Foundation: NKF Peers

kidney.org/patients/peers

Transplant Mentor Program at Barnes Jewish Hospital

barnesjewish.org/Medical-Services/Transplant/Transplant-Support-Resources/Transplant-Mentor-Program

Health insurance

Medicare Coverage of Kidney Dialysis & Kidney Transplant Services

medicare.gov/publications/10128-medicare-coverage-esrd.pdf

Medicare Savings Programs

medicare.gov/medicare-savings-programs

Missouri Department of Social Services

dss.mo.gov/mhd/general/pages/about.htm

Missouri Kidney Program (MoKP)

mokp.org
800-733-7345

Missouri State Health Insurance Program (SHIP)

missouriship.org
1-800-390-3330

National Kidney Foundation: Insurance

kidney.org/atoz/content/insurance

State-by-State Resources

dpcedcenter.org/resources/state-by-state-resources

State Health Insurance Program (SHIP)

shiphelp.org
(800) 633-4227

Getting help with financial assistance

American Kidney Fund

kidneyfund.org/get-assistance

American Transplant Foundation

americantransplantfoundation.org

Donate Life Missouri

donatelifemissouri.

Help Hope Live

helphopelive.org

Medicare Coverage

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

Mid-America Transplant Family House

midamericatransplant.org/our-foundation/family-house

The Missouri Kidney Program (MoKP) offers financial assistance for transplant. Learn more at:

mokp.org/financial-assistance

National Foundation for Transplants
transplants.org/get-help

National Kidney Foundation
kidney.org/category/financial-assistance

National Living Donor Assistance Center
livingdonorassistance.org

TriCare and Veterans Administration
tricare.mil/CoveredServices/IsItCovered/Transplants
(800) 538-9552

Two12 Sycamore
two12sycamore.org
(913) 439-8230

Advance care planning and comfort care

AARP: Find Advance Directives Forms by State
aarp.org/caregiving/financial-legal/free-printable-advance-directives

Caring Info
caringinfo.org/planning/advance-directives

Center for Practical Bioethics
practicalbioethics.org/featured-resources/caring-conversations

Compassion and Choices
compassionandchoices.org

Durable Power of Attorney for Healthcare
missourilawyershelp.org/legal-topics/durable-power-of-attorney-for-health

Durable Power of Attorney for Health Care and Health Care Directive
missourilawyershelp.org/wp-content/uploads/2023/07/DPOA-2023.pdf

Life Choices
ltgov.mo.gov/wp-content/uploads/2020/06/end-of-life-choices.pdf

Living Wills and other Advanced Directives
lsmo.org/node/304/living-wills-and-other-advance-directives

Missouri Medical Power of Attorney Form

eforms.com/power-of-attorney/mo/missouri-durable-power-of-attorney-for-health-care

Missouri Attorney General Advance Directive

https://eforms.com/images/2020/09/Missouri-Attorney-General-Advance-Directive.pdf

Missouri Secretary of State: Search for a Notary Public

https://s1.sos.mo.gov/Business/Notary/Search/NotarySearch.aspx

National Institute on Aging: Advanced Care Planning

nia.nih.gov/health/advance-care-planning-advance-directives-health-care

National Kidney Foundation (NKF) Online Communities

kidney.org/Communities

Adult transplant programs in Missouri

Barnes Jewish Hospital

1 Barnes Jewish Hospital Plaza
Saint Louis, MO 63110
Phone: (314) 747-3000
https://www.barnesjewish.org/medical-services/transplant

HCA Midwest Health Research Medical Center

2316 E Meyer Blvd
Kansas City, MO 64132
Phone: (816) 822-8257
researchmedicalcenter.com/service/transplant-institute

Saint Luke's Hospital

4320 Wornall Rd, Suite 304
Kansas City, MO 64111
Phone: (816) 932-3550
saintlukeskc.org/kidney-transplant

SSM Saint Louis University Hospital

3655 Vista Ave
Saint Louis, MO 63110
Phone: (314) 577-8867
ssmhealth.com/transplant-services

University of Missouri Hospital & Clinics

1 Hospital Drive
Columbia, MO 65201
Phone: (573) 882-8763
➪ muhealth.org/conditions-treatments/urology/kidney-transplant

Kidney Transplant Centers: Kidney Transplant Centers in Missouri

➪ kidneytransplantcenters.org/missouri

Find an adult transplant program in another state

Scientific Registry of Transplant Recipients: Transplant Center

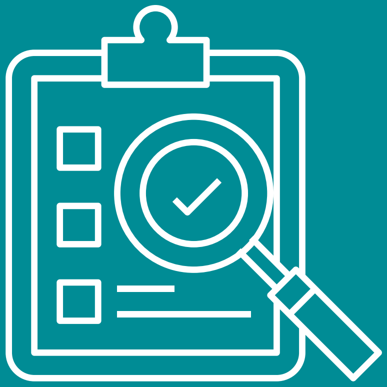
Use the Location section to find a transplant center

➪ srtr.org/transplant-centers/?organ=kidney&recipientType=adult&query=

Organ Procurement and Transplantation Network (OPTN)

Use the drop-downs to search for a transplant center

➪ optn.transplant.hrsa.gov/about/search-membership



Transplant evaluation

Use this checklist to track your evaluation progress:

☐ Step 1: Fill out evaluation application forms
☐ Step 2: Complete transplant education
☐ Step 3: Do your evaluation tests
☐ Step 4: Meet your transplant team
☐ Step 5: Get a decision about a transplant from a program

Worksheets and resources

- **Getting ready for an online transplant education class** on page 40
- **Getting ready for an in-person transplant education class** on page 43
- **Getting ready for your evaluation tests** on page 47
- **My transplant team** on page 50
- **Questions to ask your transplant team** on page 51

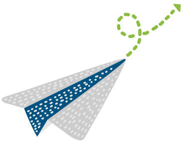
You do not need a referral from your doctor to get started with transplant evaluation. You can call the transplant programs yourself.

Step 1: Fill out evaluation applications

What to expect

During the application stage, you will need to:

Fill out an evaluation application form for each program where you want to list.



Send in your forms to those transplant programs.

Wait for the transplant programs to decide if you can move forward with evaluation.

Fill out the application forms

You will need to fill out transplant evaluation application forms for each transplant program where you want to list. Most programs have online forms, but you can request paper forms as well. Usually these application forms include:

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

You will need to sign a form so the transplant team can share some information with your care partner. If you don't have this form in your application packet, ask the transplant program. Even with this form, the transplant program may not be able to share all information.

Take your time to go through your packet and fill out all the information. You can make a list of information you may need to find:

☐ Current medicines
☐ Family health history
☐ Personal health history
☐ ______________________________
☐ ______________________________
☐ ______________________________

It's important that you fill out your forms completely. It helps the transplant team decide if you can move forward at that program.

Tip: You can ask for help from your care partner, social worker, or nurse at your dialysis center.

Person who helped me fill out my forms ______________________________

Send in your application forms

Make a copy of your applications for yourself and save a copy on your computer or keep paper copies with this workbook. Then send the originals to the transplant program.

Date I sent in my forms

_____ / _____ / _____
Month Day Year

How I sent in my forms

☐ Online submission
☐ Mail ☐ Email ☐ Fax

Wait for the transplant program's decisions

When the transplant program gets your forms, they will:

- Review the forms.
- Request your medical records.
- Review your insurance coverage.
- Decide if you can move forward with a transplant evaluation at that hospital.
- Send you a letter, email, or call you with your next evaluation step.

When you get the program's decision, share it with your healthcare team and care partner.

What to do after you get a transplant program's decision

The transplant program's decision is based on your application forms, medical records, and health insurance plan. Your next steps depend on this decision.

- **If a transplant program decides you can move forward with transplant evaluation at that hospital, they will schedule your tests.**
  This decision does not mean you will be added to the waiting list. It means you can move forward with transplant evaluation for that program.

- **If a transplant program decides you cannot move forward with transplant evaluation, don't give up.**
  This decision does not mean that you can never get a transplant. It means you cannot move forward with transplant evaluation with that program. You can talk with the program to see if there is anything you can do to move forward with evaluation or call another transplant program to be evaluated there.

Tip: Refer back to your list of programs on page 26.

Step 2: Complete transplant education

If a program decides that you can move forward with transplant evaluation, you will need to complete your transplant education class, session, or appointment. Most transplant programs offer these online.

My evaluation class is

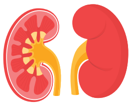
☐ Online and recorded (I can watch anytime)
☐ Online and live (I need to join at a specific day and time)
☐ In-person

I completed my class on

_____/_____/_____
Month Day Year

What to expect

During transplant education, 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 program.

Financial information, including what your insurance plan will or will not cover.

Financial information may be covered in transplant education, or it may be a separate 1-on-1 conversation, depending on the transplant program.

Tip: If the education class is in-person and on the same day as your evaluation tests, ask if the evaluation tests can be done on a different day.

How to get ready for an online class

☐ Ask your care partner to watch with you

Your care partner is the best person to watch with you, since they will help care for you before, during, and after surgery. You may want a family member to watch with you too.

Who will watch with me ______________________________

Tip: If your class is online and recorded, you may be able watch any time and multiple times.

☐ Get your device ready

You will need these:

- A computer or tablet with a working microphone and speakers (or headphones if you will be around other people).
- A strong internet connection.

You may also need to download an app if you will need to connect using a platform, such as Zoom.

Tip: If you have questions or have issues with the class, call the transplant program.

☐ Reschedule dialysis, if necessary

If your class is online and is scheduled for a specific day and time, you may need to move dialysis to a different day. Work with your dialysis center and transplant team to reschedule.

☐ Have this workbook and something to write with

Make sure you have this workbook with you and a few pens or pencils. You will learn a lot of information in your class, and taking notes can help you remember it.

Tip: Take notes in this workbook on page 42.

☐ Think about questions you need answered

When you're watching the online class, write down questions you need answered. If your class is online and live, you may be able to ask questions during the class.

Tip: Fill in the answers to the questions on the page 41.

Questions to ask in an online class

Write down answers in the space below each question.

What will evaluation testing be like?

How does the waiting list work?

What if I have a living donor?

How long will I be in the hospital after surgery?

Where can I stay nearby after surgery?

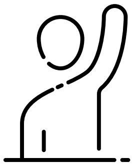
When will I need to come back for my first checkup after surgery?

Is there anyone I can talk to who has been through this?

My notes

Write any additional questions and answers, or notes in the lines below.

How to get ready for an **in-person** class



☐ Ask your care partner to come with you

You will learn a lot of information, so it's a good idea to bring someone with you to your class, such as your care partner. If they can't attend, think of someone else to bring.

Who will come with me ____

Tip: Look back at your "My people" list on page 12.

☐ Reschedule dialysis, if necessary

If your class is on the same day you have dialysis, you will need to move dialysis to a different day. Work with your dialysis center and transplant team to reschedule.

☐ Wear comfy clothes and bring the essentials

You'll want to be comfortable during the class so you can focus and participate. There are also some essentials you may need to bring, such as:

- Kidney-friendly snacks (ask your dialysis nurse or social worker for ideas).
- Your photo ID.
- All of your insurance cards.
- Any information, paperwork, or forms the program has sent you.
- Cell phone and charger.
- Consider wearing a mask to lower your chance of getting sick.

☐ Bring this workbook and something to write with

Bring this workbook and a few pens or pencils. You will learn a lot of information in your class, and taking notes can help you remember it.

Tip: Take notes in this workbook on page 45.

☐ Think about questions you need answered

Your transplant education class is a great time to ask questions. Before the class, write down some questions that you might want to have answered during the class.

Tip: Fill in the answers to the questions on page 44.

Questions to ask in an in-person class

Write down answers in the space below each question.

What will evaluation testing be like?

How does the waiting list work?

What if I have a living donor?

How long will I be in the hospital after surgery?

Where can I stay nearby after surgery?

When will I need to come back for my first checkup after surgery?

Is there anyone I can talk to who has been through this?

My notes

Write any additional questions and answers, or notes in the lines below.

Step 3: Do your evaluation tests

You must complete the full evaluation process. Your evaluation tests will be a full day with a lot of walking and waiting. Learn more about how to prepare for the evaluation tests on page 47. You may have other tests on different days.

When you and your care partner arrive at the hospital for your evaluation tests, go to the check-in or information desk.

Tips:
If you need to, ask if any testing can be done closer to where you live.

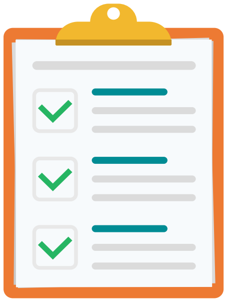
If it feels like too many tests are scheduled for one day, it is okay to ask to break up the tests over different days.

If you get too tired during the evaluation testing day, ask to reschedule the other tests.

What to expect

Some of the transplant evaluation tests may be scheduled for you, and others you may need to schedule yourself. These tests may include:

- **Blood tests** to help find a match and test your immune system.
- **X-rays and screenings** to look for any other health problems.
- **Dental evaluation** to make sure your teeth, gums, and mouth are healthy.
- **Psychosocial (mental health and social support) assessments** to make sure you are emotionally ready to have surgery, to take care of your new kidney, and that you have the social support you need.



You will need to keep up with your annual screenings and vaccines. Your transplant hospital will tell you what you need.

Tests

Write down any additional or follow-up tests below, then add the dates to your calendar.

Tip: After your evaluation, ask for a copy of your test results. You may be able to see the results in your patient portal, if you have one.

How to get ready for your evaluation tests

☐ Ask your care partner to come with you

Your care partner is the best person to take with you to your evaluation tests. You may want a family member with you too.

Who will come with me ______________________________

☐ Think about how you will get there

You will need someone to drive you because this will be a long day with a lot of testing.

Tip: Look back at your “My people” list on page 12.

☐ Follow the instructions in your information packet

Your information packet should include what you should or should not do before your tests. Depending on the type of tests, you may or may not be able to:

- Eat or drink before the tests.
- Take certain medicines.

Tip: If you have any questions, call your transplant coordinator.

☐ Reschedule dialysis, if necessary

If any of your tests are on the same day you have dialysis, you will need to move dialysis to a different day. Work with your dialysis center and transplant team to reschedule.

☐ Think about how you will be most comfortable for the day

Because it will be a long, tiring day, you will want to:

- Wear comfy clothes and shoes.
- Bring kidney-friendly snacks.
- Bring a cane or ask for a wheelchair (if needed) to move around.
- Bring a book or something to do while you wait.
- Consider wearing a mask to lower your chance of getting sick.

☐ **Bring the essentials**

Make sure you bring:

- Your photo ID.
- All of your insurance cards.
- A list of current medicines and any medicine allergies.
- Any information, paperwork, forms, hospital map, and appointment times the program has sent you.
- This workbook and something to write with.
- Cell phone and charger.

My notes

Write any additional questions and answers, or notes in the lines below.

Step 4: Meet your transplant team

Your team will support you 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 when you meet them.

Tip: Add members of your team and their contact information on page 50.

Who you may meet

Transplant Coordinator

Transplant Coordinators are usually licensed registered nurses (RN) and will help care for you before, during, and after your transplant.

Transplant Nephrologist

Nephrologists are doctors who specialize in kidney problems. Most people with kidney disease have a nephrologist who manages their medical care before a transplant. You may have another transplant nephrologist during and after your transplant.

Transplant Surgeon

Transplant Surgeons are doctors who specialize in kidney surgeries and transplants. Your surgeon will do the surgery and will be involved in your care as you recover.

Transplant Social Worker

Transplant Social Workers are specially trained to help you with your support needs before, during, and after your transplant. They can give you and your care partner resources about:

- Housing
- Community and support services
- Vocational rehabilitation, to help you return to work

Financial Counselor

Financial counselors can help you understand:

- The cost of your transplant.
- What your insurance will cover.
- Any costs your insurance doesn't cover.

Dietitian or Nutritionist

Dietitians and Nutritionists help make sure you are getting the nutrition you need before and after your transplant. A dietitian may also help you create a special diet if you have other health problems such as diabetes, high blood pressure, or high potassium levels.

Pharmacist

Pharmacists are healthcare professionals with specific training in how to prepare and dispense medicines. They can help you manage your medicines as well. They can:

- Look over the medicines you are taking.
- Make recommendations about medicines.
- Teach you about the medicines you will be taking after your transplant.
- Address your concerns or questions about your medicines.

My transplant team at ______________________________

As you meet members of your transplant team, write their names and phone numbers here:

Name	Role / Title	Phone & fax number	Email
	Transplant Coordinator		
	Transplant Nephrologist		
	Transplant Surgeon		
	Social Worker		
	Financial Counselor		
	Dietitian or Nutritionist		
	Pharmacist		

ⓘ There are extra worksheets on page 84.

Questions to ask your transplant team

Remember, your transplant team is there to support you throughout your journey. Do not be afraid to ask them any questions you have. Here are some questions you might want to ask and space to write the answers:

What is surgery like?

Do you remove my kidneys?

How long will surgery be?

How long will I be in the hospital?

Where will the incision (cut) be and what will it look like?

What will the pain be like?

What will I take for the pain?

How long will it take for me to recover?

How quickly can I return to work?

What will my after-transplant care be?

How long does it take for the new kidney to start working?

Will I need dialysis again?

There are extra worksheets on page 85.

My notes

Step 5: Get a decision about a transplant from a program

Once your evaluation is complete, the transplant program will meet to decide if you are a good candidate for a kidney transplant. It may take a few weeks.

Tip: Share the decision with your healthcare team and care partner.

What to expect

You will get a call, letter, or email from the transplant program. The transplant program will let you know if you can continue the process and be listed for a paired or deceased donor transplant with that transplant program.

- **If the transplant program decides you are a good candidate for a transplant at their hospital, they will put you on the waiting list.** Your transplant wait time began the day you started dialysis. If you have not started dialysis, your wait time begins when you are approved for the transplant waiting list.

  The national average waiting list time is 3-5 years for most transplant programs.

- **If the transplant program decides you are not a good candidate for a transplant at their hospital, they may not put you on the waiting list.** They will explain their reasons. It could be because you have:
  - Advanced heart disease.
  - Active cancer.
  - Lack of social support.
  - Lack of financial support.
  - Obesity.
  - Certain behaviors such as smoking, drug or alcohol misuse, or not following medical instructions.
  - Behavioral health conditions that will make it hard to care for yourself after your kidney transplant.

  Don’t give up. You can talk with the transplant program to see if there is anything you can do to be approved for the waiting list, or call another transplant program on your list.

  Every transplant program is different. It is possible for one transplant program to turn a patient down and another program to approve them.

  Tip: Refer back to your list of programs on page 26.

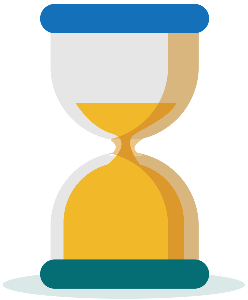
Transplant listing

In this chapter, you will:

☐ Learn what to do while you wait for your kidney transplant

Worksheets and resources

- **My waiting list status** on page 57
- **Physical activity, healthy weight, and healthy foods** on page 58
- **Healthy blood pressure and blood glucose levels** on page 59
- **My medicines** on page 60
- **Resources for transplant listing** on page 65



Keep your waiting list status active

"Active" vs "inactive" (or "on hold")

Once you are placed on the kidney transplant waiting list, you will be given an **active** or **inactive** (or **on hold**) status.

If you are **active**, the transplant hospital will tell you, and then you are in line for a kidney. You may get a call for a transplant at any time.

If you are **inactive** (or **on hold**) you are still on the waiting list. However, the transplant program found some issues you need to fix. The issues might be the need for dental work, weight loss, recovery from an infection, or updated insurance information.

While you are waiting for a kidney, your status may change back and forth. If your status changes to inactive, your transplant coordinator may contact you. You can contact your transplant coordinator or ask staff at your dialysis center if you are not sure if you are active.

How to keep your status active

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

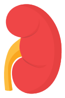
1. Stay in contact with your transplant programs

Contact them if your situation changes, such as when:

Your health insurance or medicine coverage changes.

You change your phone number or address.

You change your dialysis center or start seeing a new nephrologist.



You found a living donor who wants to donate a kidney to you.

You start or stop taking any medicines.

You get sick or get admitted to the hospital.

2. Repeat your evaluation testing

Your transplant coordinator will help you schedule this when the time is right.

ⓘ Usually you will have testing done every year.

3. Continue to get other testing or treatments

It’s important to keep up with your medical testing and treatments. This includes monthly blood draws and regular dialysis.

4. Check your status on the waiting list

Call your coordinator to make sure your waiting list status is active. You can do this every 6 months or so, or anytime you are not sure of your status.

Tip: If your status is inactive, ask how you can become active again.

My waiting list status

Use the chart below to keep track of your calls, your status at the time you called, and anything you can do to become active again:

Date I called	Am I still active?	If not, what can I do?
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	

There are extra worksheets on page 86.

Stay healthy while you wait

Staying as healthy as possible 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 healthy person on the list.

How to stay healthy while you wait:

1. Stay physically active

Ask your doctor how many days each week and how many minutes you need to exercise. You can also ask what exercises you should do. Write it below:

I should exercise: ______ days each week for _______ minutes a day

Safe exercises for me:

______________________	______________________
______________________	______________________
______________________	______________________

2. Stay at a healthy weight for you

Ask your doctor what a good weight range is for you. Write it below:

I should stay around: __________ - __________ lbs (pounds)

3. Eat healthy foods

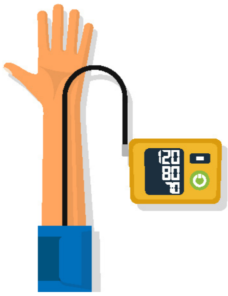
Eating right can help you stay as healthy as possible. Ask your dietitian or nutritionist what foods you should eat more or less of. Write them below:

I should eat more:	I should eat less:
______________________	______________________
______________________	______________________
______________________	______________________

4. Take your medicines

It's important to take medicines as prescribed by your healthcare team and keep track of what you are taking. Make a list of current medicines to take to your medical appointments.

Tip: Create a list of medicines using the My medicines chart on page 60.



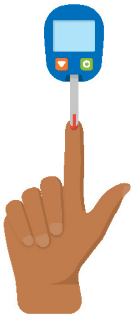
5. Keep your blood pressure at a healthy level

Eating well, being active, and taking your medicines can help keep your blood pressure at a healthy level. Ask your doctor what numbers are healthy for you. Write them below:

Blood pressure levels

I should call my doctor if it is higher than ______________ / ______________
higher number   lower number

I should call my doctor if it is lower than ______________ / ______________
higher number   lower number



6. Keep your blood sugar at a healthy level

Keeping your blood sugar levels healthy is especially important if you have diabetes. Ask your doctor what numbers are healthy for you. Write them below:

Blood sugar levels

I should call my doctor if it is higher than ______________________

I should call my doctor if it is lower than ______________________

7. Do not smoke or misuse drugs or alcohol

Behaviors such as smoking and drug or alcohol misuse can cause health problems. Some transplant programs may not list you if you use these substances.

8. Go to and complete all your dialysis treatments

Your transplant team may ask your dialysis center if you miss or skip any dialysis treatments. You may need to reschedule your dialysis appointment if an evaluation appointment is scheduled for the same date and time.

9. Continue to get yearly evaluation testing

Even though you are on the waiting list, you will still need to go through some evaluation tests every year. These tests will make sure you are still healthy enough for a kidney transplant.

Tip: Consider wearing a mask when you go the doctor or hospital to lower your chance of getting sick.

My medicines

Keep track of your medicines, what they look like (color, size, or shape), why you're taking them, dose (how much you take and when), and the doctor who prescribed them.

Medicine you are taking	**Dose**	**Doctor**
Example Name of medicine: *Aspirin* Why you are taking it: *Heart* What it looks like: *White tablet*	*25 mg daily*	*Dr. Ellis Jones*
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		

ⓘ There are extra worksheets on page 87.

Stay connected while you wait

When a donor kidney becomes available, the transplant coordinator will call you to get ready. The call can come at any time of the day or night. The coordinator will tell you when to go to the transplant hospital. **Do not delay!** There is a time limit once a kidney becomes available.

Tips to stay connected with your transplant team:

☐ Make sure your transplant team has your cell phone number and home phone number.

☐ Tell your transplant team if your phone numbers change.

☐ Give your transplant team the phone numbers of your care partner, family, and friends. This way they can find you if you are not answering your phone.

☐ Tell your transplant team if your health insurance changes.

☐ Check your phone settings:

  - Make sure your voicemail is set up and check it often.
  - Make sure you either answer unknown numbers or check your voicemail as soon as possible.

Tip: Let your care partner, family, and friends know that you gave the transplant team their phone numbers.

Stay positive while you wait

You may be waiting for a long time. It's normal to feel a range of emotions during the transplant journey. Sometimes you might feel happy, hopeful, and grateful. At other times you might feel afraid, angry, and discouraged. This may be true for your care partner too.

Causes of stress during the transplant journey

The transplant journey can be stressful for many reasons, such as:

Feelings of guilt

- Feeling like you're a burden to others
- Blaming yourself for your disease

Feelings of fear and anxiety

- Worrying about what may happen in the future
- Waiting for annual evaluation results
- Waiting to be put on the transplant waiting list
- Worrying about the risks of surgery

Social and relationship stress

- Having problems with money or insurance
- Feeling alone and helpless

These feelings are normal, but there are ways to lower your stress and feel better.

How to lower your stress and feel better

Self-care activities can help you cope when you feel afraid, angry, and discouraged. Here are some activities you can try:

Connect with someone

- Talk with a friend, family member, or spiritual leader.
- Talk with a transplant mentor (someone who has been through a successful transplant).
- Connect with a local or online support group.
- Talk with a mental health provider or social worker.

Tip: View resources to connect with transplant mentors on page 30.

Get inspired

- Re-read your "My why" to remember your motivation for wanting a transplant on page 11.
- Watch inspiring stories on page 29.
- Keep an "I am grateful for" journal using the worksheet on page 91.
- Listen to music to get inspired.

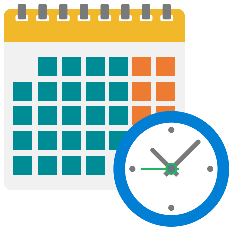
Change your focus

- Do something from your "My pick-me-up" list on page 11.
- Take a walk.
- Try relaxation strategies, like mindful breathing and meditation.
- Watch a funny movie, or a movie you love.

Learn more

- Learn more about kidney transplants and living donation transplants page 29.
- Learn more about comfort care and how to prepare for any outcome on page 32.

Think about ways to get a kidney sooner



On average, people are on the waiting list for 3-5 years before they get a kidney, but it could be much longer depending on where you live.

Here are some ways you might be able to get a kidney sooner:

Get 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 both ready.

You can find living donation resources on page 29.

Talk to your transplant coordinator as soon as possible if:

- You are listed at a transplant program that has a living donor and paired donation program, and
- You find someone to be a living donor.

Get multi-listed

Multi-listing means that you are listed at more than one transplant program. To be multi-listed, you will need to:

- Contact another transplant program.
- Be approved for a transplant.
- Be able to quickly get to that hospital if a kidney becomes available.

You can learn more about multi-listing on page 25.

My notes

Write any additional notes in the lines below.

Resources

Physical health

American Kidney Fund: Kidney-Friendly Eating at Every Stage

➪ kitchen.kidneyfund.org

Transplant Weight Loss Clinic at University of Chicago Medicine

➪ uchicagomedicine.org/conditions-services/transplant/transplant-weight-loss-clinic

Mindful breathing and meditation

Insight Timer

➪ insighttimer.com

UCLA Mindfulness

➪ uclahealth.org/programs/marc/free-programming-resources/ucla-mindful-app

Encouragement

The Living Donation Storytelling Project

➪ livingdonationstories.org

National Kidney Foundation (NKF): Online Communities

➪ kidney.org/communities

Emotional health

American Kidney Fund: Mental Health and Kidney Disease

➪ kidneyfund.org/living-kidney-disease/mental-health-and-kidney-disease

Dialysis Patient Citizens Education Center

➪ https://www.dpcedcenter.org/quality-of-life/mental-health/

Gift of Life: Mental health, depression and resources

➪ youtu.be/HsR8ogDiZac

Gift of Life: Mental and Spiritual Health for Patients & Caregivers

youtube.com/watch?v=jJK_ZOZKR7Y

National Kidney Foundation: Peers

kidney.org/peers

Self care

University Health Network

uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Documents/Coping_with_a_Transplant.pdf

Resources for caregivers

Caregiver Action Network

https://www.caregiveraction.org/

National Kidney Foundation: Family and Caregiver Resources

kidney.org/patients/resources_Caregiver

Prepare for transplant surgery

In this chapter, you will:

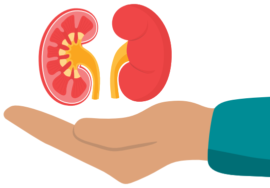
☐ Learn about and prepare for your transplant surgery

Worksheets and resources

- **Your transplant go-bag** on page 70
- **Plan for surgery day** on page 70
- **Think about your next steps** on page 72
- **Resources to help you prepare for transplant surgery** on page 73

Surgery

This is an important milestone on the transplant journey.



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, day or night.

There is a time limit once a kidney becomes available. Your coordinator will tell you when to be at the transplant hospital and where specifically to go. Grab your kidney transplant go-bag, and go!

Tip: Pack your go-bag using the list on page 70.

It is common that more than one patient is called when a kidney becomes available. However, the kidney is first offered to the patient who is the best match.

The United Network for Organ Sharing (UNOS) decides who is the best match based on factors such as:

- Their medical condition, and how sick they are.
- Where they live.
- How long they have been on dialysis.
- Blood type, organ size, and condition of organ.
- How long they have been on the transplant waiting list.

No one has to accept a kidney that is offered to them. If someone is the best match for a kidney, and they decide not to accept it, the kidney will be offered to the person who is the next best match.

What if someone else is a better match for the kidney?
The other patient will get that kidney. And it means that you may be close to getting a kidney, so **stay hopeful!**

When you are scheduled for surgery with a living donor kidney

If you have a living donor, or are doing a paired donation, your hospital will schedule a surgery date that works best for you and your donor.

What to bring

Your kidney transplant go-bag

Whether you are on the waiting list for a deceased donor kidney or have scheduled your living donor transplant, you want to be ready for your surgery day. Include the following in your kidney transplant go-bag:

- This workbook and something to write with
- Extra set of clothes
- Personal care items, such as a comb or hair brush
- Entertainment (such as music, books, videos, or a tablet)
- Headphones
- Cell phone and charger

Tip: Ask your transplant coordinator if you should bring medicines for other health conditions.

Have a plan for your surgery day

You should have a plan in place for the day of your surgery. You will need someone to drive you to your surgery, and someone who will look after any people or pets you care for.

How will I get to the transplant hospital?

Who will go with me?

Who will look after those I care for (such as kids, parents, or pets)?

Your "My people" list is on page 12.

What to expect after surgery

Medicines after surgery

The most important medicines you will be on will be immunosuppressants. Depending on your insurance coverage these may be very expensive medicines. Talk with your transplant coordinator about how to manage the cost of your medicines for as long as you will be on them.

Tip: Contact your transplant coordinator right away if for any reason your pharmacy does not have your medicines, or if you cannot afford them.

Before you leave the transplant hospital, 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!

Follow-up care after surgery

You will need to come back after surgery for doctors to check how you are healing and how your kidney is doing. The transplant coordinator will let you know how often you need to come back.

You should bring someone with you, such as your care partner, to learn about the care you need after the surgery.

You will not be able to drive for a few weeks after surgery.

Congratulations!

You have made it through your transplant surgery! We hope this workbook has been a helpful tool on your journey. Now you can focus on caring for your new kidney, follow-up care, and healthy living. We hope your journey will be filled with health and happiness.

Think about your next steps:

Reflect on your journey

Make a list of at least 3 things you are grateful for. They can be big or small, anything that has helped you in your journey. Think about the people who have supported you along the way.

Things I'm grateful for

Make the most of your new kidney

Not everyone has the opportunity to go through transplant surgery and get a new kidney. Now that you have, how will you make the most of your kidney? Think about your "My why" and what matters most to you.

How I will make the most of my new kidney

Share your story

Would you be willing to tell your story online or be a transplant mentor for someone else on their transplant journey?

Tip: Look at the resources on page 73.

How I will share my story

Honor your donor

Talk with your transplant coordinator about how you can honor or thank your donor or their family.

Resources

Transplant surgery

National Kidney Foundation

kidney.org/atoz/content/kidney-transplant#getting-transplant

National Institute of Diabetes and Digestive and Kidney Diseases

niddk.nih.gov/health-information/kidney-disease/kidney-failure/kidney-transplant

Johns Hopkins Medicine: Kidney Transplant

https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/kidney-transplant

Extra worksheets

Find extra worksheets that you can print or make copies as you journey through the transplant process

Worksheets and resources

My notes

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

Date: ______________

Type: ☐ Phone call ☐ Appointment ☐ Meeting ☐ Class ☐ Other

My notes

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

Date: ______________

Type: ☐ Phone call ☐ Appointment ☐ Meeting ☐ Class ☐ Other

My notes

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

Date: ______________

Type: ☐ Phone call ☐ Appointment ☐ Meeting ☐ Class ☐ Other

My notes

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

Date: ______________

Type: ☐ Phone call ☐ Appointment ☐ Meeting ☐ Class ☐ Other

My potential living donors

List people you may ask to be a living kidney donor for you, and their phone numbers, in the table below.

Name	Phone number

My living donor letter

Use the letter below as a starting point for writing your own donor letter or a letter for someone to write on your behalf.

Dear *(name of potential donor)*:

Thank you for asking *(how I am / how name of recipient is)* doing. *(I am / they are)* on dialysis, and hoping to get a kidney transplant as soon as possible. *(Explain a bit about your or their life on dialysis, be as transparent as possible to the degree you are comfortable).*

This letter will tell you how you can help *(me / name of recipient)* get a transplant more quickly than waiting on the list for a kidney from someone who has died. *(Explain what getting a transplant would mean to you or them)*.

Please consider being tested to be *(my / name of recipient's)* donor, or share this letter with others.

If you are willing to go through testing to be a living kidney donor, here is what you need to do:

1. Contact *(transplant coordinator or person dedicated to living donors)* at *(transplant hospital)* at *(phone number).* This is the program where *(I am / name of recipient is)* waitlisted and where *(my / their)* surgery will be.
2. Let them know if you want to learn more about what is involved with living donation with *(name of transplant program)* and that you may want to be evaluated as a living donor for *(me / name of recipient)*.
3. They may ask you some questions about your blood type and your health history. They may also have you fill out some forms.
4. If you are a good candidate, they will schedule you for some tests at their hospital.

Everything about this will be private *(confidential)*, and even kept from *(me / name of recipient)*. *(I / they)* will never know if you have made contact, completed any tests, or changed your mind about donation.

(My / name of recipient's) health insurance will cover all medical costs of your donation testing, surgery, and after-care. There are a number of options to cover your out-of-pocket costs, like hotel, meals, and transportation. The transplant coordinator assigned to you can share more with you.

If you are not a match for *(me / name of recipient),* and you are told you are a good donor candidate, you can consider donating to someone else, which allows *(*me / name of recipient*)* to get a kidney from a different donor. This is called paired donation, or a kidney swap.

Thank you for your concern and your consideration of this request.

Transplant program information sheet

Fill in the program contact information in the table below.

Name	
Address	
Website	
Phone number	
Email address	

Tip: Include your care partner on the call.

Questions to ask

Write down answers in the space below each question.

How **soon** can I get an evaluation?

How long will **my evaluation** take?

Do you take **my health insurance?**

What type of **financial help** do you offer?

How far is the hospital from my home?

What is the average **wait time to get a kidney?**

If I want to list at more than one transplant program, will your program share **my medical evaluation results with other programs?**

Does your program offer **living donation transplants?**

Does your program offer **paired donation?**

How many living donors can test to be a match for me?

How many nights do I need to **stay after surgery?**

What will I need to do **after my transplant?**

How will my transplant team **communicate with me?**

Does your program have a **patient portal** where I can see my transplant information?

My notes

Write any additional questions and answers, or notes in the lines below.

Tip: Learn more about choosing your transplant program on page 24.

My transplant team at ______________________________

As you meet members of your transplant team, write their names and phone numbers here:

Name	Role / Title	Phone & fax number	Email
	Transplant Coordinator		
	Transplant Nephrologist		
	Transplant Surgeon		
	Social Worker		
	Financial Counselor		
	Dietitian or Nutritionist		
	Pharmacist		

My transplant team at ______________________________

As you meet members of your transplant team, write their names and phone numbers here:

Name	Role / Title	Phone & fax number	Email
	Transplant Coordinator		
	Transplant Nephrologist		
	Transplant Surgeon		
	Social Worker		
	Financial Counselor		
	Dietitian or Nutritionist		
	Pharmacist		

Questions to ask your transplant team

Remember, your transplant team is there to support you throughout your journey. Do not be afraid to ask them any questions you have. Here are some questions you might want to ask and space to write the answers:

What is surgery like?

Do you remove my kidneys?

How long will surgery be?

How long will I be in the hospital?

Where will the incision (cut) be and what does it look like?

What is the pain like?

What will I take for the pain?

How long is recovery?

What will my after-transplant care be?

Will I need dialysis again?

My waiting list status

Use the chart below to keep track of your calls, status at the time you called, and anything you can do to become active again:

Date I called	Am I still active?	If not, what can I do?
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	
/ /	☐ Yes ☐ No	

Tip: Learn more about keeping your waiting list status active on page 56.

My medicines

Keep track of your medicines, what they look like (color, size, or shape), why you're taking them, dose (how much you take and when), and the doctor who prescribed them.

Medicine you are taking	**Dose**	**Doctor**
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		
Name of medicine: Why you are taking it: What it looks like:		

My phone call

Use this page to take notes when you make phone calls.

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 "Questions and answers" lines below.)

During my call

- Who am I talking to? ______________________________
- What is the date and time of the call? ______________________________
- What answers did I get from my questions? (Write them in the lines below.)

Tip: If you don't understand something, it's okay to ask questions! To make sure you understand, repeat back the information to the person you are talking to, then ask "Is that right?"

Questions and answers

Tip: Put all the notes from your calls in one place that is easy to get to. If you took out any cards or important papers for the call, remember to put them back.

My appointment

Use this page to take notes when you have medical appointments.

Details

- What is the appointment? ______________________________
- Who is the appointment with? ______________________________
- When is the appointment? ______________________________

Questions and answers

What I need to know or do next

My journal

Use this page to reflect on your transplant journey.

Date: ______________

”I am grateful for…” journal

Use this page to reflect on what you are grateful for.

Date: _______________

My calendar

Use this page to keep track of appointments and important dates.

Month and year

SUN	MON	TUES	WED	THURS	FRI	SAT

Acknowledgments

Many have contributed to the writing and development of the **My transplant-ready workbook**. A few key people are noted here. Many others also contributed to the content, reviewed and provided feedback, and helped design the look and flow of this workbook. Every individual and organization involved is passionate about kidney donation and ensuring that all Missourians who want to seek a kidney transplant have the necessary information and tools.

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Candra Asamoah, Director of Digital Media and Strategy at Health Literacy Media, provided leadership and creative direction to a team of writers, editors, and designers who brought this workbook to life. Mrs. Asamoah has a passion for collaboration and for making health information easy to use, read, and understand so people can improve their health.

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Dialysis patients and mentors also read through workbook drafts and provided constructive and vital feedback. Their personal experience and their passion to help others was evident during the development and refinement of this workbook.

My transplant-ready workbook
Second Edition Updated April 2024

Missouri Kidney Program
University of Missouri

Learn more about the Missouri Kidney Program (MoKP) at mokp.org