



# Caregiver Responsibilities

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## Organ Transplant Caregiving

Organ transplant is a complex process. Many things must happen to:

- get on the wait list,
- prepare for the transplant,
- receive the transplant, and
- live successfully with the new organ.

As a caregiver, you are very important in this process. You will care for the patient before and after the transplant, during:

- the transplant evaluation,
- their recovery in the hospital, and
- their recovery at home.

### Who are caregivers?

Caregivers are usually the patient's family members or friends. Caregivers can be spouses, significant others or partners, adult children, extended family members, friends, faith-based community members, neighbors, or co-workers.

Transplant centers have different requirements for caregivers. Ask your transplant center about their requirements for caregivers.

## **What do caregivers do?**

Being a caregiver takes time and energy. You must:

- learn about organ transplant and the care transplant patients need.
- listen to the patient and understand their needs.
- communicate with the patient's transplant team.
- care for the patient before and after the transplant.
- ask for help when you feel overwhelmed.

Transplant social workers will meet with you and the patient to help you prepare.

Transplant is a long process with many stages. The amount of time you will care for the patient depends on the kind of organ transplant and how recovery goes. Some patients require care all day, every day.

Below we list the stages of transplant and the emotions you or the patient might feel. You must be prepared for a long or difficult recovery. You and the patient might feel physically and emotionally exhausted during the process.

Learn more about:

- how being a caregiver can affect your life and how to care for yourself, in Resources below
- caregiver responsibilities for organ-specific transplant, in Resources below

### **Stages of transplant:**

Diagnosis: Learning the patient needs a transplant

- You might feel worried, sad, scared, or uncertain.
- You might feel like it cannot be true.

Transplant Evaluation Process

- The patient will have many uncomfortable medical procedures and appointments.
- The patient may need to make health changes that affect their daily life.
- You might feel worried or uncertain.

Waiting for a Donor

- The patient might have severe health problems and need to be in the hospital.
- You might have questions like,
  - "Should I hope they get sicker to get a transplant sooner?"
  - "Can I have my own life, while they wait for a transplant?"
- You might feel guilty, because "another person has to die for them to live."
- Family relationships might be stressed.

Receiving the Transplant Call

- You might feel joy, guilt, scared, numb.

## Short-term Recovery

- You and the patient might be physically and emotionally exhausted from the hospital stay.
- The patient might have medical complications, need to be in the hospital longer, or need more surgeries.
- You might need to learn a complicated medication schedule and understand side effects.
- You will need to take the patient to many appointments (blood draws, transplant check-up, etc.)
- You might need to live with the patient, so you will spend time away from your home.
- You will need to ask for (and accept) help.

## Long-term Recovery

- Recovery might be slower than you expected.
- The patient might be exhausted.
- The patient might have side effects such as tremors, difficulty with memory, or mood changes.

## Maintenance

- You will have a “new normal” -- careful planning to follow restrictions.
- You might worry the patient’s body will reject the new organ or they will need another transplant.
- You or the patient might have financial worries.
- You might have changes in your relationships with friends and family.
- You might have changes in your work, family, and daily priorities.
- You might ask where to go from here.

## Before Transplant: Caregiver Responsibilities

### Evaluation for Listing

First, the transplant team will decide if the patient:

- can survive the transplant surgery.
- will probably do well after the transplant surgery.
- is eligible to be on the transplant list.

The patient must do tests, go to appointments, and follow the treatment team’s health recommendations. Each patient is different, and each organ requires different testing. Learn about common evaluation requirements for each organ by [finding your organ’s section of the toolkit](#)<sup>1</sup>.

The patient must also identify a caregiver. If the patient identifies you as a caregiver, you must:

- go to appointments with the patient.
- learn about transplant.
- meet with the transplant social worker to talk about caregiver responsibilities.
- help the patient communicate with the transplant team.
- agree to all caregiver responsibilities.

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<sup>1</sup> <https://power2save.org/welcome-to-the-caregiver-toolkit/>

Usually, a patient cannot be on the list for a transplant until they have a caregiver who agrees to all caregiver responsibilities. Some transplant teams require a “Family Meeting,” so everyone who will support the patient learns about organ transplantation and helps create a caregiving plan.

After the evaluation, the transplant team will talk about the patient’s case at a selection committee meeting. They will decide if the patient is eligible for a transplant.

### **Listed, Waiting for a Transplant**

As a caregiver, you will support the patient while they wait for a transplant.

Wait times are different for different organs and at different transplant centers. If a living donation is possible (kidney or liver), the wait is shorter. The transplant team will give more specific information about the wait time for your patient.

Treatment teams can remove patients from the wait list if their health condition improves or they are not eligible anymore. They can also put patients on an inactive list, meaning they will **not** receive an organ, even if one is available. There are many reasons a patient can be taken off the wait list or put on an inactive list. **Help the patient communicate with their transplant team, so you and the patient can work through situations that might stop them from receiving an organ.**

Learn more about specific organ transplant evaluations and listings, below.

### During the Transplant Surgery: Caregiver Responsibilities

When an organ is available, the transplant team will call the patient and tell them what time to be at the hospital for surgery. This can happen any time during the day or night.

As a caregiver, you must make sure the patient gets to the hospital in time for surgery. You should have a transportation plan, so everyone is ready when you get the call. Usually, patients who need a liver, heart, or lung transplant stay in the hospital while they wait for a transplant.

#### **Make a Transportation Plan**

Who will drive the patient to the hospital if the call comes during the workday?

Who will drive the patient to the hospital if the call comes at night?

Who will drive the patient to the hospital if the call comes during the evening or weekend?

Who else needs to know about the transplant? Who will communicate with everyone?

What do you need to bring to the hospital?

How long will you stay with the patient in hospital?

**Please remember:** Sometimes, patients are called in for surgery, but the surgery is canceled because the organ might not be a good match for the patient. This can be disappointing. The good news is, though, the patient is high on the list, and they might get another call soon.

After surgery, when the patient is recovering in the hospital, you and the patient will have education sessions with people from the transplant team (transplant coordinator, social worker, pharmacist, physical therapist, dietitian, financial/insurance specialist, and other hospital employees).

You will learn how to care for the patient at home, after they discharge from the hospital. The transplant team starts planning for discharge the day the patient is admitted to the hospital. You will participate in discharge planning.

If you live far away from the hospital, you might need to plan on staying close, depending on how recovery goes. If the patient lives out of town, you must make travel or housing plans before discharge. The transplant social worker can help.

Learn more about organ specific transplant surgery in Resources, below.

## After Discharge: Caregiver Responsibilities

After discharge from the hospital, the patient will still be in recovery. You will take care of the patient at home until they improve enough to take care of themselves. You will:

- prepare meals,
- change wound dressings,
- complete (or ask for help with) household chores,
- help the patient with daily living and hygiene activities,
- track blood pressure, blood sugar, temperature, weight, and fluid intake (ask for tracking documents),
- take the patient to follow-up and lab appointments (weekly to start but less often as the patient improves),
- advocate for the patient, and
- help the patient report concerns or symptoms.

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.

Learn more about post-transplant needs for specific organs, in Resources below.

### Medications

After the transplant surgery, the transplant team will prescribe new medications. 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.

You must:

- help the patient take medication **exactly** when and how it is prescribed.
- order refills.
- make sure the patient is taking 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.

Transplant patients must take some medications for the rest of their lives. Some medications have side effects. For example, transplant patients must take steroids, which can impact mood. Other medications can cause delirium or confusion. Ask the transplant pharmacist if you have questions about side effects.

## Emotional Experience of Transplant Patients: Information for Caregivers

Patients who are waiting for (or have received) a transplant can have many different feelings.

Managing a chronic illness is hard. Patients often struggle with mood, irritability, depression, guilt, strong reactions to difficult situations, anxiety, and dependence on others.

Some patients struggle with body image, pain, discomfort, loss of independence or autonomy, loss of privacy, and financial stress. Many patients feel anxiety about not knowing when they will receive a transplant, having to live in a hotel or another place away from home, and leaving the hospital after surgery.

After transplant surgery, patients might worry about their body rejecting the organ, infection, and money. Also, some medications can cause irritability, changes in mood, and even anger. Ask the transplant team if you are worried about a medication side effect.

You might be confused about the patient's emotional reactions or not know how to respond. Try to remember that these are common feelings patients have as they cope with needing, waiting for, receiving, and recovering from a transplant. Watch for mental health changes in the transplant patient. Tell the transplant team if you are worried about the patient.

Remember that you also must take care of yourself and your own mental health. Being a caregiver is stressful. Ask the transplant team about support for patients and caregivers.

## Communicating with the Transplant Team

The transplant process is overwhelming. Follow these tips to communicate effectively with the transplant team:

- List the contact information of everyone on the transplant team.
  - Put a copy in your wallet or purse, in the patient's wallet or purse, on your refrigerator, and give copies to other support people.
  - See the Transplant Team Contact list at the end of this document.
- Prioritize a list of questions before you talk with the transplant team. (Think about using one notebook for all your questions.)
- Ask for help with health problems as they happen before they become emergencies.
- Give accurate (correct) information to the transplant team.
- Ask if you don't understand something.
- Be open and honest with the transplant team.
- Arrive early for appointments and be respectful of transplant providers' time.
- Ask the transplant team where you can find medical information you can trust.

If you have a conflict with someone on the transplant team, ask yourself:

- Why do I find this person difficult?
- Is the conflict triggering other feelings (I'm not good enough, I'm a failure, I'm not accepted)?
- How do our differences in values, beliefs and culture affect our relationship?
- How do I add to the conflict?
- How does the environment add to the conflict (being in a hospital, unfamiliar location)?

## Questions to Ask Your Transplant Center

- What are the specific requirements for caregivers?
  - How many caregivers are required?
  - Are paid caregivers allowed (from an agency or a friend or relative)?
  - Are there age requirements for caregivers?
- What are the travel requirements before and after transplant?
  - How close to the center must the patient and caregiver be when waiting for transplant?
  - Are there relocation requirements before or after transplant?
- What are the specific caregiver responsibilities at this center? (Share your understanding of caregiver responsibilities.) What information can you give us about the donor?
- What is the process for contacting and communicating with the donor's family?

## Resources

- The United Network for Organ Sharing (UNOS) is a private, non-profit organization that contracts with the federal government to manage policies on how to best use available organs to make sure access to organs is fair. Learn more about the organ transplant process, policies, and how organ transplants are matched with patients:
  - [United Network for Organ Sharing<sup>2</sup>](https://unos.org/)
  - [How Organs are Matched with a Recipient<sup>3</sup>](https://unos.org/transplant/how-we-match-organs/)
- Several non-profit organizations provide free education, peer support, and more resources to family caregivers in the US:
  - [Caregiver Action Network<sup>4</sup>](https://caregiveraction.org/)
  - [Share the Care<sup>5</sup>](https://www.sharethecare.org/)
- The Transplant Recipients International Organization (TRIO) is a transplant specific non-profit organization that provides transplant specific education and resources:
  - [Transplant Recipients International Organization \(TRIO\)<sup>6</sup>](https://www.trioweb.org/)
- The United Hospital Fund created “Next Step in Care: Family Caregivers and Health Care Professionals Working Together” to help transition from the hospital to home. Find practical advice and easy-to-use guides:

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<sup>2</sup> <https://unos.org/>

<sup>3</sup> <https://unos.org/transplant/how-we-match-organs/>

<sup>4</sup> <https://caregiveraction.org/>

<sup>5</sup> <https://www.sharethecare.org/>

<sup>6</sup> <https://www.trioweb.org/>

- [Next Step in Care, Caregivers Guides and Checklists<sup>7</sup>](#)
- Talking to healthcare providers can create stress and anxiety. The National Institute of Health provides videos and written information about communicating clearly with your doctors:
  - [Communications with Providers<sup>8</sup>](#)
- EduMed provides a comprehensive guide with tools, resources, and practical solutions for caregivers:
  - [The Caregiver's Handbook<sup>9</sup>](#)
- Transplant patients often must be careful when they prepare and handle food. The US Department of Agriculture offers a guide for how to handle food safely:
  - [Food Safety for Transplant Patients<sup>10</sup>](#)

## References

1. “Your Caregiver & You: Partners in Success.” Banner University Medicine Transplant Institute. 2020.
2. Engle D. (2001). Psychosocial aspects of the organ transplant experience: what has been established and what we need for the future. *Journal of clinical psychology*, 57(4), 521–549. <https://doi.org/10.1002/jclp.1027>
3. Jesse MT, Hansen B, Bruschein H et al Findings and recommendations from the organ transplant caregiver initiative: Moving clinical care and research forward. *AJT*, 2021; 21(3): 950-957
4. Stages of Transplant (adapted from Balliet, W., 2019)

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<sup>7</sup> [https://www.nextstepincare.org/Caregiver\\_Home/](https://www.nextstepincare.org/Caregiver_Home/)

<sup>8</sup> <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/talking-your-doctor>

<sup>9</sup> <https://www.edumed.org/resources/caregivers-online-handbook/>

<sup>10</sup> [https://www.fsis.usda.gov/sites/default/files/media\\_file/2021-04/at-risk-booklet.pdf](https://www.fsis.usda.gov/sites/default/files/media_file/2021-04/at-risk-booklet.pdf)





## Transplant Team Contact List

	Name	Office Address	Phone Number	Email
<b>Surgeon(s)</b>				
<b>Physicians (Doctors)</b>				
<b>Pre-Transplant Nurse Coordinator</b>				
<b>Post-Transplant Nurse coordinator</b>				
<b>After hours/on-call nurse Coordinator</b>				
<b>Social Worker</b>				
<b>Pharmacist</b>				
<b>Dietician</b>				
<b>Financial Coordinator</b>				
<b>Psychiatrist/ Psychologist</b>				
<b>Other Transplant Team Members</b>				