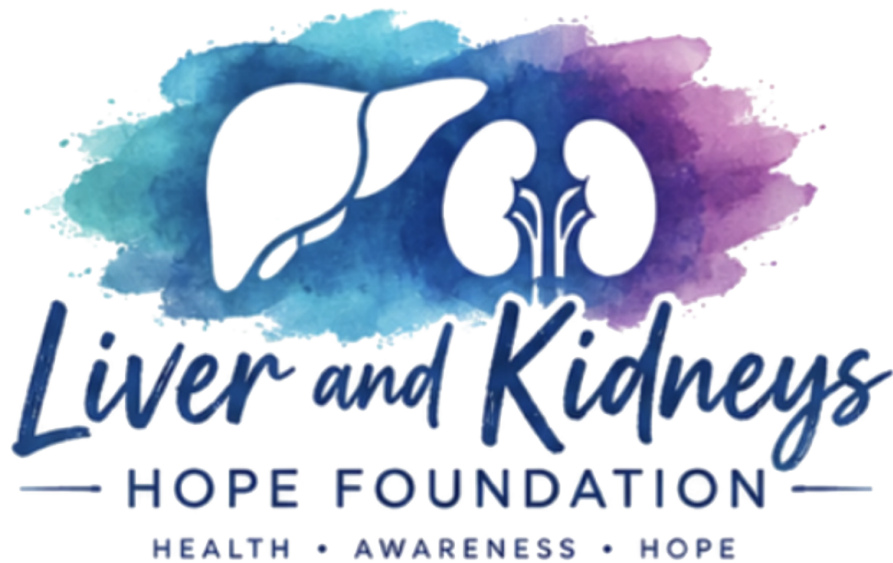




KIDNEY TRANSPLANT

The Complete Patient & Family Guide

From first questions to a lifetime of living well

Inside this guide

- Evaluation, waiting list, and living donation
- Surgery, hospital stay, and early recovery
- Anti-rejection medicines and safe medicine use
 - Rejection, infection, and long-term health
- Food safety, activity, mental health, work, travel, and pregnancy
- 26 fill-in worksheets, glossary, FAQ, and resources

For patients, families, living donors, and caregivers

Educational purposes only. The Liver and Kidney Hope Foundation is not a medical provider. This guide does not replace the advice of your transplant team.

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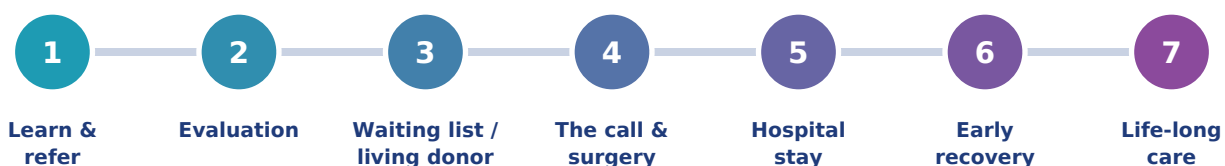
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Welcome

If you are reading this guide, you or someone you love may be facing one of the biggest health decisions of a lifetime. A kidney transplant can give people more energy, more freedom, fewer restrictions, and, for most, a longer life than staying on dialysis. It also asks a lot: many tests, weeks or years of waiting, an operation, and a lifelong commitment to medicines and follow-up care.

This guide was written by **The Liver and Kidney Hope Foundation (TLHF)** to walk with you through every stage, in plain language, from your first "should I even consider a transplant?" question to living well with a transplanted kidney for decades. It is written for **patients, family members, living donors, and caregivers**.

THE TRANSPLANT JOURNEY AT A GLANCE



How this guide is organized

Part	What it covers
Part 1: Understanding	Kidney failure, what a transplant is, benefits and risks, and who can have one
Part 2: Getting Ready	Evaluation, choosing a center, insurance, the waiting list, living and deceased donors, preparing your body, mind, and home
Part 3: Surgery & Hospital	The call, the operation, and your hospital stay
Part 4: Medicines	Anti-rejection medicines, other drugs, interactions, and staying on schedule
Part 5: Recovery & Monitoring	The first months, rejection, infection, long-term complications, and labs
Part 6: Living Well	Food safety, activity, skin care, vaccines, mental health, work, travel, pregnancy, family, special situations
Part 7: Tools & Reference	26 worksheets you can fill in, a glossary, FAQ, and resources

How to use it

You do not need to read this cover to cover. Start with the chapter that matches where you are today. Use the worksheets (marked in purple) as working pages: print them, write in them, and bring them to appointments.

One rule above all others

Every transplant center has its own protocols, target lab levels, medicine choices, and rules. **When this guide and your transplant team disagree, follow your team.** They know your body and your history. Use this guide to understand the "why" and to help you ask better questions.

Medical disclaimer and about TLHF

This guide is provided for **educational purposes only**. The Liver and Kidney Hope Foundation is a Nevada 501(c)(3) nonprofit organization that provides liver and kidney health education, community support, and outreach. **TLHF is not a medical provider** and does not diagnose, treat, or prescribe. Nothing in this guide is a substitute for professional medical advice, diagnosis, or treatment.

Transplant medicine changes. Allocation rules, drug names, target ranges, screening recommendations, and insurance rules are updated over time. Numbers in this guide (such as survival rates, wait times, and lab targets) are general ranges that vary widely by center, region, donor type, and individual health. Ask your own transplant center for its *center-specific* data, and review public data such as the Scientific Registry of Transplant Recipients (SRTR).

Emergency - call 911

- Chest pain, trouble breathing, fainting, sudden weakness, or a seizure
- Vomiting blood or black, tarry stools
- A fever with shaking chills, confusion, or feeling extremely unwell
- Severe pain, or any situation you believe is life-threatening

If you are having thoughts of harming yourself, call or text **988** (Suicide & Crisis Lifeline in the United States) right away.

Words we use in this guide

- **Transplant team:** the surgeons, nephrologists (kidney doctors), coordinators, nurses, pharmacists, dietitians, social workers, and others who care for you.
- **Recipient:** the person receiving the kidney. **Donor:** the person giving the kidney, living or deceased.
- **Graft:** another word for the transplanted kidney. **Graft function** means how well it is working.
- **Immunosuppressants** (anti-rejection medicines): drugs that quiet your immune system so it does not attack the new kidney.
- **Creatinine** and **eGFR:** the two most-watched kidney numbers. You will learn them well.

A word from TLHF

You are not alone. Thousands of people receive a kidney transplant every year in the United States, and millions more worldwide are living with transplanted kidneys. Ask questions, lean on your support network, and remember: **hope is part of treatment.**

PART 1

Understanding Kidney Transplant

CHAPTER 1

Your Kidneys and Kidney Failure

What kidneys do, what happens when they fail, and your treatment options

What healthy kidneys do

Your kidneys are two fist-sized organs tucked under the lower ribs on each side of the spine. Together they filter about a cup of blood every minute, removing waste and extra fluid and returning what your body needs. Healthy kidneys quietly do far more than make urine:

- **Clean the blood** of waste products such as urea and creatinine, and of many drugs.
- **Balance fluid, salts, and minerals:** sodium, potassium, calcium, phosphorus, and acid-base balance.
- **Help control blood pressure** through hormones and fluid balance.
- **Make erythropoietin**, the hormone that tells bone marrow to make red blood cells.
- **Activate vitamin D**, which keeps bones strong.

When kidneys fail

Chronic kidney disease (CKD) is measured in five stages using the **eGFR**, an estimate of how much filtering your kidneys still do. **Kidney failure** (also called end-stage kidney disease, ESKD, or ESRD) means kidney function has fallen to about 15% of normal or less (eGFR under 15), or dialysis is needed to stay well.

CKD stage	eGFR (mL/min/1.73 m ²)	What it means
Stage 1	90 or higher	Normal filtering, but there are signs of kidney damage (such as protein in urine)
Stage 2	60 - 89	Mildly reduced function
Stage 3a / 3b	45 - 59 / 30 - 44	Mild-to-moderate / moderate-to-severe reduction. Complications begin to appear
Stage 4	15 - 29	Severe reduction. Time to plan for dialysis or transplant
Stage 5	Under 15	Kidney failure. Dialysis or transplant needed

Common causes of kidney failure include **diabetes**, **high blood pressure**, glomerular diseases (such as IgA nephropathy, FSGS, and lupus nephritis), polycystic kidney disease (PKD), and inherited or structural conditions. Sometimes the cause is never found.

Your three treatment paths

	Kidney transplant	Hemodialysis	Peritoneal dialysis	Conservative care
What it is	A healthy kidney is placed in your body and does the work of filtering	A machine filters your blood, usually 3 times a week	Fluid in the belly filters blood through the abdominal lining, often nightly at home	Symptom-focused care without dialysis or transplant
Replaces	Most (not all) of normal kidney function	A small fraction of normal function	A small fraction of normal function	Nothing. Focus is comfort and quality of life
Time burden	Surgery, then clinic visits that taper over time	About 12+ hours a week including travel	Daily exchanges or nightly machine	Regular supportive visits
Medicines	Lifelong anti-rejection drugs	Many, plus binders and others	Many, plus binders and others	Symptom control
Typical outlook	Longest survival for most who qualify	Depends on age and other illnesses	Similar to in-center dialysis early on	Shorter, focused on quality of life

The big picture

Transplant is considered the best treatment for most people with kidney failure who are healthy enough for surgery. It is not a cure: the new kidney needs lifelong protection, and it can eventually fail. But most people feel it is worth it.

CHAPTER 2

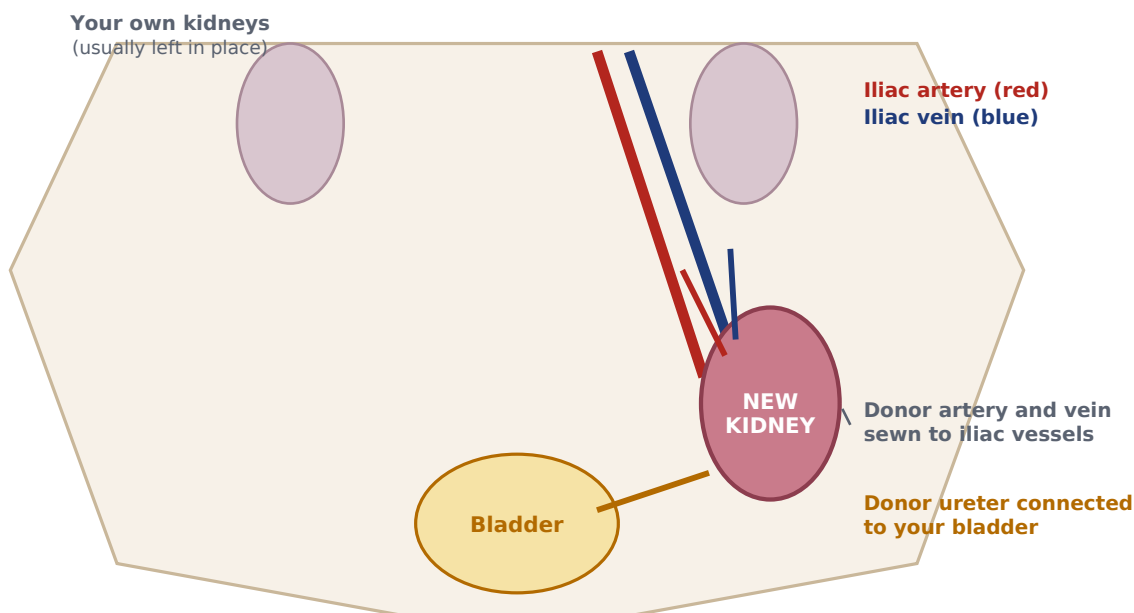
What Is a Kidney Transplant?

The operation, the benefits, the risks, and the myths

~27,000 kidney transplants performed in the U.S. each year (recent years)	90,000+ people on the U.S. kidney waiting list at any time	~3 in 4 kidney transplants come from deceased donors	1 kidney is enough: donors live well with one
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Statistics are approximate and change every year. See OPTN and SRTR for current national data.

In a kidney transplant, a surgeon places a healthy kidney from a donor into your body. The new kidney is usually placed in the lower front of the abdomen, on one side, in a spot called the iliac fossa. Its blood vessels are attached to large blood vessels in your pelvis, and its ureter (the tube that carries urine) is connected to your bladder. **Your own kidneys are usually left where they are.**



Simplified schematic (front view of the lower abdomen and pelvis). Not to scale.

Where the kidney comes from

	Deceased donor	Living donor
Who	A person who has died and whose family (or registered choice) allowed organ donation	A relative, friend, coworker, community member, or altruistic stranger who chooses to donate
Timing	You must wait on the national list; wait varies from months to many years	Can be scheduled at a time that suits both, including before dialysis begins
Typical graft life	Often 10 to 15+ years	Often 15 to 20+ years
Immediate function	More likely to be slow to start	Usually starts working right away
Donor risk	None (donor has died)	Surgery risk and small long-term risk; see Chapter 7

Benefits of transplant compared with staying on dialysis

- **Longer life** for most people, especially when the transplant occurs before or early in dialysis.
- **More energy, better sleep, better appetite**, and a clearer mind for many.
- **Fewer diet and fluid restrictions** than dialysis, though healthy eating still matters.
- **Freedom from dialysis schedules**: work, school, travel, and family life become easier.
- **Better fertility and sexual health** for many people; pregnancy is possible with careful planning.
- **Lower long-term cost** to the health system compared with years of dialysis.

Risks of transplant

- **Surgical risks**: bleeding, infection, blood clots, wound problems, urine leak or blockage at the ureter connection, and anesthesia risks.
- **Rejection**: the immune system attacks the kidney. Usually treatable when caught early (Chapter 16).
- **Delayed graft function**: the new kidney is slow to start, and you need temporary dialysis (Chapter 10).
- **Infections**, because anti-rejection medicines lower your defenses (Chapter 17).
- **Medicine side effects**: high blood pressure, high blood sugar, weight gain, tremor, bone thinning, and more (Chapter 12).
- **Higher risk of some cancers**, especially skin cancer (Chapter 18).
- **Return of the original kidney disease** in the new kidney, which is possible with some conditions (Chapter 18).
- **The kidney may not last forever**. Many people need dialysis again or a second transplant one day (Chapter 26).

Myths and facts

Myth	Fact
"A transplant means I will be cured."	A transplant is a treatment, not a cure. It replaces kidney function but you need lifelong medicines and follow-up.
"I am too old for a transplant."	There is no fixed age cutoff. Many people in their 70s and beyond benefit. Overall health matters more than age.
"I should wait until I need dialysis."	Not necessarily. Transplant before dialysis (preemptive) often gives the best results.
"Living donors are at high risk."	Careful screening makes donation safe for most donors, though there is a small long-term increase in risk. See Chapter 7.
"Anti-rejection medicines are optional once I feel fine."	Never stop or change them on your own. Missing doses is one of the leading causes of graft loss.
"Transplant patients cannot live normal lives."	Many work, exercise, travel, raise families, and live for decades with a working kidney.
"I cannot get a transplant because I am on dialysis."	Most people who get transplants were on dialysis first. Being on dialysis does not disqualify you.

CHAPTER 3

Are You a Candidate?

Who benefits, who may need to wait, and what can be worked on

Almost everyone with kidney failure should **ask** about a transplant. The decision is not made by your dialysis clinic or by a single test: your transplant center weighs your overall health, your ability to manage medicines and follow-up, and your support system.

General goals of the evaluation

- You are **likely to be helped**: expected survival and quality of life are better with a transplant than without.
- You are **healthy enough for surgery and anti-rejection medicines** (heart, lungs, blood vessels, and other organs are assessed).
- You can **take your medicines and attend follow-up** reliably, with help if needed.
- You have **no condition that would make a transplant unsafe or unlikely to help** at this time.

Conditions that may delay or prevent transplant

Rules differ from center to center. Many of the items below are **reasons to wait and treat**, not permanent "no" answers.

Concern	Why it matters	What often happens
Active or recently treated cancer	Anti-rejection medicines can allow cancer to grow or return	Waiting period after cancer treatment, depending on cancer type and stage
Active serious infection	Immune suppression could make infection life-threatening	Treat the infection first, then proceed
Severe heart or lung disease	Surgery and anesthesia may be unsafe	Testing, treatment (stents, bypass, other), and re-evaluation
Obesity (BMI limits vary; many centers use 35 to 40)	Raises risks of wound problems, delayed graft function, and other complications	Weight-loss programs, dietitian support, sometimes bariatric surgery
Active substance use (alcohol, drugs, smoking, vaping)	Harms your health and your ability to follow the treatment plan; smoking raises heart and cancer risks	Treatment programs and a period of sustained abstinence
Unstable mental health	Can make self-care and medicines difficult	Treatment and support first; most people with mental health conditions can be transplanted when stable
Difficulty taking medicines or attending visits	Missed medicines are a major cause of graft loss	Social work, pharmacy, and caregiver planning
Lack of transportation, housing, or caregiver	Post-surgery care needs support	Social work helps build a plan

Conditions that were once barriers but often are not today

- **Hepatitis C:** effective cures now exist. Many centers accept both candidates and donor kidneys with hepatitis C.
- **HIV:** well-controlled HIV is not a barrier at many centers, and transplants have been done successfully.
- **Older age:** many centers transplant people well into their 70s and sometimes older.
- **Prior transplant:** second and third transplants are common.
- **Diabetes:** often successful. Some people with type 1 diabetes may qualify for a combined kidney-pancreas transplant.

If you are told "not a candidate"

If a center says no, ask **why** and **what could change the answer**. Ask for it in writing. Different centers have different criteria, so it is reasonable to seek a second opinion or apply to another center.

Preemptive transplant

A **preemptive** transplant happens before you ever start dialysis. Research shows that people who avoid dialysis or spend little time on it tend to have better graft and patient survival. You can be listed for a deceased-donor kidney once your eGFR is 20 or lower (or you have started dialysis), and a living-donor transplant can be done earlier. **Ask your kidney doctor for a referral as soon as your eGFR falls into the range of Stage 4**, and no later than when dialysis planning begins.

Do not wait to ask: speak up if

- You have kidney disease and your doctor has not talked to you about transplant
- Your eGFR is under 30 and you have not been referred to a transplant center
- You have been on dialysis for months without a transplant evaluation

PART 2

Getting Ready for Transplant

CHAPTER 4

The Transplant Evaluation

The tests, the visits, and what the team is looking for

The evaluation is a series of visits and tests, usually completed over a few weeks to a few months. Its goals are to make sure a transplant is safe and likely to help you, to find and treat problems before surgery, and to help you and your team plan. **Bring a family member or friend** to at least one visit; you will hear a lot of information.

Who you will meet

Team member	Role in your care
Transplant nephrologist	A kidney doctor who manages your medical readiness and long-term follow-up
Transplant surgeon	Explains the operation, donor options, and surgical risks
Transplant coordinator (nurse)	Your day-to-day contact: schedules tests, answers questions, explains the list
Social worker	Assesses support, transport, finances, and coping; connects you to resources
Dietitian	Reviews nutrition and weight goals before and after transplant
Pharmacist	Reviews all your medicines, allergies, and how you will manage the new ones
Financial coordinator	Verifies insurance and explains coverage for the operation and medicines
Psychologist or psychiatrist (if needed)	Supports mental health and coping

Common tests and why they are done

Test	Purpose
Blood type (ABO), checked twice	Match with donor blood type. Two separate samples prevent errors
HLA typing and antibody screening (PRA / cPRA)	Finds "tissue type" and antibodies that could attack a donor kidney. A higher cPRA can mean fewer compatible donors
Infectious disease screening	HIV, hepatitis B and C, CMV, EBV, syphilis, TB, and others. Some infections must be treated before or after transplant
Heart tests	EKG, echocardiogram, and stress testing or heart catheterization when risk is higher
Imaging	Chest X-ray, ultrasound or CT of the abdomen and pelvis to check blood vessels and organs
Cancer screening	Age-appropriate tests: colonoscopy, mammogram, Pap test, prostate discussion, skin exam, lung CT if high risk
Dental exam	Infected teeth are a risk once you take immune-lowering medicines
Routine blood work	Blood counts, liver tests, bone and mineral tests, blood sugar, cholesterol
Vaccine review	Catch up on vaccines before transplant, since some work best before immune suppression

The psychosocial evaluation

Transplant is a team effort that continues for life. The social worker and other staff will ask about your home, work, family, transportation, insurance, and how you handle stress. They are not judging you. They are looking for **gaps they can help fill**. Be honest about substance use, mental health, and money worries: the team can only help with what it knows.

Staying on track

- Keep a single folder or use Worksheet 6 to track every test and result
- Write questions down between visits
- If a test is delayed, call your coordinator: incomplete evaluations are a common reason for delayed listing
- Keep all your dialysis records, medicine lists, and old test results handy

What happens after the evaluation

A selection committee reviews your results. Possible outcomes: **approved and listed**; **approved for living donor transplant only**; **more testing or treatment needed** ("deferred"); or **not approved at this time**. In any case, you should receive a clear explanation and next steps.

CHAPTER 5

Choosing a Center, Insurance & Costs

Comparing programs and planning for the money side

You can choose your center

In the U.S. you may be evaluated at more than one transplant center and, in most cases, **listed at more than one**. This is called **multiple listing** and may shorten your wait, because each center may receive different offers. Insurance approval, travel, and being able to reach the center quickly all matter.

Questions to compare centers (see Worksheet 4)

- How many kidney transplants does the center do each year (deceased and living donor)?
- What are its one-year and five-year **graft survival** and **patient survival** compared with expected (see SRTR.org)?
- What is the typical wait for someone with my blood type and antibody level?
- How often does the center accept "hard-to-place" or higher-risk kidneys, and how do they decide?
- Do they offer living donor support, paired exchange participation, and desensitization?
- How far is it? Where would I stay after discharge? How quickly can I get there when called?
- What is the follow-up plan, and who do I call at night or on weekends?

Insurance and paying for transplant

Transplant involves several costs: the evaluation, the operation and hospital stay, the donor's care, anti-rejection medicines (the largest ongoing cost), and follow-up. The **financial coordinator** at your center will verify your benefits. Common coverage sources:

Source	What to know
Medicare (Parts A and B)	People with kidney failure may qualify for Medicare at any age. Medicare generally covers the transplant, and covers the donor's costs when the recipient is a Medicare recipient. Part B covers immunosuppressive drugs when Medicare covered the transplant.
Medicare ESRD coverage timeline	If you qualify only because of kidney failure, coverage generally ends 36 months after transplant unless you qualify another way (age, disability). There is an immunosuppressive drug benefit (Part B-ID) for some people who would otherwise lose coverage. Ask about current rules.
Medicaid	Varies by state. Many states cover transplant and medicines for eligible people.
Employer or private insurance	Check transplant benefit limits, networks (Centers of Excellence), pre-authorization, and prescription coverage. Ask about COBRA and how long coverage lasts if you cannot work.
Veterans benefits (VA), TRICARE	Transplants are covered for eligible veterans and families. Ask about approved centers.

Source	What to know
Nonprofit and manufacturer help	Assistance may help with travel, lodging, copays, and medicines. Social workers know which programs are active.

Plan for the long run

Losing coverage for anti-rejection medicines is a leading financial risk. Ask your social worker **early**: What happens to my insurance in 1, 3, and 5 years? What medicine assistance programs exist? Never stretch or skip doses because of cost. Call your transplant team first.

Costs that often surprise people

- Travel, gas, parking, and lodging near the center for weeks after surgery
- Lost income for you and your caregiver during recovery
- Copays and coinsurance for frequent lab tests and visits
- Medicines not covered by your plan, and premiums after coverage changes
- Home supplies: blood pressure cuff, thermometer, scale, pill organizer, sunscreen, and food safety tools

Use **Worksheet 5** to build a simple budget, and ask your center about fundraising support. TLHF and other nonprofits can help you think about safe and ethical ways to raise funds.

CHAPTER 6

The Waiting List and How Kidneys Are Matched

Getting listed, how offers work, and how to wait well

In the United States, deceased-donor organs are allocated through the **Organ Procurement and Transplantation Network (OPTN)**, which is run under federal oversight. Organs are offered by computer to compatible candidates based on national policy, not by wealth, fame, or personal connection.

Getting on the list

- Once approved, your center registers you with OPTN. Your **waiting time** is counted from the date you started regular dialysis *or* the date you were registered with an eGFR of 20 or lower, whichever is earlier.
- Adults with an eGFR of 20 or less can be listed. Living donor transplant can be done at any eGFR the team judges appropriate.
- Tell your center about every change: new insurance, phone number, health problems, infections, and hospitalizations. A candidate who cannot be reached, or is temporarily too ill, may be marked **inactive** (Status 7) and skip offers, though waiting time is generally kept.

How matching works (simplified)

When a kidney becomes available, the system creates a ranked list of candidates and offers it in order. Many factors influence rank:

- **Blood type compatibility.** Type O candidates often wait longest because O kidneys can go to anyone.
- **Antibody compatibility** (crossmatch, cPRA). Candidates with high cPRA receive extra priority points because compatible kidneys are rare for them.
- **Waiting time** (points for each year).
- **HLA matching.** A zero-mismatch kidney has additional priority.
- **Distance:** kidneys are offered locally first, then in widening circles around the donor hospital.
- **Priority groups:** children, prior living donors who need a kidney, and certain multi-organ candidates.
- **Longevity matching.** Kidneys expected to last longest (low KDPI) are directed toward candidates expected to live longest (low EPTS).

KDPI and EPTS

Two scores you may hear: **KDPI** (Kidney Donor Profile Index) describes the donor kidney on a scale of 0-100%. A lower number means longer expected function on average. **EPTS** (Estimated Post-Transplant Survival) estimates how long a candidate will need a kidney compared with others. Top-scoring EPTS candidates (lowest 20%) get first access to the lowest-KDPI kidneys.

While you wait: your responsibilities

- ☐ Keep your phone charged and on. Answer calls from unfamiliar numbers, and check voicemail often
- ☐ Give the center two or three backup contacts, and keep them updated (Worksheet 11)
- ☐ Keep your **go-bag** and transportation plan ready (Worksheet 9)
- ☐ Send blood samples on schedule: centers must test your blood regularly for antibodies
- ☐ Attend dialysis, take medicines, and keep other appointments
- ☐ Complete cancer screening, dental care, and vaccinations on time
- ☐ Report any illness, hospitalization, or medicine change to the coordinator quickly
- ☐ Maintain healthy weight, activity, and eating to stay transplant-ready

Waiting is hard

Waiting can be the hardest part. It is normal to feel anxious, impatient, guilty, or discouraged. Ask about support groups and talk to a counselor: you will be stronger for the day the call comes if you look after your mind as well as your body.

CHAPTER 7

Living Donor Kidney Transplant

For recipients, potential donors, and families

A living donor kidney is the best available option for many people. It often **lasts longer**, usually **starts working right away**, and can be **scheduled** before dialysis is needed. Roughly one in four U.S. kidney transplants uses a living donor.

Who can be a living donor?

Living donors are adults (usually 18 or older) in good physical and mental health who are donating freely, without pressure or payment. Donors may be family, friends, coworkers, neighbors, members of a faith community, or strangers who choose to give (**non-directed or altruistic donors**). **Selling organs is illegal**, and donors cannot be pressured or rewarded.

Reasons a person may not be able to donate

- Uncontrolled high blood pressure or diabetes; existing kidney disease or significant kidney stones
- Active cancer, HIV (rules differ), or active serious infection
- Significant heart, lung, or other chronic disease; severe obesity
- Untreated mental illness, or feeling pressured to donate
- Use of certain illegal drugs, or unsafe home situation for recovery

The donor evaluation

Donors are evaluated by a **separate team** from the recipient's team so that the donor's interests are protected. This team includes an **independent living donor advocate**. It includes blood and urine tests, imaging of the kidneys and their blood vessels, screening for infections and cancers, a psychosocial evaluation, and a discussion of risks. A donor may say "no" at any point, and the team will protect the donor's privacy about the reason.

Surgery and recovery for the donor

- Most donor kidneys are removed with **laparoscopic or robot-assisted surgery** through small incisions and one slightly larger incision for removal.
- Hospital stay is usually 1 to 3 days. Many donors return to desk work in 2 to 4 weeks and heavier activity in about 6 to 8 weeks.
- The remaining kidney enlarges over time and compensates for much of the lost function. Donors usually have about 60 to 75% of prior kidney function afterward.

Donor risks, honestly

- **Surgical risks:** pain, bleeding, infection, hernia, blood clots, bowel problems, and rarely, death (roughly 1 in 3,000 or less).

- **Long-term:** living donors have a small absolute increase in the risk of kidney failure and of high blood pressure compared with well-matched non-donors. Lifelong yearly checkups are recommended.
- **Priority:** living donors who later need a kidney receive extra allocation priority.
- **Emotional:** relief and pride are common, but so are fatigue, mood changes, and worry if the graft has problems. Donor support groups help.

Money and work for donors

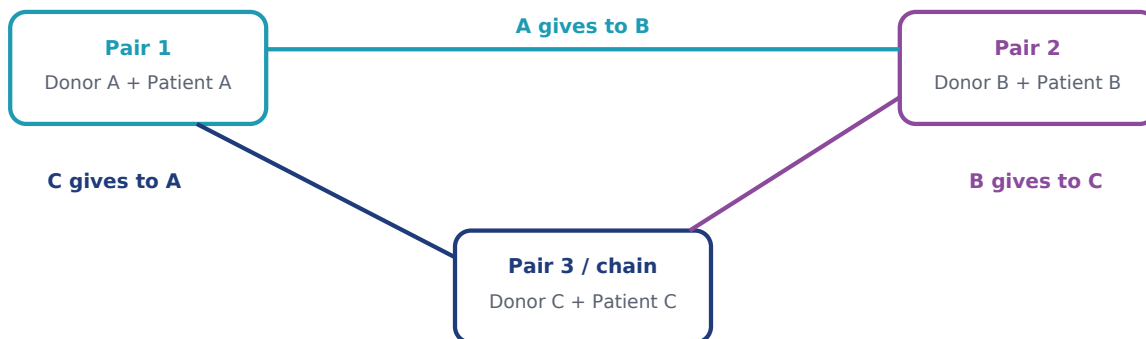
The **National Living Donor Assistance Center (NLDAC)** can reimburse eligible donors for travel, lodging, and meals connected with donation. The recipient's insurance pays for the donor's evaluation and surgery. Federal FMLA may protect donor jobs; a few states offer paid leave or other protections. Ask the donor's social worker.

If your donor is not a match

Being incompatible does not have to end the story. Options include:

- **Paired (or chain) kidney exchange.** Your donor gives to someone else and you receive a compatible kidney from another donor. Programs such as the National Kidney Registry and center-run exchanges make hundreds of transplants possible each year.
- **Voucher or advanced donation programs,** where a donor gives now and their loved one receives priority later.
- **ABO-incompatible transplant** with special treatment before and after surgery to remove or prevent antibodies.
- **HLA-incompatible transplant (desensitization)** for highly sensitized patients at centers that offer it.

PAIRED KIDNEY EXCHANGE (EXAMPLE): each donor is not a match for their own loved one, but is for someone else



How to talk about living donation

Many patients feel uncomfortable asking. Try to **share your story** rather than **ask directly**. For example: "I need a new kidney and I am learning about living donors. If you are curious, I can share what I have learned." Give people time, give them the center's living-donor phone number, and keep the decision **their own**. Use **Worksheet 7** to prepare your talking points and keep track of who has contacted the donor team.

Stay safe

Never accept or offer money for a kidney. Be careful of online offers or solicitations from strangers who want payment: organ trafficking is illegal and dangerous. All legitimate donations go through a transplant center.

CHAPTER 8

Deceased Donor Kidneys

Understanding offers, risk profiles, and hard decisions

Deceased donor kidneys come from people who have died, usually after a brain injury or heart stopping, and whose families or own registrations gave permission. Every donation is a profound gift, and your team will use it with respect and care.

Types of deceased donors

Type	What it means
Donation after brain death (DBD)	The donor has died by neurological criteria; the heart is still beating on a ventilator until organs are recovered
Donation after circulatory death (DCD)	Organs are recovered after the heart stops. DCD kidneys are more likely to have delayed function but generally do well in the long term
Standard-criteria and expanded-criteria donors	Historically used to describe donors by age and health; KDPI is now used to describe risk on a continuous scale

Getting the offer

When an offer arrives, your coordinator or surgeon will tell you about the donor (age, cause of death, kidney quality, and any infections or risk factors). You will be asked whether to accept. Because time is limited (kidneys can be preserved for many hours but function is best when transplanted promptly), **decisions must be made quickly**. It is best to discuss your preferences **before** the call.

Decisions to think about ahead of time

Kidney type	What to consider
High KDPI (e.g., over 85%)	Shorter average life than low-KDPI kidneys, but may allow you to be transplanted sooner. For older candidates or those with long waits, the trade-off can favor accepting
DCD kidneys	Higher chance of temporary dialysis after surgery; long-term outcomes are usually similar to brain-dead donor kidneys
Hepatitis C-positive donor	Modern antiviral drugs cure hepatitis C in the recipient in most cases. Accepting may shorten waiting time. Requires consent and treatment plan
"Increased infectious risk" donors (PHS increased-risk)	Behavior history suggests slightly higher chance of a very recent infection not yet detected by tests. Actual risk of transmission is very low, and recipients are tested after transplant
Donors with small cancers or other conditions	Rare situations; team will explain risks and monitoring

Saying no to an offer

You can discuss your **acceptance preferences** when you are listed. Saying "no" to an offer usually does **not** cost you your place on the list. Ask your center what happens after a declined offer.

While the surgery is being planned

- Your team will do a final **crossmatch** test (mixing your blood with donor cells) to check for antibodies.
- You may need a short dialysis session before surgery.
- You may be asked to stop eating and drinking right away.
- Sometimes the offer is turned down after your arrival (a "dry run"), because the kidney turns out to be unsuitable or a crossmatch fails. This is disappointing but common. Your place on the list remains.

CHAPTER 9

Preparing Your Body, Mind, and Home

Getting stronger while you wait

Physical preparation

Area	What to do
Movement	Walk daily if approved. Even 10 minutes helps. Ask about physical therapy or a "prehab" program. Stronger patients recover faster
Weight	Work with the dietitian toward the center's weight range. Avoid crash diets and supplements
Nutrition	Follow dialysis diet guidance. Eat enough protein if you are on dialysis. Practice food safety habits now
Blood pressure and sugar	Keep both as controlled as possible. Uncontrolled diabetes raises surgery and infection risk
Tobacco, vaping, alcohol, cannabis, other substances	Stop tobacco and vaping: they raise the risk of heart problems, wound problems, and cancer. Ask the team about alcohol and cannabis
Dental and skin	Complete dental work. Get a baseline skin exam. Begin daily sunscreen habits
Vaccines	Update flu, COVID-19, pneumococcal, hepatitis B, Tdap, shingles (recombinant), and others while immune function is stronger. Live vaccines cannot be given after transplant

Mental and emotional preparation

- Talk openly with a counselor or peer mentor. Your center may connect you with someone who has been through it.
- Plan for uncertainty: the call may come at 3 a.m., or not for years. Both are normal.
- Let go of "what if it fails." Focus on what you can control: preparation and follow-up.
- Ask your caregiver how they are doing. Caregiver strain is real (see Chapter 24).

Prepare your home

- ☐ Home is clean, with an easy-to-clean bathroom and kitchen. Clean out expired food and moldy areas
- ☐ Set aside a spot for medicines, pill organizer, and supplies
- ☐ Buy a digital thermometer, blood pressure monitor, and a scale
- ☐ Stock hand sanitizer, sunscreen, unscented soap, and a soft toothbrush
- ☐ Prepare a "recovery corner": a comfortable chair or bed on the main floor if stairs are hard
- ☐ Freeze simple, safe meals for the first weeks
- ☐ Arrange rides for appointments, and pet care for the hospital stay (someone else cleans litter boxes and bird cages)
- ☐ Talk with your workplace or school about leave and paperwork (FMLA, short-term disability)

Pack the go-bag

Keep a packed bag near the door. **Worksheet 9** gives a full checklist. Essentials: photo ID, insurance cards, medication list, phone charger, loose comfortable clothes, slip-on shoes, glasses, toiletries, and a notebook. Leave valuables at home.

Practice the plan

Prepare your family too. Explain what the phone call means, who will drive, who will take time off, and what to do if you are already at dialysis. Rehearse the plan once: it makes the real day calmer.

PART 3

Surgery and Hospital Stay

CHAPTER 10

The Call and the Operation

What happens from the phone call to the recovery room

When the call comes

Your coordinator will tell you a kidney may be available. Stay calm and follow instructions. Typical steps:

- 1 **Stop eating and drinking** immediately unless told otherwise.
- 2 **Do not take extra doses** of medicines. Ask which of your medicines to skip.
- 3 Bring your **go-bag** and medication list. Arrange a driver: you should not drive yourself.
- 4 Notify family and your caregiver. Notify dialysis if scheduled.
- 5 Go to the hospital exactly where and when instructed. Traffic and weather can delay you, so call if problems arise.

At the hospital you will have blood drawn (including the final crossmatch), an EKG, chest X-ray, and an exam. You may have dialysis first if labs show high potassium or fluid overload. You will sign consent forms and meet the anesthesia team. Ask questions. If any test shows a problem, the operation may be postponed or the offer declined (a "dry run").

The operation

- **Anesthesia:** general anesthesia; you will be asleep. A breathing tube is used and removed at the end, often in the operating room.
- **Length:** about 2 to 4 hours, longer for complex cases. Families wait in a designated area and receive updates.
- **Incision:** a curved cut in the lower abdomen on one side. Robotic-assisted approaches are available at some centers.
- **Placement:** the donor kidney is placed outside the muscle wall in the lower belly (see the diagram in Chapter 2).
- **Connections:** the donor artery and vein are sewn to your large pelvic vessels; the donor ureter is joined to your bladder, often over a small temporary **stent** that is removed weeks later.
- **Your own kidneys** usually stay in place unless they are infected, extremely large (as in some cases of PKD), or causing uncontrolled blood pressure or bleeding.
- **Tubes and lines** you may wake up with: a urinary catheter, IV lines, sometimes a surgical drain near the kidney, and a pain control pump or nerve block.

Right after surgery

You will wake in a recovery area or intensive care unit. A urine bag may show urine already (common with living donor kidneys) or very little (common with deceased donor kidneys). Nurses will check blood pressure, fluids, urine output, and pain often. **Your new kidney may be sleepy for a few days.**

Slow start (DGF)

Delayed graft function (DGF) means the new kidney is slow to start and you need dialysis in the first week. It affects roughly 1 in 4 to 1 in 5 deceased-donor transplants and less than 1 in 10 living-donor transplants. Most kidneys with DGF recover function, although rejection and other problems must be excluded with tests and sometimes a biopsy. It may make hospital stay longer, but it is **not** a sign that the kidney will fail.

Possible surgical complications

Complication	What it is	Warning signs
Bleeding or hematoma	Blood collects near the new kidney	Falling blood counts, swelling, pain
Blood clot in artery or vein	Rare but serious clot that stops blood flow to the kidney	Sudden drop in urine, pain; needs emergency care
Urine leak	Leak from the connection to the bladder	Swelling, fluid from wound, pain, rising creatinine
Ureter narrowing	Scarring narrows the drainage tube, causing back-up of urine	Rising creatinine, swelling of the kidney on ultrasound
Lymphocele	Fluid pocket near the kidney	Swelling, leg swelling, pain, rising creatinine
Wound infection or hernia	Skin or deep infection; weak spot in abdominal wall	Redness, drainage, fever; new bulge
Blood clots in legs or lungs	Related to surgery and reduced movement	Leg swelling or pain; chest pain or breathlessness (emergency)

Keep it in perspective

Serious complications are uncommon. Most people go through surgery smoothly. The team watches closely so problems are found early.

CHAPTER 11

Your Hospital Stay

Days 1 through discharge

Most people stay in the hospital about **3 to 7 days** after a kidney transplant. Delayed graft function, complications, or medical problems can lengthen the stay.

Day by day (typical)

Time	What usually happens
Day 0 (surgery)	Recovery unit. Frequent checks. IV fluids. Pain control. Anti-rejection medicines begin (induction medicine, plus others)
Day 1	Blood tests, ultrasound to check blood flow. You sit in a chair and take short walks with help. Diet is advanced
Days 2-3	Walking more. Bowel function returns. Teaching begins: your new medicines, blood pressure, temperature, and daily weight
Days 3-5	The urinary catheter (and sometimes a drain) is removed. Pharmacy teaches the medicine plan. You meet the dietitian again
Discharge	Creatinine is trending down, you can eat, walk, and take pills, and you have your medicine supply and follow-up schedule

What helps recovery

- **Move early and often.** Walking prevents clots, pneumonia, and constipation.
- **Use your incentive spirometer** (breathing device) 10 times per hour while awake.
- **Ask for pain relief before pain gets bad.** You will not be given anti-inflammatory pain pills (NSAIDs) such as ibuprofen: these can harm the kidney.
- **Support your incision** with a pillow when you cough, sneeze, or stand.
- **Drink fluids as directed** and track them. Fluid needs after transplant differ from dialysis rules.
- **Learn your medicines** in the hospital: names, doses, timing, side effects. Ask the pharmacist to go over them until you feel confident.

What the team is watching

Measure	Why it matters
Urine amount and color	Shows how the new kidney is working. Some blood is normal early
Creatinine and potassium	Show kidney function and safety of medicines
Blood pressure	High pressure strains the new kidney. Low pressure can reduce its blood flow
Tacrolimus (or other drug) level	Ensures the dose is high enough to prevent rejection and low enough to avoid toxicity
Temperature and wound	Detect infection early
Blood sugar	Steroids and tacrolimus can raise it, even in people without diabetes

Preparing to go home

- ☐ You know all medicines: name, dose, time, purpose, and what to avoid
- ☐ You have at least a 2-week supply and a plan for refills (know who to call)
- ☐ You know your lab and clinic schedule for the first weeks
- ☐ You have a thermometer, blood pressure cuff, and scale, and know how to use them
- ☐ You know the warning signs and whom to call, day or night (Worksheet 17)
- ☐ You know activity limits: no heavy lifting, no driving while on opioid pain medicine
- ☐ Your caregiver has been trained and knows how to reach the team
- ☐ You have a plan for a place to stay near the center if required

PART 4

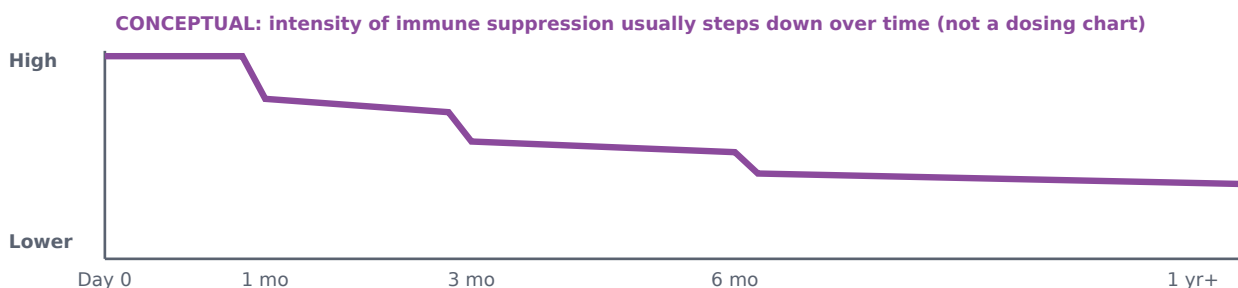
Your Medicines

CHAPTER 12

Anti-Rejection Medicines

Immunosuppression: what it is, what you take, and why it matters

Your immune system is designed to attack anything that is not "you." Without medicines to calm it, your body would recognize the new kidney as foreign and destroy it. **Immunosuppressants** (anti-rejection or transplant medicines) tone down that response. You will take them **every day for as long as you have the kidney.**



Induction, maintenance, and rescue

- **Induction:** a strong, short course of medicine around the time of surgery to prevent early rejection. Examples: basiliximab, anti-thymocyte globulin (thymoglobulin), alemtuzumab.
- **Maintenance:** the medicines you take for life. Most people take a combination of two or three.
- **Rescue:** stronger treatments used when rejection is found (Chapter 16).

Extended-release and generics

Different brands and generic versions of tacrolimus can behave slightly differently in your body. Your pharmacy should **not** change your product without telling you and your team. Check the pill appearance and label at every refill. If anything looks different, ask before taking.

Common maintenance medicines

Medicine (examples)	How it works	Common side effects and cautions
Tacrolimus (Prograf, Envarsus XR, Astagraf XL, generics)	Calcineurin inhibitor. The cornerstone of most regimens. Blood levels are monitored	Tremor, headache, high blood sugar, high potassium, low magnesium, high blood pressure, kidney toxicity at high levels, hair thinning. Many drug and food interactions. Do not switch brands without team approval
Mycophenolate (CellCept, Myfortic)	Slows the growth of immune cells	Nausea, diarrhea, low white cell counts. Can cause birth defects and pregnancy loss; contraception and planning are essential
Prednisone (steroid)	Broad anti-inflammatory and immune-calming effect	Weight gain, mood changes, sleep problems, high blood sugar, bone thinning, acne, thin skin, cataracts. Often reduced or stopped at some centers
Cyclosporine (Neoral, Gengraf)	Calcineurin inhibitor, used when tacrolimus is not suitable	High blood pressure, gum overgrowth, hair growth, high cholesterol, kidney toxicity
Azathioprine (Imuran)	Older antiproliferative drug; sometimes used in pregnancy or when mycophenolate is not tolerated	Low blood counts, liver effects, nausea. Interacts with allopurinol
Sirolimus (Rapamune) and everolimus (Zortress)	mTOR inhibitors. Sometimes used to lower calcineurin inhibitor exposure or with skin cancer history	Mouth sores, swelling, high cholesterol, slow wound healing, protein in urine
Belatacept (Nulojix)	Given by infusion, usually monthly. Blocks a co-stimulation signal in immune cells	Higher early rejection risk; risk of post-transplant lymphoproliferative disorder, especially if not previously exposed to EBV; not used in EBV-negative recipients

Rules for every transplant medicine

- **Never** skip, stop, double, or change doses on your own, even if you feel great, have side effects, or cannot afford them. Call the team first.
- Take your medicines at the **same times each day** and in the same relationship to food. Twice-daily medicines are taken about 12 hours apart.
- If you vomit soon after a dose, or have severe diarrhea, call your team. You may need a repeat dose or a blood level.
- If you miss a dose, follow your team's written instructions. Do not double the next dose unless instructed.

Blood level monitoring (tacrolimus example)

The **trough level** is your blood level just before the next dose. Draw labs **before** taking your morning tacrolimus, and bring the dose with you to take after the blood draw. Target ranges are individual: usually higher in the first months (for example, around 8 to 12 ng/mL) and lower later (for example, around 4 to 8 ng/mL). **Use your own center's goals.** Too low can lead to rejection; too high can cause kidney damage, tremor, and other side effects. Both can be silent, which is why labs matter.

CHAPTER 13

Other Medicines, Interactions & Supplements

Protecting your kidney and your levels

Other medicines you may take after transplant

Medicine type	Purpose	Typical duration
Valganciclovir (or letermovir in some cases)	Prevents cytomegalovirus (CMV) infection	About 3 to 6 months, depending on donor and recipient CMV status
Trimethoprim-sulfamethoxazole (Bactrim, Septra)	Prevents Pneumocystis pneumonia, some urinary and other infections	Often 6 to 12 months or longer
Nystatin or clotrimazole	Prevents thrush (yeast) in the mouth	First weeks to months
Blood pressure medicines	Protect the kidney and heart	Long term
Statins or other cholesterol medicines	Lower heart disease risk; may need dose adjustments with some transplant medicines	Long term
Insulin or other diabetes medicines	Manage steroid- or tacrolimus-related high blood sugar	Varies
Stomach acid protection	Protects the stomach early after surgery and while on steroids	Weeks to months
Aspirin or blood thinners	Only if specifically prescribed by your team	Varies
Vitamin D, calcium, or other bone medicines	Protect bone health	Varies

Drugs and substances that change tacrolimus, cyclosporine, or sirolimus levels

Many medicines and foods speed up or slow down the liver enzyme system that breaks down these drugs. **Always tell every doctor, dentist, and pharmacist that you are a transplant recipient, and check with your transplant team or pharmacist before starting or stopping anything.**

Effect	Examples (not a complete list)
Raise levels (risk of toxicity)	Azole antifungals (fluconazole, voriconazole, ketoconazole), macrolide antibiotics (clarithromycin, erythromycin), diltiazem, verapamil, protease inhibitors, grapefruit, pomelo, Seville (bitter) oranges
Lower levels (risk of rejection)	Rifampin, phenytoin, carbamazepine, phenobarbital, St. John's wort
Harm the kidney directly	NSAIDs (ibuprofen/Advil/Motrin, naproxen/Aleve, high-dose aspirin, diclofenac, celecoxib), some antibiotics, contrast dye, some herbal products

Effect	Examples (not a complete list)
Raise potassium	ACE inhibitors, ARBs, potassium supplements and salt substitutes, trimethoprim, spironolactone

Never do these without asking

- Avoid **NSAIDs** unless your transplant team specifically approves. Use acetaminophen (Tylenol) within the daily maximum your team advises.
- Avoid **herbal and dietary supplements** unless cleared: many are not tested for safety or drug interactions, and some (such as St. John's wort, echinacea, and high-dose "immune boosters") can harm you.
- Avoid **grapefruit, pomelo, and Seville oranges** when you take tacrolimus, cyclosporine, or sirolimus.
- Tell your team about **every** new prescription, including antibiotics for even a simple infection. Ask if levels should be checked.

Over-the-counter medicine guide

Symptom	Usually reasonable (check with your team first)	Avoid unless approved
Pain or fever	Acetaminophen (Tylenol) at approved doses	Ibuprofen, naproxen, aspirin at pain doses
Cold and allergy	Saline spray, some antihistamines (loratadine, cetirizine)	Decongestants with pseudoephedrine (may raise blood pressure), herbal remedies
Heartburn	Ask pharmacist which product; some antacids can affect mycophenolate absorption if taken together	High-dose antacids without advice
Constipation or diarrhea	Ask team first; diarrhea can change medicine levels and needs a call	Magnesium or aluminum laxatives without advice
Sleep	Ask your team or pharmacist	Herbal sleep aids (valerian, kava)

CHAPTER 14

Taking Your Medicines Every Day

Adherence: the most important thing you control

Missing anti-rejection medicines is one of the most common and most preventable causes of graft loss. It is not about willpower or being "good" or "bad": it is about building systems that make taking medicines almost automatic and about asking for help early when something makes it hard.

Every dose	12 hrs	Same time	Call first
matters: rejection can happen even after a few missed days	apart for twice-daily doses	each day, with or without food, the same way every time	before stopping or changing anything

Why people miss doses (and solutions)

Barrier	Solutions
Forgetting	Phone alarms, pill organizer with days and times, link doses to daily habits (brushing teeth), medication reminder apps
Side effects	Call your team. Dose timing, formulation, or medicine changes can help. Do not stop on your own
Cost or insurance problems	Call your social worker, pharmacy, and transplant team at the first sign of trouble. Assistance programs exist
Feeling well ("I do not need it")	Feeling well is the medicines working. Levels and labs show the true picture
Confusion about changes	Keep one up-to-date list (Worksheet 13). Ask the pharmacist to review it at every visit
Depression, anxiety, or fatigue	Tell your team. Mental health treatment improves both wellbeing and adherence
Travel and disruptions	Pack extra medicine in carry-on luggage. Keep a written list. Keep home-time routines in a new time zone as instructed
Refill gaps	Set refills to auto-renew; reorder when 7 to 10 days remain; use one pharmacy that knows transplants

Build your system

- One list.** Keep a current list of every medicine, dose, and time (Worksheets 13 and 14). Carry a copy in your wallet or phone.
- One organizer.** Fill a weekly pill box on the same day each week.
- Two reminders.** A phone alarm plus a visual cue (pill box next to your toothbrush or coffee maker).

- 4 One backup person.** Ask a family member to check in, especially in the first year.
- 5 One pharmacy.** Use the same pharmacy so interactions can be checked.
- 6 One habit for problems.** When something goes wrong, call the transplant team the same day.

Call the transplant team the same day if

- You missed one or more doses of anti-rejection medicine
- You ran out, or you are about to run out of any transplant medicine
- You vomited within 30 to 60 minutes of a dose, or have severe diarrhea
- You are having side effects that make you want to skip medicines
- You cannot afford your medicines or your insurance changed

No judgment

Everyone misses a dose sometimes. The most important step is honesty and a fast phone call, not shame. Your team would much rather hear it early.

PART 5

Recovery and Monitoring

CHAPTER 15

The First Three Months at Home

Your recovery roadmap

The first three months are the highest-risk and highest-attention period. Expect **frequent lab draws and clinic visits**, medicine changes, and a lot of learning. By three months, most people are stable, more energetic, and settling into routine.

TYPICAL FOLLOW-UP SCHEDULE (varies by center)



Daily home routine

Task	How and when
Weigh yourself	Every morning after using the bathroom, before eating, same scale and clothing. Write it down
Check blood pressure	Once or twice daily at the same times, seated and rested for 5 minutes
Take temperature	Daily, and any time you feel unwell, chilled, or flushed
Check urine	Note amount and color. Ask what amount is normal for you
Blood sugar (if advised)	As instructed, particularly while on steroids
Look at your incision	Redness, warmth, swelling, drainage, or opening the edges
Take medicines	At scheduled times; log them (Worksheets 14 and 15)
Walk and drink fluids	Walk several times a day. Drink as advised (often more than on dialysis, but ask)

Activity and wound care

- **No lifting** more than about 10 pounds (a gallon of milk weighs 8) for about 6 to 8 weeks, or as advised.
- **Avoid** straining, contact sports, and pressure on the kidney site (for example, seat belts should be worn with a folded towel or pad over the area if it bothers you) for the first months.
- **Shower** as instructed; keep the incision clean and dry; no baths, hot tubs, lakes, or pools until approved.

- **Driving:** usually okay after 2 to 4 weeks, when off narcotic pain medicine and able to brake quickly and turn without pain.
- **Sex:** usually safe when comfortable, often after 4 to 6 weeks; ask your team. Use protection as advised (Chapter 23).
- **Walking** is the best exercise early. Increase gradually. Ask about cardiac rehab or physical therapy.

Call your transplant team right away for

- Temperature 100.4°F (38°C) or higher, or shaking chills
- Much less urine than usual, or none
- Pain, tenderness, or swelling over the new kidney
- Sudden weight gain (2 to 3 pounds in a day or 5 in a week) or new swelling
- Redness, warmth, pus, or opening of the incision
- Vomiting or diarrhea that stops you taking medicines
- Blood pressure or blood sugar far outside your ranges
- Any new symptom that worries you: trust your instincts

CHAPTER 16

Rejection

Understanding, detecting, and treating it

Rejection happens when your immune system recognizes the new kidney as foreign and attacks it. It is common enough that every recipient should know about it, but it is **usually treatable**, especially when caught early. It does not mean you did something wrong.

Types of rejection

Type	What happens	Typical treatment
T-cell mediated (cellular)	Immune T cells attack the kidney tissue	High-dose steroids; if severe, anti-thymocyte globulin; adjust maintenance drugs
Antibody-mediated (humoral)	Antibodies attack the kidney's blood vessels. Can be harder to treat, especially if it develops later	Plasma exchange (plasmapheresis), IVIG, rituximab or other targeted drugs, plus steroids and optimized maintenance
Acute	Happens over days to weeks, most often in the first year	Depends on type and severity
Chronic	Slow, silent scarring over months to years from long-term immune injury and other stress	Focus on preventing further injury: optimize medicines, control blood pressure, treat other causes

Symptoms (and why you often will not feel any)

Most rejection has **no symptoms**. It is usually found on routine blood tests when creatinine rises. When symptoms do occur they may include: fever, flu-like feeling, less urine, swelling, weight gain, new high blood pressure, and tenderness over the kidney. **Do not wait for symptoms:** keep every lab appointment.

How rejection is diagnosed

- **Rising creatinine** or falling eGFR, sometimes with protein in the urine.
- **Ultrasound** to exclude blockage, fluid collections, or blood flow problems.
- **Drug levels** to check whether immunosuppression is too low or too high.
- **Donor-specific antibody (DSA)** testing to look for antibodies against the donor.
- **Donor-derived cell-free DNA (dd-cfDNA)** blood tests at some centers, which can suggest injury to the graft.
- **Kidney biopsy**, the definitive test. A thin needle takes small tissue samples under ultrasound guidance. You go home the same day or after brief observation. Pathologists grade findings using the **Banff classification**.

Other causes of a rising creatinine

Not every rise means rejection. Dehydration, infection, blockage, medicine toxicity (for example, high tacrolimus level), BK virus, and returning original disease can all look similar. Your team works through the possibilities, which is why **a call and a repeat blood test are always the right first step.**

Reducing the risk of rejection

- ☐ Take every dose on time, every day
- ☐ Keep every lab appointment, and take the morning dose after the blood draw when directed
- ☐ Avoid interacting medicines and supplements (Chapter 13)
- ☐ Tell your team about vomiting, diarrhea, or illnesses that can change drug levels
- ☐ Never change brands or doses without approval
- ☐ Call promptly when your creatinine or symptoms change

Hope

Many people experience a rejection episode and go on to have long, healthy years with their kidney. Rejection that is treated early has the best chance of full recovery.

CHAPTER 17

Infections and Vaccines

Staying protected while your immune system is lowered

Because transplant medicines calm your immune system, infections are more likely and can be more serious. The risk is greatest in the **first 6 months** when doses are highest, but it never goes away completely. Prevention, early detection, and quick treatment keep most infections mild.

Key infections to know

Infection	Notes
CMV (cytomegalovirus)	A common virus. Risk depends on donor and recipient status; prevented with valganciclovir or monitored with blood tests. Symptoms: fever, fatigue, diarrhea, low blood counts
BK virus	Can injure the kidney graft. There are no symptoms; found by blood (and sometimes urine) PCR tests. Treatment is usually to lower immunosuppression
Urinary tract infection (UTI)	Common, especially in the first year. Symptoms: burning, urgency, cloudy urine, fever, back or graft pain
Pneumonia and respiratory viruses	Flu, COVID-19, RSV, and others can be more severe. Early testing and treatment matter
Shingles (herpes zoster)	Painful blistering rash; risk rises with immune suppression. Vaccine (recombinant) is recommended
Hepatitis B, C; HIV	Screened before transplant and monitored as needed
Fungal and opportunistic infections	Prevented by medicines early; rare later. Report any cough, fever, or shortness of breath
Food-borne infections	Listeria, salmonella, and others. See food safety (Chapter 20)

Everyday prevention

- **Hand washing** often: before eating, after bathroom, after touching pets, after being in public places.
- In the first months, wear a **mask** in crowded indoor places and avoid sick contacts, construction sites, and gardening or dusty work unless cleared.
- **Do not clean litter boxes, bird cages, or fish tanks.** Ask someone else, or use gloves and mask if you must.
- **Safe sex** practices; talk to your team about sexually transmitted infection screening.
- **Dental hygiene:** brush and floss gently; see your dentist every 6 months. Ask your team about antibiotics before dental procedures.
- **Insect bites:** use repellent; avoid areas with high disease risk when possible.
- **Wound care:** clean minor cuts promptly; call for any sign of infection.

Vaccines after transplant

Vaccine	Notes
Inactivated influenza (flu shot), yearly	Recommended. High-dose or adjuvanted forms may be preferred. Not the nasal spray
COVID-19	Recommended. Ask about current schedule and extra doses
Pneumococcal	Recommended series
Tdap / Td	Recommended every 10 years, and in each pregnancy
Recombinant zoster (Shingrix)	Recommended for adults on immunosuppression; the live shingles vaccine is not given
Hepatitis B, HPV, meningococcal, RSV	Recommended when indicated; ask your team
Live vaccines (avoid)	MMR, varicella (chickenpox), live intranasal flu, yellow fever, oral typhoid, and others are not given after transplant unless your team says otherwise. Household members can usually receive most vaccines; ask about specifics

Timing matters

Vaccines may work less well during the first months after transplant. That is why vaccination **before** transplant is so valuable. Ask when your center allows each vaccine after surgery (often after 1 to 3 months, depending on medicines).

CHAPTER 18

Long-Term Health After Transplant

Protecting the whole body, not only the kidney

A well-functioning kidney is a great start, but the medicines and the years of kidney disease can affect other parts of your health. The leading causes of death in people with working transplants are **heart disease and cancer**, so preventive care is part of protecting your kidney.

Common long-term issues

Issue	What to know	What helps
High blood pressure	Very common, worsened by tacrolimus, cyclosporine, and steroids; damages the graft and heart	Home monitoring; low-sodium eating; exercise; medicines as prescribed
High cholesterol	Related to medicines and diet. Adds to heart disease risk	Diet; statin if needed
Post-transplant diabetes	Steroids, tacrolimus, and weight gain can cause new diabetes. It can be managed, and sometimes reversed if caught early	Screening; lower steroid dose; weight and activity; medicines or insulin
Weight gain	Better appetite plus steroids often causes 10 to 20 or more pounds. Excess weight harms the kidney and the heart	Dietitian; activity; portion awareness
Bone disease	Pre-existing kidney bone disease plus steroids raises fracture risk	Bone density scans; calcium and vitamin D as directed; weight-bearing exercise
Anemia	Common early on; can result from medicines, infection, or graft function	Check labs; treat cause
Gout	High uric acid is common with cyclosporine and tacrolimus	Ask before using colchicine or allopurinol (interactions)
High potassium, low magnesium	Tacrolimus side effects	Lab checks; diet; supplements only as directed
Hair, skin, tremor, teeth	Cosmetic side effects can be distressing	Talk to your team: doses and drugs can be adjusted

Cancer risk and screening

Transplant recipients have a higher risk of certain cancers because the immune system is less able to find and destroy abnormal cells, and because some cancer-related viruses are more active.

- **Skin cancer** is the most common: squamous cell carcinoma is far more frequent than in the general population. **Use broad-spectrum sunscreen SPF 30+ every day, wear hats and long sleeves, avoid tanning beds, and see a dermatologist at least yearly.** Check your skin monthly.

- **Post-transplant lymphoproliferative disorder (PTLD):** abnormal growth of lymphoid cells, often associated with EBV; watch for fever, swollen glands, weight loss, night sweats, and persistent fatigue.
- **Other cancers:** lip, cervical, anal, colorectal, breast, prostate, lung, and kidney (native) cancers need **age-appropriate screening**. Ask your team for a schedule.

Recurrence of the original disease

Some kidney diseases can return in the transplanted kidney. Risk depends on the cause: for example, IgA nephropathy and FSGS can recur, and some rare conditions (such as atypical HUS and primary hyperoxaluria) require special planning before transplant. Ask your team about the recurrence risk for **your** disease and what monitoring (such as urine protein checks) is planned.

Keep a plan

Ask for a written **long-term care plan** at your one-year visit. It should include blood pressure and cholesterol goals, cancer screening dates, vaccine schedule, bone health plan, and which doctor manages what. Use **Worksheet 20** to keep track.

CHAPTER 19

Labs, Numbers, and Monitoring

Learning to read your own results

Blood and urine tests are your early warning system. Learn your baseline numbers, and ask for a copy after every visit. Small changes in the **direction** of your numbers often matter more than one single value.

Test	What it shows	What to know
Creatinine	A waste product filtered by kidneys; rises when function falls	Your new "normal" is your own. A rise of 20-25% or more from baseline is worth a call
eGFR	Estimated filtering rate calculated from creatinine, age, and sex	Higher is better. Values vary by donor, age, and other factors
BUN (urea nitrogen)	Waste from protein; rises with dehydration or high protein intake	Interpreted along with creatinine
Potassium	Key mineral for heart rhythm	May run high from tacrolimus; low if using diuretics
Magnesium, phosphorus, calcium	Minerals for bones, nerves, and muscles	Often low after transplant; supplements only as directed
Tacrolimus (or other drug) level	Shows drug exposure	Draw before the morning dose and take medicine after
CBC (blood counts)	White cells, red cells, platelets	Low white cells: possible medicine effect or infection; low hemoglobin: anemia
Glucose and A1c	Blood sugar control	Screen for post-transplant diabetes
Urine protein (UPCR, ACR)	Leaked protein signals kidney stress	Protein rising over time needs evaluation
BK virus and CMV PCR	Virus in blood	Regular screening early on
Donor-specific antibodies; dd-cfDNA	Immune and injury markers	Used at some centers on a schedule or when creatinine rises

Tips for the lab

- Arrive on time, and follow fasting instructions if given.
- For drug levels: **hold your morning dose** until after the blood draw (trough level), unless told otherwise, and note the time of your last dose.
- Keep a log (Worksheet 16) and note reasons for changes (illness, medicine change, missed dose).
- Ask for an app or patient portal login so you can see results quickly.

Be your own best advocate

Knowing your own numbers makes you an active member of your transplant team. Bring your log to appointments and ask, "What is my goal for this number?"

PART 6

Living Well With a Transplant

CHAPTER 20

Eating Well and Food Safety

Nutrition for your new kidney and your whole body

Food after transplant has two jobs: **protect your health** (heart, weight, blood sugar, bones) and **protect you from food-borne infection** while your immune system is lowered. Your dietitian will personalize the plan; the guidance below is general.

The first weeks vs. the long term

	Early (first weeks to months)	Long term
Appetite	Steroids and a return of appetite can make you hungry. Aim for balance	Aim for steady weight, avoid weight gain
Potassium and phosphorus	Your team may limit or encourage them based on labs. Low phosphorus and magnesium are common after transplant, high potassium can occur with tacrolimus	Usually liberalized; follow labs
Sodium	Limit salt to help blood pressure and swelling	Continue limiting salt; many aim for under 2,000 to 2,300 mg per day
Protein	Slightly more protein helps wound healing	Moderate, from lean sources
Fluids	Often more than on dialysis. Follow your team's plan	Drink enough water to keep urine pale yellow
Sugar and fats	Limit sweets, sugary drinks, and saturated fat, especially on steroids	Heart-healthy pattern (Mediterranean or DASH)

A heart-healthy pattern

- Fill half your plate with **vegetables and fruit**, a quarter with **whole grains**, a quarter with **lean protein**.
- Choose **olive oil**, nuts, and fish instead of butter, fried foods, and processed meats.
- Read labels: aim for low sodium; avoid **salt substitutes** (potassium chloride) unless approved.
- Choose water first. Limit sugary drinks, juice, alcohol, and energy drinks.
- Work with a dietitian if you have diabetes, kidney stones, gout, or a history of high potassium.

Food safety rules

Do	Avoid
Wash hands, cutting boards, knives, and counters often	Raw or undercooked meat, poultry, fish, shellfish, sushi, and eggs (including runny yolks, homemade eggnog, cookie dough)
Cook meat to safe internal temperatures (poultry 165°F/74°C; ground meat 160°F/71°C; whole cuts 145°F/63°C)	Unpasteurized milk, juices, cider, and soft cheeses (brie, feta, queso fresco) unless labeled pasteurized
Wash all fresh produce under running water	Raw sprouts (alfalfa, bean, radish)
Refrigerate leftovers within 2 hours and eat within 3 days	Deli meats and hot dogs unless heated until steaming
Use a food thermometer, and keep the fridge at 40°F or below	Leftovers, buffets, salad bars, and unrefrigerated foods left sitting out
Choose pasteurized dairy, juices, and honey products	Grapefruit, pomelo, Seville oranges, and juices made from them (with tacrolimus, cyclosporine, sirolimus)
Use bottled or tested water when traveling	Herbal teas, supplements, and "detox" products unless approved

Supplements

Do not take dietary supplements, herbal remedies, or protein powders without checking with your transplant team or pharmacist. Some contain ingredients (such as potassium, licorice, or herbs that affect drug levels) that are unsafe for transplant recipients.

Get expert help

Ask for a referral to a dietitian who works with transplant patients. Bring a 3-day food diary to your visit. Small, steady changes work better than rigid diets.

CHAPTER 21

Activity, Weight, and Skin Care

Movement, healthy weight, and sun protection

Exercise after transplant

Regular activity lowers blood pressure, blood sugar, cholesterol, and cancer and heart risk, improves bones and mood, and helps control weight. Most people can return to full activity within 2 to 3 months. Talk with your team before starting a new program.

Phase	Suggested activity
First 6 weeks	Short walks several times daily. Gentle stretching. No heavy lifting (no more than about 10 pounds)
6 to 12 weeks	Increase walking time. Add light resistance exercises and stationary cycling if cleared
After 3 months	Build to at least 150 minutes per week of moderate activity plus 2 days of strength training. Swimming when incisions are healed and infection risk is low
Ongoing	Consistency beats intensity. Choose activities you enjoy

Sports and safety

Contact sports (football, hockey, martial arts) carry a risk of direct injury to the kidney in the lower abdomen. Many transplant recipients can play with protective padding or choose non-contact options; discuss it with your team. Staying hydrated in hot weather protects kidney function.

Maintaining a healthy weight

- Expect appetite to rise; steroids make it stronger. Plan healthy snacks.
- Weigh yourself regularly, but watch for **sudden** gains (swelling) as well as gradual gains (fat).
- Aim for gradual weight loss of 1 to 2 pounds per week if overweight, with dietitian guidance. Avoid fad diets, cleanses, and diet pills.
- If weight is a serious health concern, ask about medically supervised programs; bariatric surgery may be an option for some recipients.

Protecting your skin

Skin cancer is the most common cancer after transplant, and it can be more aggressive in transplant recipients. Sun protection is a **daily habit for life**.

- ☐ Broad-spectrum sunscreen SPF 30 or higher on all exposed skin every day, reapplied every 2 hours outdoors
- ☐ Wide-brimmed hat, sunglasses, and long sleeves or UV-protective clothing
- ☐ Avoid peak sun (10 a.m. to 4 p.m.) and **never use tanning beds**
- ☐ Monthly self-exam (use a mirror; note new, changing, bleeding, or non-healing spots)
- ☐ Yearly full-skin exam with a dermatologist (more often if you have had skin cancer)

- ☐ Some medicines (voriconazole, some antibiotics) increase sun sensitivity; ask
-

ABCDE of moles

Asymmetry, **B**order irregular, **C**olor uneven, **D**iameter larger than a pencil eraser, **E**volving or changing. Also report any sore that does not heal in 4 weeks, or a rough, scaly patch.

CHAPTER 22

Emotional Health and Wellbeing

The feelings are real, and support is available

A transplant is a physical event and an emotional one. Many people expect only joy and are surprised by a mix of relief, gratitude, fear, sadness, and exhaustion. That mix is **normal**.

Common feelings

Feeling	What may help
Anxiety about rejection	Learn the warning signs and your plan. Focus on routines you control. Ask about counseling or peer support
Guilt or "survivor" feelings	Common toward the donor and the donor's family. Writing a thank-you letter (if your center allows) and giving back can help
Mood swings and sleep changes	Steroids can cause these; talk to your team, since dose changes or short-term help may be possible
Body image changes	Scars, weight, and skin or hair changes can be upsetting. Speak up: treatments and doses can be adjusted
Feeling like a patient forever	Set life goals beyond health: hobbies, work, relationships
Depression	More common than most realize. Persistent sadness, hopelessness, or loss of interest lasting more than two weeks need attention
Strain in relationships	Involve family in appointments; consider counseling together
Living donor feelings	Donors may feel let down if the graft struggles or if there is little contact. Donor support groups can help

Ways to look after yourself

- Keep a routine for sleep, meals, and activity.
- Stay connected: a peer mentor, support group, or faith community.
- Practice stress skills: paced breathing, gentle stretching, mindfulness, journaling.
- Limit social media and search-engine "doom scrolling" about complications.
- Celebrate milestones: 1 week, 1 month, 1 year: your **transplant anniversary**.

You matter

If you have thoughts of harming yourself or feel you cannot go on, call or text **988** (U.S. Suicide & Crisis Lifeline) or call 911. You deserve support, and help is available at any hour.

Support is treatment

Asking for mental health help is part of good transplant care, just like taking your medicines. Tell your team: they can connect you with a counselor or psychiatrist who understands transplants.

CHAPTER 23

Work, Travel, Intimacy & Pregnancy

Getting back to your life

Returning to work or school

- Many people return to **desk work in 6 to 12 weeks**, physical jobs in about 3 months, and school after 6 to 12 weeks, depending on recovery.
- Ask your team for a **return-to-work letter** and any workplace accommodations. The FMLA and the Americans with Disabilities Act can offer protections.
- Avoid heavily infectious environments early on (health care, day care, animals, construction dust) or discuss precautions with your team.
- Plan clinic and lab times with your employer or school.

Travel

Situation	Guidance
First 3 months	Stay close to your transplant center; travel only with team approval
Before any trip	Get the team's okay, a medication list, a doctor's letter, and the nearest transplant center or hospital at your destination
Medicines	Carry all medicines in your carry-on in original bottles, plus a 7 to 10 day extra supply. Keep to your home-time schedule for the first days, then transition per instructions
Vaccines and travel medicine	See your team 4 to 8 weeks before international travel. Live vaccines (such as yellow fever) are usually not allowed
Food and water safety	Drink bottled or purified water, avoid ice and raw foods in areas with poor sanitation, wash hands often
Sun and insects	Sunscreen daily. Use insect repellent; avoid areas with malaria or dengue when possible
Insurance	Consider travel medical insurance that covers pre-existing conditions and evacuation

Intimacy and sexual health

Fatigue, fear, medicines, and kidney disease can all affect desire and function. Many people notice **improvement** after transplant as hormones and energy recover. Sexual activity is usually safe when you feel ready and your incision is comfortable (often around 4 to 6 weeks). Ask your team about sexually transmitted infection prevention and contraception. Do not be embarrassed: sexual health is health.

Pregnancy and fatherhood

- **Women:** fertility often returns quickly after transplant, sometimes within weeks, even after years without periods. **Use reliable contraception unless you are ready to conceive.**
- Many centers advise waiting about **1 year** after transplant, with stable kidney function, blood pressure under control, and no recent rejection, before conceiving.
- **Mycophenolate** (CellCept, Myfortic), sirolimus, and everolimus, ACE inhibitors, ARBs, and some other medicines must be changed **before** conception. Tacrolimus, azathioprine, and prednisone are generally used in pregnancy. Never change medicines on your own.
- Pregnancy after transplant is **high-risk** but most pregnancies with careful planning succeed. Involve both your transplant nephrologist and a high-risk obstetrician.
- **Men** who take mycophenolate should ask about current recommendations for contraception and planning. Many men have fathered healthy children after transplant.
- Breastfeeding decisions depend on your medicines; ask your team.

Call your transplant team before anything else if

- You might be pregnant, or you missed a period
- You want to become pregnant in the next year
- You take mycophenolate and are having sex without effective contraception

CHAPTER 24

Family, Caregivers, and Donors

Supporting each other

For caregivers

A caregiver may be a spouse, parent, adult child, friend, or neighbor. The role can be rewarding and exhausting. Most centers require a **named caregiver** for the first weeks. Common tasks:

- Driving to appointments and labs, and staying at the hospital during the stay
- Keeping track of medicines, appointments, and questions
- Helping with meals, laundry, cleaning, and wound care
- Watching for warning signs and calling the team
- Emotional support and quiet company

Caregiver self-care

- Sleep, eat, and get outdoors. You cannot pour from an empty cup
- Accept help. Keep a list of tasks friends can do
- Share the load: rotate caregivers when you can (Worksheet 8)
- Ask about caregiver support groups or counseling
- Talk about how you are feeling with someone you trust

For family and friends

- Ask what the patient needs. Avoid unsolicited medical advice or supplements
- Do not visit when sick. Wash hands. Respect limits in the early months
- Help with rides, meals, and errands. Kids can help too
- Keep the household as normal as possible; include the patient in family life

For living donors

- Take the full recovery time. Do not rush back to lifting or heavy work.
- Attend follow-up visits at 6 months, 1 year, and 2 years (required by transplant programs), and keep up yearly checkups after that.
- Avoid NSAIDs when possible, keep blood pressure and weight healthy, and tell all doctors you have one kidney.
- Expect a range of feelings; some donors feel pride, some feel let down or anxious. Connect with donor peers.
- Your involvement in the recipient's life is your choice, and theirs. Communication is best kept respectful and unpressured.

For children in the household

Explain in age-appropriate words that a doctor is helping a family member get a healthy kidney. Reassure them that they did not cause the illness and that they are still loved and safe. Keep routines steady. Child life specialists at many hospitals can help.

Team family

Transplant is not just the recipient's journey. It is a journey for everyone who loves them. Care for each other.

CHAPTER 25

Special Situations

Children, older adults, diabetes, sensitized patients, and combined transplants

Group	What to know
Children and adolescents	Kidney transplants work well in children and give the best chance for normal growth and development. Children receive allocation priority. Pediatric centers offer child life, school, and family support. Adolescents and young adults have higher rates of missed medicines; planning for the move from pediatric to adult care is important (start early), and peer support helps
Older adults	Many people over 65 or 70 benefit greatly from transplant compared with dialysis, provided they are otherwise healthy. Your team will look at frailty, heart health, and support. Older-donor kidneys may shorten waiting; ask about "older-for-older" programs
People with diabetes	Transplant can be very successful. Blood sugar control and heart evaluation are key. People with type 1 diabetes may be considered for simultaneous pancreas-kidney (SPK) transplant. Post-transplant diabetes can also appear in people who did not previously have it
Highly sensitized patients (high cPRA)	Prior transplants, pregnancies, or transfusions can create antibodies. Allocation gives extra priority. Options: paired exchange, desensitization, and acceptable-mismatch programs
Second (or later) transplants	Common and often successful. The team will study why the last kidney failed. Sensitization can lengthen waiting
Polycystic kidney disease (PKD)	Large native kidneys sometimes need to be removed before or during transplant. PKD does not return in the new kidney
Recurrent glomerular disease (IgA, FSGS, membranous, others)	Risk of recurrence varies; some patients get extra treatments (such as plasma exchange or rituximab) and closer monitoring
Atypical HUS, primary hyperoxaluria, and other rare diseases	May need specialized planning, medicines (for example, complement inhibitors), or combined organ transplant. Choose a center with experience
Multi-organ candidates	People with both kidney and liver, heart, or pancreas failure may qualify for combined transplants, which have their own allocation rules
Hepatitis C or HIV	Highly effective treatments make transplant safe for most. Special monitoring and medicine interactions require a team experienced in these conditions
People with limited English or health literacy	You have the right to an interpreter and clear explanations at every visit. Ask for teach-back: "Let me explain it back to make sure I understand"
Rural or remote patients	Ask about telehealth, local labs, travel assistance, and where to stay near the center. Plan how to reach the hospital fast when the call comes

Your situation matters

Whatever your situation, your care team can tailor a plan. If you feel your needs are not understood, ask for the social worker, a patient advocate, or a second opinion.

CHAPTER 26

When a Transplant Fails and What Comes Next

Honest information and hope

No transplant lasts forever. A kidney can fail early, or after decades. When function declines, it is a painful moment. It is **not** a personal failure, and there are still options.

Why kidneys fail

Cause	Notes
Rejection (acute or chronic)	The most common causes over the long term
Missed or reduced medicines	A leading and preventable cause
Recurrent original disease	Some diseases return
Infection (for example BK virus), blockage, medicine toxicity	Often treatable if found early
Heart, blood vessel, or other illness; surgical problems (early)	Healthy habits reduce this risk

What to expect as function declines

- Your team will discuss **options early**: dialysis planning (fistula or catheter, peritoneal dialysis), re-listing for a second transplant, and a living donor search.
- Ask when to **re-list**. Waiting time may count from the date you go back on dialysis, or be preserved based on rules. Ask your coordinator right away.
- Your **immunosuppression plan** will be individualized: some people slowly taper medicines to reduce infection and cancer risk; others stay on lower doses to avoid sensitization (making new antibodies). Do not adjust on your own.
- A failing kidney may sometimes remain useful for a while (making urine, helping with fluid balance). Talk about how to protect remaining function.

Emotional impact

Grief, anger, guilt, and fear are all natural. Talk to a counselor and peer supporters. Living donors and families may need support too.

Second transplants

Many people go on to have successful second transplants. Studies show that repeat transplant offers a survival advantage over staying on dialysis for most people who qualify. The new evaluation will consider why the first kidney failed, antibody levels, and your overall health. Ask whether preemptive re-transplant (before returning to dialysis) is possible.

Questions to ask your team if function is declining

- ☐ What is causing the decline, and can any part of it be treated or slowed?
- ☐ How much time do we likely have before dialysis is needed?
- ☐ Should I be re-listed now, and how is my waiting time counted?
- ☐ Can my living donor search or paired exchange start again?
- ☐ What should happen to my anti-rejection medicines as function falls?
- ☐ Which dialysis type suits me best, and when should access be placed?
- ☐ What emotional and social support can you connect me with?

Hope continues

A transplant that gave you years of better health still counted. If you need another chapter, your team, your family, and your community are here to help you write it.

CHAPTER 27

Sick Days, Emergencies, and Other Doctors

What to do when life happens

Minor illnesses can become serious quickly when you take anti-rejection medicines, and even a simple stomach bug can change your drug levels and stress your kidney. The rule is simple: **call early**. Your team would rather hear from you about a small problem than treat a big one.

Sick-day guide

Situation	What to do
Vomiting	Call your team. If you vomit within about 30 minutes of a dose, ask whether to repeat it. Sip fluids in small amounts. Do not skip anti-rejection medicines without instructions
Diarrhea	Call the same day. Diarrhea can raise tacrolimus levels and cause dehydration. You may need an early blood test, fluids, and stool tests for infection
Fever (100.4°F / 38°C or higher)	Call right away, day or night. Do not wait to see if it improves and do not take acetaminophen just to "mask" the fever before you have called
Cough, sore throat, shortness of breath	Test for COVID-19 and flu as advised, and call the same day. Early antiviral treatment works best when started quickly
Painful, burning urination	Call for a urine test. UTIs after transplant can spread to the kidney
Blistering rash	Possible shingles: call the same day. Early antivirals help
Hot weather or heavy sweating	Drink water regularly, avoid overheating, and call if you feel dizzy, faint, or make little urine
Injury or surgery elsewhere	Tell every doctor and surgeon that you have a transplant. Contact your team before elective procedures or new medicines

COVID-19 treatment needs your transplant team

Some COVID-19 antiviral medicines, especially ritonavir-boosted nirmatrelvir (Paxlovid), interact strongly with tacrolimus, cyclosporine, sirolimus, and everolimus and can cause dangerous drug levels. Do not start or stop any antiviral without your transplant team's direct involvement. Alternatives exist. Call as soon as you test positive.

"Sick day" medicine adjustments

During dehydrating illnesses (vomiting, diarrhea, high fever), some medicines may need to be held for a day or two, such as certain blood pressure medicines (ACE inhibitors, ARBs), diuretics, SGLT2 inhibitors, and metformin. **Never adjust these on your own.** Ask your team at discharge: "Which medicines should I hold when I am sick, and when do I restart them?" and write the answer on Worksheet 23.

At the emergency room or a new doctor

- ☐ Show your **wallet card** (Worksheet 23) and medication list (Worksheet 13)
- ☐ Say clearly: "I have a kidney transplant and take anti-rejection medicines"
- ☐ Ask the ER to **call your transplant team**, ideally before giving antibiotics, contrast dye, or new medicines
- ☐ Do not accept NSAIDs (ibuprofen, ketorolac/Toradol) for pain. Ask for alternatives
- ☐ Ask whether IV contrast dye is essential; if it is, ask about hydration and monitoring
- ☐ Ask for kidney function and drug levels to be checked
- ☐ Bring your caregiver to help you remember instructions
- ☐ Follow up with your transplant team within a day or two after any ER visit

Advocate for yourself

You are the expert on your own transplant. Many doctors see few transplant patients. Speaking up clearly can prevent errors.

CHAPTER 28

Your First Year, Month by Month

A roadmap of what to expect

Every person recovers differently, and every center has its own schedule. Use this as a general map, and write in what your own team tells you.

When	Visits and labs	Medicines and safety	Life and activity
Week 1 (hospital)	Daily labs, ultrasound, possible biopsy	Induction and maintenance medicines started; teaching	Walking, breathing exercises, learning your routine
Weeks 2-4	Labs 2-3 times a week, then weekly. Clinic weekly. Catheter or stent plan	Highest doses. Drug levels frequent. Antiviral and antibiotic prevention	Short walks, no lifting, rest, wound care. Stay near center as instructed
Month 2	Labs every 1-2 weeks. Stent removed if not already. BK and CMV checks	Doses may start to step down. Watch for infections	More energy. Light housework. Driving if cleared
Month 3	Labs every 2 weeks. Clinic every 2-4 weeks	Steroid tapers at some centers. Review side effects	Return to work or school, if cleared. Gentle exercise
Months 4-6	Labs monthly. Visits monthly. Possible surveillance tests	Prophylaxis for CMV may end. Vaccines updated as allowed	Regular exercise plan. Travel if approved. Emotional check-in
Months 7-9	Labs every 1-2 months. Visits every 2-3 months	Stable maintenance doses. Long-term issues reviewed	Most daily activities. Planning for future goals
Months 10-12	Labs every 2-3 months. One-year visit	Review of all medicines. Skin and dental checks	Celebrate your 1-year transplant anniversary . Set long-term health goals

Milestones worth celebrating

- **First urine** from the new kidney and the first creatinine that drops
- **Coming home** and the first night in your own bed
- **First full week** without missing a pill or lab
- **Catheter and stent** removal
- **Back to walking** around the block, then the neighborhood
- **Return to work, school, or a favorite activity**
- **Six-month** and **one-year** visits

Not a straight line

Recovery is not a straight line. Good days and tired days both happen. Fatigue, mood changes, and weight changes are common in the first year. If something feels wrong, call.

After the first year

Visits and labs become less frequent but never disappear. Most people are seen every 3 to 6 months in the second year and at least yearly for life, with routine labs more often. Keep your yearly skin exam, vaccines, bone density checks, and cancer screening on schedule. Your **transplant anniversary** is a good day to review your Long-Term Health Plan (Worksheet 20).

CHAPTER 29

Your Rights and Speaking Up

Informed decisions, advance planning, and getting the care you deserve

You have the right to

Right	What it means
Clear information	To have things explained in plain language, with an interpreter if needed, and to ask for teach-back
Informed consent	To hear benefits, risks, and alternatives, and to say yes or no to any test or treatment
A second opinion	To consult another transplant center or specialist
Records	To see and get copies of your medical records, labs, and biopsy reports
Respect and privacy	To be treated with dignity and to have your health information protected
Know your center's data	To see how the center performs (SRTR) and how selection decisions are made
Raise concerns	To speak with a patient advocate, and to file a complaint without losing care
Bring support	To have a trusted person with you at visits, within hospital policy

Advance care planning

Planning ahead does not mean giving up. It means your wishes are known if you cannot speak for yourself, such as during surgery or a serious complication.

- **Health care proxy (health care power of attorney):** choose someone you trust to speak for you, and talk with them about your values.
- **Advance directive or living will:** write down what you would want if you were very ill. Give copies to your proxy, your doctors, and your go-bag (Worksheet 9).
- **Review it** after big life changes, and at least yearly.

How to be a strong partner in your care

- **Prepare:** write questions before every visit (Worksheet 3).
- **Bring someone** to take notes. Ask them to record details.
- **Repeat back** what you heard: "So my next step is..."
- **Ask why:** "What is my goal for this number?" and "What are my other options?"
- **Tell the truth** about missed doses, drinking, mood, or money problems. Your team can only solve what it knows.
- **Use the portal:** check results, message the team for non-urgent needs, and update medication lists.
- **Follow up:** if you do not hear back about a test, call.

Where to turn if you are stuck

If you have a concern that is not resolved by your care team, ask for the **patient advocate** or **patient relations** office. The OPTN also operates a patient services line for concerns about transplant centers or the allocation system (check optn.transplant.hrsa.gov for the current number).

You belong at the table

The best transplant outcomes happen when patients, caregivers, and care teams work together. You are a full member of the team.

Quick Reference: Do and Don't

Tear out or photocopy this page. It summarizes the most important habits from the whole guide.

DO	DO NOT
• Take every anti-rejection dose on time, every day • Keep every lab and clinic appointment • Check weight, blood pressure, and temperature daily • Call the team early about fever, vomiting, diarrhea, or less urine • Use sunscreen SPF 30+ and check skin monthly • Wash hands, cook food thoroughly, and wash produce • Tell every doctor, dentist, and pharmacist you have a transplant • Keep an up-to-date medication list (Worksheet 13) • Stay active and keep a healthy weight • Get flu, COVID-19, pneumococcal, and shingles (recombinant) vaccines as advised • Ask about pregnancy planning before conceiving • Reach out for emotional support when you need it	• Stop, skip, or change medicines on your own • Take ibuprofen, naproxen, or other NSAIDs without approval • Eat grapefruit, pomelo, or Seville oranges (with tacrolimus, cyclosporine, sirolimus) • Use herbal remedies or supplements (such as St. John's wort) without checking • Eat raw or undercooked meat, eggs, sprouts, or unpasteurized foods • Receive live vaccines unless your team approves • Use tanning beds or skip sun protection • Smoke or vape • Wait to see if a fever or pain will go away on its own • Clean litter boxes, bird cages, or fish tanks without precautions • Get pregnant while taking mycophenolate • Hide missed doses, drinking, or money problems from your team

Call your transplant team today for

Fever of 100.4°F (38°C) or higher • much less urine • pain or swelling over the kidney • weight up 2-3 lb overnight • vomiting or diarrhea • missed or lost medicines • wound redness or drainage

PART 7

Tools and Reference

REFERENCE

Glossary of Terms

Plain-language definitions of words you will hear

ABO blood type	Your blood group (A, B, AB, or O). Donor and recipient must be compatible unless special treatment is used.
Acute rejection	Rejection that develops over days to weeks, most often in the first year.
Allocation	The system of rules for offering donated organs to candidates.
Antibody-mediated rejection (AMR)	Rejection caused by antibodies attacking the graft's blood vessels.
Anti-thymocyte globulin (ATG)	A strong induction or rescue drug that depletes T cells.
Banff classification	International system pathologists use to grade transplant biopsies.
Belatacept	An intravenous anti-rejection drug given by infusion, usually monthly.
BK virus	A common virus that can damage the transplanted kidney when immunosuppression is high.
BUN	Blood urea nitrogen, a waste product measured in blood tests.
Calcineurin inhibitor	Class of anti-rejection drug that includes tacrolimus and cyclosporine.
CMV	Cytomegalovirus, a common virus that can cause serious illness after transplant.
Coordinator	The transplant nurse who is your main point of contact.
cPRA	Calculated panel reactive antibody: the percentage of donors you would be incompatible with. Higher means harder to match.
Creatinine	A waste product of muscle; a blood level that rises when kidney function falls.
Crossmatch	Test mixing recipient blood with donor cells to check for harmful antibodies.
DCD / DBD	Donation after circulatory death / donation after brain death.
Delayed graft function (DGF)	A new kidney that is slow to start, needing dialysis in the first week.
dd-cfDNA	Donor-derived cell-free DNA: a blood test suggesting injury to the graft.
Desensitization	Treatment to lower antibodies so that a transplant can be done despite incompatibility.
Donor-specific antibody (DSA)	An antibody in the recipient directed against the donor's HLA.
eGFR	Estimated glomerular filtration rate: a calculation of kidney function.
EPTS	Estimated post-transplant survival score, 0 to 100%, used in matching.
ESKD / ESRD	End-stage kidney disease: kidney failure needing dialysis or transplant.
Graft	The transplanted organ. Graft survival is how long it keeps working.

HLA	Human leukocyte antigens: proteins on cells that the immune system uses to tell self from non-self.
Immunosuppression	Medicines that reduce immune activity to prevent rejection.
Induction	Strong immune-suppressing therapy given around the time of transplant.
Iliac fossa	The lower side of the abdomen where the transplanted kidney usually sits.
KDPI	Kidney Donor Profile Index: a 0 to 100% score of donor kidney quality and expected longevity.
Living donor advocate	Independent professional who protects the interests of the potential donor.
Lymphocele	A collection of lymph fluid near the transplanted kidney.
Maintenance therapy	The long-term anti-rejection medicines you take daily.
Mycophenolate	Anti-rejection drug (CellCept, Myfortic) that can cause birth defects.
NSAIDs	Non-steroidal anti-inflammatory drugs (ibuprofen, naproxen). Avoid unless approved.
OPO	Organ procurement organization: the agency that coordinates donation and recovery.
OPTN / UNOS	The national organ transplant network and the organization that manages it under federal contract.
Paired exchange	Swapping incompatible donor-recipient pairs so each recipient receives a compatible kidney.
Preemptive transplant	A transplant done before dialysis is needed.
PTLD	Post-transplant lymphoproliferative disorder: abnormal lymphoid growth linked to immune suppression and EBV.
Rejection	The immune system attacking the transplanted organ.
SRTR	Scientific Registry of Transplant Recipients: publishes center-specific outcomes.
Stent (ureteral)	A small tube in the ureter to protect the connection after surgery, removed later.
Tacrolimus	The most common anti-rejection drug (Prograf, Envarsus XR, Astagraf XL).
T-cell mediated rejection	Rejection driven by T lymphocytes.
Trough level	Drug level in the blood just before the next dose.
Ureter	The tube carrying urine from the kidney to the bladder.
Waiting time	Time counted toward priority on the waiting list.
Xenotransplantation	Transplant of organs from animals; being studied in clinical research.

REFERENCE

Frequently Asked Questions

Quick answers to common questions

How long will I wait for a kidney?

It varies widely by blood type, antibody level, region, and center. Some wait months; many wait several years. A living donor, paired exchange, or accepting more kidney types can shorten the wait. Ask your center for its median wait for people like you.

How long does a transplanted kidney last?

On average, deceased-donor kidneys last about 10 to 15 years and living-donor kidneys about 15 to 20 years, and many last longer. Individual results depend on age, donor, medicines, and overall health.

Can I stop my medicines if I feel fine?

No. Anti-rejection medicines are needed as long as you have the kidney. Stopping can cause rejection, often without symptoms.

Can I drink alcohol?

Ask your team. Small amounts may be fine for some, but alcohol can affect the liver, blood pressure, weight, and medicine interactions. Some people should avoid it entirely.

Can I smoke or vape?

No. Smoking and vaping raise the risk of heart disease, infection, lung problems, and cancer after transplant. Ask about quit programs.

Is cannabis safe after transplant?

Ask your team. Smoking cannabis can cause lung infections, and some products interact with medicines. Policies vary by center.

Can I have a pet?

Usually yes, with precautions: wash hands, avoid cleaning litter boxes, cages, and tanks, and keep pets healthy and vaccinated.

When can I drive?

Typically 2 to 4 weeks after surgery, off narcotic pain medicine, and when you can react quickly without pain.

Can I get pregnant or father a child?

Yes, with planning. See Chapter 23. Certain medicines must be changed first.

Can I donate blood or my own organs later?

Transplant recipients usually cannot donate blood. Organ and tissue donation after death is sometimes possible; ask your team.

Will I need dialysis after transplant?

Some people need temporary dialysis if the kidney is slow to start. Most do not need it for long.

What if I catch a cold?

Rest, fluids, and call your team if you have fever, worsening cough, or shortness of breath. Ask before using cold medicines: decongestants and some products are not advised.

Will my own kidneys be removed?

Usually not. They stay in place unless problems make removal necessary.

Can I switch transplant centers?

Yes, you may transfer or be listed at more than one center. Ask about how waiting time is handled.

Do I have to pay back a living donor?

No, and it is illegal to pay for an organ. Donor costs are usually covered by the recipient's insurance and assistance programs.

Can I write to my donor's family?

Most organ procurement organizations help with anonymous thank-you letters. Ask your coordinator.

REFERENCE

Questions to Ask Your Team and Trusted Resources

Bring these to your next visit; verify all contact details

Ten questions to ask

- 1 What is my eGFR now, and how quickly is it changing?
- 2 Am I a candidate for transplant? What would make me a better candidate?
- 3 How many transplants does your center do, and what are its outcomes?
- 4 What is the typical waiting time for my blood type and antibody level?
- 5 How does the center handle living donors and paired exchange?
- 6 Which kinds of donor kidneys would you recommend I accept?
- 7 What medicines will I take, and what side effects should I watch for?
- 8 Who do I call at night or on weekends?
- 9 What happens to my insurance and medicine coverage over time?
- 10 How will my original kidney disease affect the transplant?

Trusted resources

Organization	What it offers
OPTN / UNOS (optn.transplant.hrsa.gov, unos.org, transplantliving.org)	National waiting list policies, data, and patient education (Transplant Living)
SRTR (srtr.org)	Center-specific transplant outcomes to compare programs
National Kidney Foundation (kidney.org)	Patient education, peer mentoring, and helpline
American Kidney Fund (kidneyfund.org)	Education and financial assistance programs
National Kidney Registry (kidneyregistry.org)	Paired exchange and donor-chain programs
NLDAC (livingdonorassistance.org)	Financial help for eligible living donors' travel and lodging
Donate Life America (donatelife.net); organdonor.gov	Donor registration and information
American Society of Transplantation (myast.org)	Professional society with patient resources
Medicare (medicare.gov; 1-800-MEDICARE)	Coverage information for kidney failure and transplant
988 Suicide & Crisis Lifeline (call or text 988)	Emotional crisis support, 24/7 (U.S.)
Poison Control (1-800-222-1222)	Medicine or ingestion emergencies (U.S.)

Web addresses and phone numbers can change. Confirm through your transplant center or a trusted search before relying on them. This guide does not cite specific studies; ask your team for the current evidence and data on your situation.



WORKSHEET 1

My Transplant Team and Key Contacts

Fill in once and keep a copy in your go-bag and on your phone.

Transplant center

Main phone

After-hours / emergency number

Coordinator (name / phone)

Transplant nephrologist

Transplant surgeon

Social worker

Dietitian

Transplant pharmacist

Financial coordinator

Local nephrologist

Primary care doctor

Dermatologist

Preferred pharmacy (phone)

Dialysis unit (phone)

Insurance ID (last 4)

Emergency contact 1

Emergency contact 2

Notes:



WORKSHEET 2

My Health Snapshot

A one-page summary to share with new doctors and emergency staff.

Name	_____	Date of birth	_____
Blood type	_____	Cause of kidney disease	_____
Date first on dialysis	_____	Type of dialysis	_____
Allergies	_____	Other conditions	_____
Past surgeries (living / deceased)	_____	Date of transplant	_____
Baseline weight	_____	Baseline creatinine	_____
		Usual blood pressure	_____

Important notes (implanted devices, vaccine dates, special instructions):

WORKSHEET 4

Transplant Center Comparison

Compare up to three centers. SRTR.org has outcomes data.

Question	Center A	Center B	Center C
Distance / travel time			
Kidney transplants per year			
1-year graft survival vs expected			
5-year graft survival vs expected			
Typical wait (my blood type)			
Accepts hard-to-place kidneys?			
Living donor / paired exchange?			
Accepts my insurance?			
Where to stay after surgery			
After-hours contact			
Support groups / mentors			
Overall impression			

WORKSHEET 5

Insurance and Cost Planner

Ask your financial coordinator to help fill this in.

Primary insurance	_____	Policy phone	_____
Secondary insurance	_____	Prescription plan	_____
Transplant coverage limit	_____	Pre-authorization	_____
Medicare start date	_____	Medicare end date (if kidney-only)	_____

Expected cost	Monthly / one-time	Covered by	My share
Evaluation copays			
Surgery / hospital			
Anti-rejection medicines			
Other prescriptions			
Labs and visits			
Travel and lodging			
Lost income			
Home supplies			

Assistance programs to contact:

WORKSHEET 6

Evaluation Test Tracker

Track every test, date, result, and follow-up.

Test / consult	Ordered	Done	Result / status
Blood type (2 samples)			
HLA / antibody testing			
Infectious disease labs			
EKG / echo / stress test			
Chest X-ray / imaging			
Colonoscopy			
Mammogram / Pap / prostate			
Skin exam			
Dental exam			
Social work visit			
Dietitian visit			
Pharmacist visit			
Surgeon visit			
Financial visit			
Vaccines up to date			



WORKSHEET 7

Living Donor Conversation Planner

Share your story, do not pressure. Give people the donor team’s number and time.

My story in 3 sentences (what I need, what I have learned, what I hope):

- ☐ Get the transplant center’s living donor phone number and website
- ☐ Prepare a short written note or email (not asking directly)
- ☐ Share the donor information sheet from the center
- ☐ Tell people they can contact the donor team privately
- ☐ Never accept money or pressure anyone

Person	Talked (date)	Contacted donor team?	Notes

WORKSHEET 8

Support Network and Caregiver Plan

Name your people. Share the plan with them.

Task	Primary person	Backup person	Phone
Ride to the hospital when called			
Caregiver at hospital			
Caregiver first 2 weeks at home			
Rides to appointments and labs			
Meals and groceries			
Pet care			
Child care			
Work / school liaison			
Communicating with family			
Medication helper			

How I will look after the caregiver (rest, breaks, thanks):

WORKSHEET 9

Transplant Go-Bag Checklist

Keep the bag by the door. Check it monthly.

- ☐ Photo ID and insurance cards
- ☐ This guide, Worksheets 1, 2, 13 (contacts, health snapshot, medicines)
- ☐ Phone and long charging cable
- ☐ List of all medicines with doses and times (and current bottles if allowed)
- ☐ Loose, comfortable clothing, robe, slip-on shoes, socks
- ☐ Toiletries, unscented lotion, lip balm
- ☐ Glasses, hearing aids, dentures, CPAP machine if used
- ☐ Notebook and pen; list of questions
- ☐ Small pillow for the car ride and for coughing later
- ☐ Cash or card for parking
- ☐ Copies of advance directive / health care proxy
- ☐ Items for comfort: book, headphones, photos
- ☐ Snacks approved by dietitian (for later)
- ☐ Caregiver's own overnight bag

WORKSHEET 10

Home Preparation Checklist

Get your home ready before you need it.

- ☐ Deep clean bathroom and kitchen; fix mold and leaks
- ☐ Stock unscented soap, hand sanitizer, disinfectant wipes
- ☐ Digital thermometer
- ☐ Blood pressure monitor (upper-arm cuff)
- ☐ Bathroom scale
- ☐ Weekly pill organizer (AM/PM) and phone reminders set
- ☐ Sunscreen SPF 30+, hat
- ☐ Food thermometer; separate cutting boards for raw meat
- ☐ Freezer meals prepared; fridge stocked
- ☐ Bed or chair set up on the main floor
- ☐ Rides and time-off arranged
- ☐ Pets: someone else to handle litter, cages, tanks
- ☐ Clear tripping hazards; night lights
- ☐ Place for medicine records and Worksheets

WORKSHEET 11

Waiting List Contact and Call Plan

Update whenever any detail changes.

Date listed	_____	Center(s) listed at	_____
Blood type	_____	cPRA / antibody level	_____
Waiting time start date	_____	Status (active / inactive)	_____
Phone(s) center will call	_____	Backup contact 1	_____
Backup contact 2	_____	Where you will go if roads are closed	_____
Travel time to hospital	_____		_____

- ☐ Phone always on and charged; voicemail cleared
- ☐ Monthly blood sample sent to center for antibody testing
- ☐ Told center of new insurance, address, or phone
- ☐ Told center about any illness or hospital stay
- ☐ Practiced "the call" plan with family
- ☐ Reviewed my preferences about types of kidneys with the team

WORKSHEET 12

Hospital Stay Daily Log

Ask your caregiver to help you fill it in.

Day	Urine (mL)	Creatinine	Weight	Pain 0-10	Walked	Questions
Day 1						
Day 2						
Day 3						
Day 4						
Day 5						
Day 6						
Day 7						
Day 8						
Day 9						
Day 10						

Things I learned / to remember:

WORKSHEET 13

My Medication List

Update after every change. Give a copy to every doctor and pharmacist.

Medicine (brand / generic)	Dose	Times	Purpose	Started / notes

Allergies / reactions



WORKSHEET 14

Weekly Medication Schedule

Check off each dose as you take it.

Medicine / time	Mon	Tue	Wed	Thu	Fri	Sat	Sun

Missed doses or problems this week (call the team):



WORKSHEET 15

Daily Home Monitoring Log (14 days)

Record every morning. Bring to each visit.

Date	Weight	BP	Temp	Urine	Glucose	Meds taken?	Notes

Call for: temperature 100.4°F (38°C) or higher; weight gain 2-3 lb in a day or 5 lb in a week; much less urine; blood pressure or glucose out of your team's range.

WORKSHEET 16

Lab Results Tracker

Ask for your results after every draw and write them here.

[illegible]

WORKSHEET 17

When to Call: My Action Plan

Fill in with your team at discharge. Post on the fridge.

Call 911

- Chest pain, trouble breathing, fainting, seizure
- Vomiting blood or black stools
- Confusion or severe drowsiness
- Signs of a stroke (face droop, arm weakness, speech trouble)

Call the transplant team the same day

- Fever 100.4°F (38°C) or higher, or chills
- Much less urine than normal; blood in urine
- Pain, swelling, or tenderness over the kidney
- Weight up 2-3 lb overnight or 5 lb in a week; new swelling
- Vomiting or diarrhea; cannot keep medicines down
- Missed doses, ran out of medicines, or new medicines started
- Redness, drainage, or opening at the incision
- Cough, shortness of breath, burning with urination
- New skin spots, lumps, or rash

Team daytime number

After-hours number

Nearest ER

Driver / backup



WORKSHEET 18

Appointment Tracker

Plan for rides, fasting, and drug-level timing.

Date / time	Clinic or lab	Fasting? Hold meds?	Ride	Questions / results



WORKSHEET 19

Wellbeing Check-In

Rate each area 0 (poor) to 10 (great). Notice trends and share with your team.

Week of	Mood	Sleep	Energy	Worry	Support	What helped / what I need

Do not wait

If mood is low for two weeks, or you have thoughts of self-harm, tell your team or call/text 988 today.

WORKSHEET 20

Long-Term Health Plan

Complete with your team at your one-year visit and update annually.

Item	My goal	Last done	Next due
Blood pressure			
Cholesterol / statin			
Blood sugar / A1c			
Weight / BMI			
Skin exam (dermatology)			
Cancer screening (per age)			
Bone density			
Eye exam			
Dental exam			
Flu / COVID / other vaccines			
Kidney labs and urine protein			
Mental health check			

Goals for next year:

WORKSHEET 21

Travel Checklist

Complete 4-8 weeks before any trip beyond your region.

- ☐ Team approval to travel; know the timing rules for your transplant
- ☐ Nearest transplant hospital or ER at destination
- ☐ Letter from my team listing diagnoses and medicines
- ☐ All medicines in carry-on, original bottles, plus 7-10 extra days
- ☐ Copy of Worksheets 1, 2, and 13
- ☐ Time-zone plan for medicine times
- ☐ Travel vaccines reviewed (no live vaccines)
- ☐ Travel medical insurance including evacuation
- ☐ Sunscreen, repellent, hand sanitizer, masks
- ☐ Thermometer and blood pressure cuff
- ☐ Safe water and food plan
- ☐ Lab draws arranged if trip is long

WORKSHEET 22

Decision Balance Sheet

Use this before or during the evaluation. Discuss it with family and your team. There is no perfect answer, only the one that fits you.

What I hope a transplant gives me	What worries me about a transplant

What I hope to avoid (dialysis burdens)	What worries me about staying on dialysis or conservative care

Importance of transplant (0-10)

Confidence with medicines (0-10)

Confidence in my support (0-10)

What would help me feel readier:



WORKSHEET 23

Sick-Day Plan and Wallet Card

Complete with your team at discharge. Cut out the card and keep it in your wallet.

**Medicines to HOLD if
vomiting/diarrhea**

When to restart them

Who to call first

Number (day / night)

Lab place near home

Thermometer normal for me

Cut-out wallet card

TRANSPLANT RECIPIENT CARD

I have a **kidney transplant** and take anti-rejection medicines. Please contact my transplant team before giving new medicines, antibiotics, or contrast dye. **No NSAIDs** (ibuprofen, naproxen, ketorolac).

Name: _____ Transplant date: _____

Transplant center: _____ Phone: _____

Medicines (attach list): _____

Allergies: _____ Emergency contact: _____

My sick-day notes:

WORKSHEET 24

First-Year Milestone Checklist

Check off milestones and write the date. Small victories count.

Milestone	Date	How I felt
First urine from new kidney		
Creatinine trending down		
Walked in the hall		
Home from hospital		
First week at home with no missed doses		
Catheter / stent removed		
First lab visit on my own schedule		
Drove again		
One month		
Back to work or school		
Three months		
First vacation or trip (with approval)		
Six months		
Started a new exercise routine		
One year: transplant anniversary		

WORKSHEET 25

Gratitude and Anniversary Planner

Gratitude can heal. Ask your coordinator how thank-you letters to donor families are handled at your center.

People who helped me get here (family, friends, staff, donor):

Draft thank-you note (focus on what the gift means to you; follow your center's guidelines on privacy):

- ☐ Pick a date to celebrate my transplant anniversary each year
- ☐ Plan one healthy way to celebrate (walk, meal, visit, service project)
- ☐ Review my Long-Term Health Plan (Worksheet 20) each anniversary
- ☐ Consider giving back: peer mentoring, donor registry awareness, or volunteering with TLHF

WORKSHEET 26

Symptom and Side-Effect Diary

Note anything new so you can tell your team exactly what happened and when.

Date / time	Symptom or side effect	How bad (0-10)	What I did	Told team?

Patterns I noticed (timing with medicines, food, activity):

NOTES

Notes

Space for your own questions, reminders, and milestones

NOTES

Notes (continued)

Space for your own questions, reminders, and milestones