



Kidney Transplant

In this chapter, you will find:

End Stage Kidney Disease and Transplant: General Information	1
Before Kidney Transplant: Caregiver Responsibilities	3
During Transplant: Caregiver Responsibilities	5
After Transplant: Caregiver Responsibilities	6
Questions to Ask Your Kidney Transplant Center	8
A Kidney Transplant Caregivers' Perspective: Alexis C.	9
Resources	10
References	10

End Stage Kidney Disease and Transplant: General Information

A kidney transplant is:

- surgery to receive a healthy kidney from a donor (living or dead).
- for patients with kidney failure or end stage renal (kidney) disease (ESRD).

Most people are born with two kidneys.

Your kidneys filter (or clean) your blood. Kidneys send waste and extra fluid from your blood to your bladder. The waste and fluid then leave your body when you urinate (pee).

If your kidneys don't work, the waste and extra fluid stay in your blood.

Kidney Failure

The 2 types of kidney failure are:

- acute kidney injury - there are many different causes and they can often be treated without a transplant
- chronic kidney disease - a condition that slowly gets worse until the kidneys stop working.

End Stage Renal Disease (ESRD)

ESRD is when the kidneys completely stop working and cannot filter and remove waste.

ESRD can be caused by:

- **Diabetes** – Too much glucose (sugar) in the blood can damage the kidney's filters. A protein called albumin can then get past the damaged filters and go through the blood into the urine. (The first sign of kidney disease is often protein in the urine.)

- **Hypertension (high blood pressure)** – Hypertension is when blood pushes against the walls of blood vessels with too much force. This can damage blood vessels in the kidneys. The damaged kidneys cannot filter waste and fluid. (Extra fluid can also cause high blood pressure.)
- **Glomerulonephritis** – This disease damages the kidney’s filters (glomeruli). Protein gets past the filters and into the blood then urine.
- **Polycystic Kidney Disease** – With this genetic disorder, cysts can grow in the kidneys. The cysts can cause high blood pressure and problems with blood vessels in the brain and heart.
- **Autoimmune diseases (Lupus, Goodpasture’s Disease, etc)** – These diseases cause the body’s immune system to attack its own cells and organs.

Alport’s Syndrome, infection, drug toxicity, heavy metal poisoning, hemolytic uremic syndrome in children, IgA vasculitis, chronic dehydration, and renal artery stenosis can also cause ERSD.

Common symptoms of ESRD are:

- | | |
|---|-------------------------|
| • high blood pressure | • weight loss |
| • changes in how much you urinate (pee) | • no appetite |
| • swelling of feet and ankles | • nausea |
| • fatigue | • vomiting |
| • drowsiness | • trouble sleeping |
| • itching or numbness in your body | • trouble concentrating |
| • dry skin | • darkened skin |
| • headaches | • muscle cramps |

Learn more about kidney disease in Resources, below.

Treatment Options for Patients with ESRD

- **Dialysis** uses machines to filter the patient’s blood. There are different options for dialysis. Ask the patient’s doctor why type of dialysis is best for them. If the patient is eligible, the doctor will refer them for a transplant evaluation.
- Kidney transplant from a living or deceased (dead) donor.

Kidney Transplant Waitlist

Patients who are eligible for kidney transplant might wait a long time for a kidney. The wait time depends on:

- how long they have been on dialysis,
- their blood type,
- if they are compatible with a kidney from a donor (tested by antigens and antibodies)
- previous transplants,
- if they are waiting for a kidney from a living or dead donor, and
- if they are a child.

Learn about [national policies for kidney transplant wait time and allocation](#)¹.

Ask your transplant team about **increased-risk donors**.

- Patients who accept organs from increased-risk donors usually wait less time for an organ.
- An increased-risk donor is a deceased donor with higher risk of spreading one of the following undiagnosed diseases to a transplant patient (Abara et al., 2019):
 - human immunodeficiency virus (HIV),
 - hepatitis B, or
 - hepatitis C (HCV).
- Organs from increased-risk donors are not lower quality.

Living Donor Kidney Transplant

A living person can volunteer to donate a kidney. Healthy adults without kidney disease or other medical problems can live a long, healthy life with only one kidney.

Living donation:

- can happen between family members, friends, or strangers.
- is faster than waiting for a deceased (dead) donor.

Learn more about [living donation](#).²

Learn more about kidney transplant waitlist and allocation in Resources, below.

Before Kidney Transplant: Caregiver Responsibilities

There are a lot of steps before kidney transplant. The patient must:

- talk with their doctor about ESRD treatment options, such as dialysis and transplant,
- choose a transplant center,
- receive transplant education
- complete the evaluation process
- and, if approved, be listed for transplant.

To receive a kidney transplant, the patient must complete an evaluation with the transplant team. This team can include:

- transplant nephrologist (kidney doctor),
- transplant surgeon,
- nurse coordinator,

¹ <https://optn.transplant.hrsa.gov/learn/patient-education/frequently-asked-questions-about-kidney-transplant-evaluation-and-listing/>

² <https://www.myast.org/caregiver-toolkit/living-donor>

- social worker,
- psychologist,
- psychiatrist,
- dietician,
- pharmacist, and
- financial counselor.

Evaluation includes many appointments and tests to evaluate the patient's kidneys and general health. The treatment team reviews test results to decide if the patient is eligible for transplant. Transplant centers have different evaluation requirements, and every patient has a different health background.

If the patient is eligible, they are placed on the transplant waitlist. Then they must wait for a kidney donor (living or dead) to be evaluated. Waiting can be frustrating and stressful. As a caregiver, you will support the patient while they wait.

To stay on the transplant waitlist, the patient must:

- continue with regular dialysis,
- be re-evaluated every year (or more), and
- complete regular lab work.

Supporting the Patient

As a caregiver, you can help the patient navigate this overwhelming process. You can:

- learn about the patient's diagnosis (there are many reasons they may need a transplant).
- go to the evaluation and follow-up appointments with the patient.
- take notes and ask questions during the evaluation and follow-up appointments.
- pack lunches and snacks to get through the full day of evaluation appointments.
- help the patient follow recommendations from the transplant team and dialysis centers.
- work with the transplant team's financial counselor and social worker to make sure the patient has insurance for treatment and access to medication.
- help the patient follow good health habits.
- listen to the patient.
- offer comfort and encouragement to the patient.

The waiting period before transplant can be stressful. Ask the transplant social worker for support. While waiting for transplant, many patients experience:

- worsening health,
- anxiety,
- depression,

- panic, and
- lower quality of life.

As a caregiver, you must [take care of yourself during this time](#)³. You might feel:

- fatigue,
- anxiety, and
- depression.

During Transplant: Caregiver Responsibilities

When the transplant team accepts a kidney for the patient, they will:

- call the patient and tell them to come to the hospital. This can happen any time during the day or night. The team will call you if they need help contacting the patient.
- **not** give information about the donor to the patient, caregivers, or family (due to federal law).

You should come to the hospital with the patient. When the patient is admitted to the hospital they will:

- have blood tests.
- not be able to eat or drink before surgery (NPO, or nothing by mouth).
- meet with the intake nurse.
- sign consents before starting surgical preparation.
- have an X-Ray.
- go to different places in the hospital for testing and surgery preparation. Staff will update you as they can.
- receive anesthesia 1-1.5 hours before surgery. They will not be awake during the surgery or feel any pain.
- receive a breathing tube. Intubation is a normal part of surgery.
- The surgeon might tell you how long surgery could take. This is an estimate and can change.
- The medical team will update you as often as they can.

Important! Sometimes, transplant surgery is canceled because the organ might not be a good match for the patient. This is disappointing, but it means the patient is at the top of the waitlist. They might get another call soon.

After surgery you will support the patient. Many different providers will go in the patient's room throughout the day. You should spend most of the day at the hospital, so you can:

- meet the providers,
- learn about the different teams,
- know the patient's daily schedule,

³ <https://www.myast.org/caregiver-toolkit/self-care-for-the-caregiver>

- hear all the updates, and
- ask questions.
- attend educational sessions about post-transplant care.
- You will learn how to care for the patient at home (wound care, medication management, etc.).

Caregiving for a kidney transplant patient is a big job. You must also [take care of yourself](#)⁴.

- Go home and rest. Do not sleep at the hospital.
- Trust the hospital staff to care for your patient and call you with any needs.
- Talk to the transplant social worker if you are feeling overwhelmed.
- Talk about how you are feeling.
- Ask for help. Don't try to do everything alone.

After Transplant: Caregiver Responsibilities

Taking care of a new kidney is a big job.

After discharge from the hospital, the patient will need a lot of help. You will take care of the patient at home until they improve enough to take care of themselves. You will:

- learn about the new medication the patient must take (use, dosage, and side effects),
- help the patient take their medications exactly as prescribed,
- use a pill box to help the patient organize their medication,
- look for side effects (hand tremors, shakiness, etc.),
- track blood pressure, blood sugar, temperature, weight, and fluid intake (ask for tracking documents),
- take the patient to lab appointments (weekly to start but less often as the patient improves),
- prepare meals,
- change wound dressings,
- complete (or ask for help with) household chores,
- help the patient with daily living and hygiene activities, and
- help the patient report concerns or symptoms.
- monitor the patient's mental health.

Recovery can take time. Talk often with the transplant team to monitor the patient's recovery. Make a list of all appointments, procedures, and medication changes to help you, the patient, and the transplant team.

⁴ <https://www.myast.org/caregiver-toolkit/self-care-for-the-caregiver>

Post-Transplant Medications

After surgery, the transplant team will prescribe many medications. Some will have very specific instructions. For example:

- Some immunosuppressant medication must be taken 12 hours apart.
- Other medication cannot be taken before laboratory blood draws.

If the patient does not take their medication correctly, their body can reject the new organ. This means that their immune system will attack the new organ because their body doesn't recognize it. Rejection is most common for kidney transplant patients who miss medications.

As a caregiver, you must:

- help the patient take medication exactly when and how it is prescribed.
- order refills.
- make sure the patient takes the correct dose (doses change often).
- help the patient organize their medications.

Ask the transplant pharmacist or nurse to help you organize medications before the patient is discharged from the hospital. They might recommend you use a pill box.

Lab and Clinic Appointments

You will help the patient go to all lab and clinic appointments to monitor:

- the patient's general health.
- how the new kidney is working.
- early signs of rejection.
- signs of infection. (Urinary tract infections (UTIs) can damage the kidney if not treated.)
- how the patient's body is handling anti-rejection medication.
- talk about any changes the patient should make.
- pain. Tell the transplant team immediately if the patient has pain. Pain over the kidney area can be a sign of rejection.

Hydration

You must help the patient drink enough water to keep the new kidney healthy. Ask the transplant team how much water the patient should be drinking every day.

The patient should drink mostly water. It can be difficult to drink a lot of water. Healthy ways to increase water intake:

- water infused with:
 - fruits (strawberries, lime, peaches, lemon),
 - herbs (mint, basil), or
 - vegetables (cucumbers).
- sparkling flavored water (no sugar added).
- plain sparkling water.
- Plain decaffeinated coffee or tea. (Drink a glass of water for every cup of coffee or tea.)

The patient **cannot** have drinks with a lot of:

- caffeine (diet or regular soda) or
- sugar (juice or punch).

Drinking enough water can be difficult, especially if the patient is used to drinking less water during dialysis. The patient might use the restroom a lot in the beginning, while they re-train their bladder muscles to hold more water. Plan frequent trips to the restroom at night and when you travel.

Other Caregiver Responsibilities

For the first 4-6 weeks (at least), you will need to:

- drive the patient to their clinic appointments,
- prepare meals,
- lift anything 10 pounds or more,
- and help the patient drink enough water.

Call the transplant center immediately if the patient has a fever or acts out of character.

Being a kidney transplant caregiver is rewarding and challenging. You must [take care of yourself](#).

- Remember to ask for help, to avoid caregiver burnout.
- Attend support groups for caregivers.
- Remember to take care of your own health.
- Go to your scheduled medical appointments.
- Don't stop taking your prescription medicine.

Questions to Ask Your Kidney Transplant Center

Kidney transplant can be unexpected or planned. Either way, consider asking these questions to help yourself prepare:

- What are the risks and benefits of receiving a kidney transplant?
- What is the wait time for a kidney transplant in this region?
- What options are there to receive a kidney transplant sooner?
- Can they receive a kidney from a living donor?

- Can the patient be listed at more than one transplant center?
- What are the risks and benefits of accepting an organ from an increased risk donor?
- Can I be the donor and the caregiver?
- If the recipient gets called in in the middle of the night, how will we know where to go?
- After the transplant, can I leave the patient for 1-2 hours while I go to the grocery store or do errands?
- Are there certain foods the recipient should not eat after transplant?
- What happens if I get sick while I am a caregiver?
- Are there other requirements for caregivers before, during, or after transplant?

A Kidney Transplant Caregivers' Perspective: Alexis C.

Every Kidney Transplant Caregiver should know: “The role of caregiving is a daunting yet liberating task. In being a caregiver for my mother, a kidney transplant recipient, I have learned a plethora of things and gained new insights. Furthermore, I believe there is importance and value in being informed in your loved one’s care throughout dialysis treatment and transplantation. Being informed throughout my mother’s care allowed my family and me to make the best decisions for my mom and our family.”

As a caregiver I wish I would have known: “I do not believe you can ever be fully prepared for caregiving. Depending on the age and health condition of the individual in care, caregiving can look very different for each individual. Although my mother was very self-sufficient, there were aspects of her care that required my immediate attention, time, and devotion. In addition to my total commitment, I had to learn a lot when it came to her disease prognosis, treatment plan, and care.”

The most difficult aspect of being a caregiver: “I believe knowing when to take time for myself was the most difficult aspect of being a caregiver. My mother’s needs were always placed above mine, and she remained my top priority. For example, oftentimes I would maneuver my schedule to ensure my mother was able to make her doctor’s appointments.”

The most rewarding aspect of being a caregiver was: “The most rewarding aspect of caregiving was being able to give back to the person that gave me life. Furthermore, being able to witness my mom’s health and life improve after transplant has been a continually rewarding aspect of caregiving. She is 3 years post-transplant, and her quality of life has improved immensely. I love seeing her re-engage in activities that she was deprived while in need of a kidney. Additionally, being a caregiver for my mom has influenced my decision to pursue a career in health services research.”

I was most surprised as a caregiver by: “Since being a caregiver for my mother, a kidney transplant recipient, she has become my best friend. The bond we have formed has surprised me the most. Prior to my mother’s illness she was just my mom; however, after I took on this role as caregiver, she has become someone I talk to and confide in every day.”

How I would recommend other caregivers prepare and take care of themselves for this experience and take care of themselves: “The role of caregiving is a huge task that should not be taken lightly. As a caregiver, I believe it is important to remember you have support, and you are not

alone in your role as a caregiver. My family played a major role in providing care for my mother. We acted as a team, which helped in not allowing one person to become overwhelmed and overworked. One recommendation I would suggest to anyone considering caregiving, would be to discuss openly with friends and family about your loved one's needs. I believe having the support of my family was immensely important throughout my mother's transplantation experience."

Resources

- National Kidney Foundation: <https://www.kidney.org/>
- American Kidney Fund: <https://www.kidneyfund.org/>
- National Institute of Diabetes and Digestive and Kidney Disease: <https://www.niddk.nih.gov/>
- US Department of Health & Human Services Organ Procurement and Transplantation Network: <https://optn.transplant.hrsa.gov/learn/professional-education/kidney-allocation-system>
- American Association of Kidney Patients: <https://aakp.org/center-for-patient-engagement-and-advocacy/support-groups/>
- Transplant Strong: <https://transplantstrong.com/>

References

- National Institute of Diabetes and Digestive and Kidney Diseases, <https://www.niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd/causes>. 2020.
- United Network For Organ Sharing, <https://unos.org/transplant/how-we-match-organs/>. 2020.
- American Kidney Fund, <https://www.kidneyfund.org/kidney-disease/kidney-failure/treatment-of-kidney-failure/kidney-transplant/transplant-waitlist/>. 2020.

The AST Caregiver Toolkit is generously supported by: North American Transplant Coordinators Organization (NATCO), Novartis, Henry Ford Transplant Institute, Society of Transplant Social Workers, International Society for Heart and Lung Transplantation (ISHLT), and National Kidney Foundation (NKF).