



# Legal and Financial Considerations for Caregivers

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As a caregiver, you are important to a successful transplant. It's a big job, so you must make sure you are ready.

This section will describe legal and financial parts of being a caregiver. You might ask yourself:

- Can I take time off work to be a caregiver?
- Will I lose income?
- Is my job protected?

## Legal Considerations in Caregiving: Caregiver Rights and Protections

### Family Medical Leave Act (FMLA)

FMLA allows eligible employees to take time off to care for a spouse, child, or parent (not a parent in-law) with a serious health condition. Public and private employers with 50+ employees must provide FMLA benefits.

With FMLA, you can:

- take up to **12 unpaid weeks** per year.
- keep your group health insurance.
- return to the same (or equivalent) position.
- choose to take **continuous leave**. (You have to provide start and end dates for leave. You do not work during that time.)
- choose to take **intermittent leave**. (You take time off as needed, to care for the patient. You don't have a regular schedule for time off.)

Ask your transplant team if they recommend continuous or intermittent leave.

To use FMLA, you must:

- have worked 1,250 hours during the 12 months before the leave starts.
- ask your Human Resources (HR) Department to confirm you are eligible for FMLA.
- tell your employer 30 days before you need to use FMLA, if possible.
- tell your employer as soon as you can, if you cannot give 30-day notice.
- ask the transplant team to complete paperwork for your HR Department.

Learn more about FMLA in Resources, below.

### **Family Responsibilities Discrimination (FRD)**

Being a caregiver can make it difficult to manage responsibilities at work. Family Responsibilities Discrimination, or Caregiver Discrimination, is discrimination (real or perceived) against an employee who is also a caregiver.

Caregiver Discrimination can include:

- not being offered a job or promotion,
- harassment,
- less pay, or
- negative employment action because of your caregiving responsibilities.

Federal law does not directly prohibit Caregiver Discrimination, but some federal and state laws offer protection:

- Title VII of the Civil Rights Act of 1964
- American with Disabilities Act
- Equal Pay Act
- Family Medical Leave Act.

If you think you are experiencing discrimination at work because you are a caregiver, you can file a complaint with the Equal Employment Opportunity Commission or with your state. Learn more about the Equal Employment Opportunity Commission or with your state in Resources, below.

### **Legal Consideration in Caregiving: Advanced Care Planning**

Sometimes, patients cannot make decisions about their medical care, money, or other life areas. In healthcare, this can be temporary, long-term, or permanent. For example, a patient who is sedated for surgery is temporarily unable to talk to their doctor.

Advanced Care Planning gives direction and legal protection to the patient and family. The medical decisions made for the patient follow the patient's wishes, beliefs, and values.

There are different Advanced Care Planning documents for different areas of the patient's life. We recommend you work with a lawyer to complete these documents.

## **Advanced Directives**

Document: **Power of Attorney for Healthcare** (or **Medical Power of Attorney** or **Healthcare Proxy**)

- A patient uses this legal document to identify an agent (or proxy).
- The agent can make medical decisions for the patient, following the patient's wishes.
- The patient can include restrictions for decision making.
- The agent can only make decisions if the patient's medical team decides the patient cannot make decisions.
- Every agent and every healthcare provider must have a copy of this document.

Document: **Living Will**

- A patient uses this legal document to document their wishes for medical treatment.
- Living Wills cover: CPR, breathing tubes, tube feeds, antibiotic medications, pain management, dialysis, organ and tissue donation, etc.
- A Living Will is limited to the information everyone has at the time it is written.
- Every agent and every healthcare provider must have a copy of this document.

Patients and agents must talk about the patient's values, wishes, and priorities, especially how important independence and self-sufficiency are to the patient. For example, does the patient want treatment to stay alive, even if they need a feeding tube?

The American Bar Association has a Health Care Advance Planning Toolkit to help with these conversations. Learn more about the Health Care Advance Planning Toolkit in Resources, below.

Find state specific or universal power of attorney forms in Resources, below.

If a patient does not have a medical power of attorney, they can ask for the document at the hospital (if they are competent enough to sign it).

## **Legal Next of Kin**

When a patient cannot make medical decisions but they don't have a Power of Attorney for Health Care, the legal next of kin can make decisions.

Most states have laws that decide who is a patient's legal next of kin. Usually, if the patient is legally married, the spouse is the legal next of kin. Consult with your healthcare team for clarification of the rules specific to your state.

## **Power of Attorney for Finances**

Document: **Power of Attorney for Finances**

- A patient uses this legal document to identify an agent (or attorney-in-fact).
- The agent can make money decisions for the patient.
- This document can be effective immediately or when a specific situation happens.
- Patients should work with a lawyer to complete this document.

## **Managing Social Security/Veterans Benefits**

The Social Security Administration and Veterans Affairs will **not** recognize a Power of Attorney for Finances.

If the patient receives Social Security Benefits (like retirement), they must identify a “representative payee.” The payee will receive Social Security Benefits and manage them for the patient.

If the patient receives Veterans’ Benefits (like disability), they must identify a “VA fiduciary.” The VA fiduciary will receive VA benefits and manage them for the patient.

Learn more about social security and veterans’ benefits in Resources, below.

## **Guardianship**

Rarely, an adult patient may need a guardian if they cannot care for their own well-being because of a mental incapacity or disease.

Guardianship:

- is a legal process that goes through the court system.
- takes rights away from a person who cannot make decisions by themselves.
- gives decision-making authority to a court-appointed guardian.
- differs by state. Learn more in the American Bar Association’s “Adult Guardian Handbooks by State in Resources, below.

If needed, talk about guardianship with the transplant team to choose appropriate caregivers.

## **Financial Considerations for Caregiving**

Unfortunately, caregivers do not receive many financial incentives. In the United States, caregivers cannot receive short-term disability or tax breaks.

Sometimes, Medicaid benefits offer paid caregiving. This is different by state. There are some contingencies. Learn more about your state in Resources, below. Some caregivers use paid leave programs or fundraising to help with money.

## **Paid Leave Programs**

The United States does not have a Federal paid leave program. Some states and cities have paid leave programs. Learn more about state paid leave programs in Resources, below.

## **Fundraising**

Fundraising organizations can help transplant patients and caregivers raise money for caregivers’ expenses. These organizations:

- raise money for caregivers’ transportation, parking, lodging, and meals.
- are non-profit agencies, so donors can usually claim tax deductions.
- hold the money, so donations do not affect caregivers’ income or eligibility for income-based programs.
- can also help you with your fundraising activities. See Resources, below.

## Questions to Ask Yourself and Your Transplant Center

- Will I lose income?
- How will I make up the lost income?
- Can I afford to lose that income?
- Am I eligible for FMLA benefits at work?
- Have I talked to my employer about taking time off?
- How much paid vacation time do I have?
- Do I have legal protection through my employer or state government?
- Can I keep my insurance if I take time off work?
- Do I have to pay my insurance premium out of pocket?
- Do other people depend on me financially? Will they be affected?
  - Do I care for other people? Will I have to pay for their care?
  - Do I have children that will need childcare or afterschool programs?
  - Do I have a pet that will need boarding?
- What extra costs will I have, as a caregiver? For example, buying food for the patient, hotels costs while the patient is hospitalized, transportation for appointments, etc.
- If I am caring for someone in another state, can I pay for a last-minute plane ticket and other travel expenses?
- Can I pay my bills if I take time off work? For example, utilities, phone, credit card, house, etc.
- Am I responsible for making sure the patient's bills are paid?
- Have I talked with the patient about Power of Attorney for Healthcare and Finances?
- If the patient has already completed Power of Attorney for Healthcare and Finances, can I provide the original copies?

## Resources

- Family Medical Leave Act (FMLA):
  - <https://www.dol.gov/agencies/whd/fmla/faq>
  - US Department of Labor: Need Time? The Employee's Guide to the Family and Medical Leave Act: <https://www.dol.gov/agencies/whd/fmla/employee-guide>
  - FMLA Breakdown by State: <http://www.employmentlawhq.com/state-by-state-map.html>.
- Family Responsibilities Discrimination
  - File Complaints Through the Equal Employment Opportunity Commission: [www.eeoc.gov](http://www.eeoc.gov)
  - File Complaints Through Your State: <https://www.workplacefairness.org/filing-discrimination-complaint>
- Power of Attorney for Healthcare
  - American Bar Association Healthcare Advance Planning Toolkit: [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2020-tool-kit-hcap.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-tool-kit-hcap.pdf)

- State Specific Advance Planning Forms: [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2018-Inks-to-st-specific-advance-directive-forms.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-Inks-to-st-specific-advance-directive-forms.pdf)
- Universal Power of Attorney for Health Care Form (not valid for use in New Hampshire, Ohio, Texas, Wisconsin, and Indiana)
- State specific statutes for legal next of kin: [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2019-sept-default-surrogate-consent-statutes.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-sept-default-surrogate-consent-statutes.pdf)
- Managing Social Security/Veterans Benefits
  - Social Security Administration: [www.ssa.gov](http://www.ssa.gov)
  - Veteran's Administration: [www.va.gov](http://www.va.gov)
- Guardianship
  - American Bar Association Adult Guardian Handbook by State: [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2019-gshp-adult-gship-hdbks-state.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-gshp-adult-gship-hdbks-state.pdf)
- Paid Leave Programs by State: <https://nationalpartnership.org/economic-justice/state-paid-leave-laws/>
- Fundraising
  - Help Hope Live: <https://helphopelive.org/>
  - National Foundation for Transplants: <https://transplants.org/>

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