

## Quick Guide to Caregiving

When someone you care about is diagnosed with cancer, there is a natural desire to find a way to help and support that person. For caregivers there are several things to think about, including legal protections and benefits at the federal, state, and even city levels that may be helpful to balance your caregiving responsibilities with your employment and help replace lost income. It is also important to keep in mind that as a caregiver, you need to care for yourself, and there are resources to support you.

There are a number of places to look for information about your employment rights as a caregiver:

**Fair Employment Laws:** provide caregivers with protection against discrimination at work

- **Federal law: Americans with Disabilities Act (ADA)**
  - Title I of the ADA provides protections in the workplace for individuals with disabilities and caregivers.
  - Employers covered by Title I of the ADA:
    - Private employers with 15+ employees
    - Employment agencies, labor organizations, and joint labor-management committees
    - State and local governments of any size
    - Employees of the federal legislative branch (e.g., employees of the Senate, House of Representatives, and agencies that support Congress). Note: federal executive branch employees (e.g., U.S. Post Office, agencies, etc.) covered by Rehabilitation Act of 1973.
  - Employee's eligible for protection under the ADA:
    - Are “qualified individuals (i.e., they can perform the essential functions of the job, with or without reasonable accommodations), and have a physical or mental impairment that substantially limits one or more major life activities (i.e., sleeping, concentrating, operation of major bodily functions, etc.)
    - Includes protection for individuals with disabilities who currently have a disability, have a history of having a disability, or are regarded as having a disability by their employer
    - Also includes protection for individuals who “associate with an individual with a disability” (i.e., caregivers)
  - For more information about the ADA: [TriageCancer.org/QuickGuide-ADA](http://TriageCancer.org/QuickGuide-ADA)
  - Title I of the ADA also requires employers to provide reasonable accommodations to eligible employees. While caregivers are not entitled to reasonable accommodations under the ADA, they may still want to consider asking their employer for the types of work adjustments that could be considered reasonable accommodations (e.g., a flexible schedule, telecommuting, etc.).
  - For more information about reasonable accommodations: [TriageCancer.org/QuickGuideReasonableAccommodations](http://TriageCancer.org/QuickGuideReasonableAccommodations) or watch this animated video [TriageCancer.org/Video-SideEffectsatWork](http://TriageCancer.org/Video-SideEffectsatWork)
- **State laws:** Most states also have a state fair employment law, similar to the ADA, but may also be more protective, so it is important to look at state laws, as well: [TriageCancer.org/StateLaws](http://TriageCancer.org/StateLaws)



**Leave Laws:** allows employees to take time off work and provide some job protection and health insurance protection

- **Federal law: Family & Medical Leave Act (FMLA)**

- The FMLA allows eligible employees to take up to a total of 12 weeks of unpaid, job-protected leave, per year, either for their own serious medical condition, or as a caregiver of a spouse, parent, or child with a serious medical condition:
  - Parents
  - Spouses (note: includes common law spouses and same-sex spouses as of 3/27/15, but not domestic partners)
  - Children (biological, foster, adopted, step, or in loco parentis)
    - The law allows for caregiving of children over the age of 18, if the child is “incapable of self-care because of a mental or physical disability.”
- Types of caregiving duties include:
  - Providing care when the family member is unable to care for his or her own basic medical, hygienic, nutritional, or safety needs, or is unable to transport himself or herself to the doctor, etc.;
  - Providing psychological comfort and reassurance; or
  - Filling in for others who normally care for the family member or to make arrangements for changes in care.
  - Note: the employee does not need to be the only person available to provide caregiving.
- Employers covered by the FMLA, are:
  - Private employers with 50+ employees in 20 or more workweeks in the current or preceding calendar year;
  - Public agencies, including a local, state, or federal agency, regardless of number of employees; or
  - Public or private elementary or secondary schools, regardless of number of employees.
- Employees eligible for leave under the FMLA:
  - Have worked for the same covered employer for at least 12 months in the last 7 years;
  - Have at least 1,250 hours of service for the employer during the 12-month period immediately prior to leave; and
  - Work at a location where the employer has at least 50 employees within 75 miles of the employee’s worksite.
- Medical Certification: your employer is entitled to a medical certification from a health care provider to show why you are eligible for medical leave.
  - If you are concerned about protecting your privacy in the workplace, read: [TriageCancer.org/QuickGuide-Disclosure](http://TriageCancer.org/QuickGuide-Disclosure).
  - The U.S. Department of Labor has a model FMLA form for caregivers: [TriageCancer.org/FMLACert-Family-Family](http://TriageCancer.org/FMLACert-Family-Family).
- For more information about the FMLA: [TriageCancer.org/QuickGuide-FMLAExtended](http://TriageCancer.org/QuickGuide-FMLAExtended)



- **State and local laws:** Some states, counties, and cities also provide laws that allow people to take time off for a variety of caregiving reasons. For example:
  - Some states have a family and medical leave law similar to the FMLA, that covers smaller employers. Ex: CA (5), DC (20), ME (15 private employers, 25 public employers), MD (15), MN (21), NY (all private employers), OR (25), RI (30 for public employers), VT (15), WA (all employers)
  - Some state family and medical leave laws have a broader definition of who you can care for, such as: CA, CT, DC, HI, MD, ME, NJ, NY, OR, RI, VT, WA, WI
  - Some states allow employees to use unpaid leave to take family members to routine medical visits, such as MA and VT. And, some states allow employees to use their sick time to care for a child. These are called kin care or kinship laws. Some states require employers to provide general leave.
  - For more information about state laws: [TriageCancer.org/StateLaws](https://TriageCancer.org/StateLaws). For more information about county and city laws: [TriageCancer.org/StateResources](https://TriageCancer.org/StateResources).

**Employment Contracts:** Employees who work under a contract or union bargaining agreement, may have additional rights or benefits that are included in those contracts.

**Employer Policies:** The federal and state laws are the minimum of what employers must provide to their employees. Many employers provide additional benefits. Check your employee handbook or with your employer to learn more about what your specific employer provides. Things to look for:

- Insurance benefits
- Policies that allow for telecommuting or flexible schedules
- Policies that allow a caregiver to use their own sick leave or paid time off (PTO) for caregiving
- Policies that allow co-workers to donate their leave hours to you
- Process for asking for medical leave as a caregiver

**Income for Caregivers:** There are some limited options for caregivers to replace the wages lost while taking time off work as a caregiver.

- State Paid Leave for Caregivers: a few states offer programs that provide paid leave for caregivers who need to take time off work: CA, CT, DC, NH (for state employees, voluntary for private employers), MA, NJ, NY, RI, WA. These states have new laws: OR (9/3/23), CO (1/1/24), MD (1/1/25), DE (1/1/26).
- In-Home Support Services: through a state's Medicaid program, if someone is eligible for Medicaid, they may be able to not only get caregiving services, but have a family member paid for providing those services. For more information about these state options: [TriageCancer.org/StateLaws](https://TriageCancer.org/StateLaws).

**Other Considerations for Caregivers:** Other things to think about include managing family finances, lowering your out-of-pocket medical expenses, and planning ahead. These resources can help:

- Practical Guide to Cancer Rights for Caregivers: [TriageCancer.org/Guide-Caregiver](https://TriageCancer.org/Guide-Caregiver)
- Cancer Finances: [CancerFinances.org](https://CancerFinances.org)
- Checklist to Minimize Financial Toxicity: [TriageCancer.org/Checklist-FinancialToxicity](https://TriageCancer.org/Checklist-FinancialToxicity)
- Financial Resources: [TriageCancer.org/Financial](https://TriageCancer.org/Financial)

**Support for Caregivers:** Caregiving can be stressful. These resources can provide support:

- Embracing Carers: [www.embracingcarers.com](https://www.embracingcarers.com)
- Stress Management Resources: [TriageCancer.org/StressManagement](https://TriageCancer.org/StressManagement)
- MyLifeLine: [www.MyLifeline.org](https://www.MyLifeline.org)
- Lotsa Helping Hands: [www.lotsahelpinghands.com](https://www.lotsahelpinghands.com)
- Meal Train: [www.mealtrain.com](https://www.mealtrain.com)
- Cancer Care: [www.CancerCare.org](https://www.CancerCare.org)

## Estate Planning & Medical Decision Making Considerations for Caregivers

Depending on how you are related to the person you are caring for, the law may treat you differently, and you may have additional things to consider. There may come a point when your loved one is unable to express their wishes about their finances or their medical care.

In those cases, estate planning documents such as a financial power of attorney and an advance health care directive are useful tools for them to express their wishes as well as name an agent to make decisions on their behalf. Although estate planning plays a crucial role in financial and health care decisions, many people do not even have the most basic document, a will. There are a variety of documents that could make up an estate plan.

If you are your loved one's agent for estate planning decisions, it is important to have a conversation to make sure you understand, and can execute, their wishes.

- For information about different types of estate planning documents: [TriageCancer.org/QuickGuide-EstatePlanning](https://TriageCancer.org/QuickGuide-EstatePlanning).
- For help with getting organized: [TriageCancer.org/Checklist-GettingOrganized](https://TriageCancer.org/Checklist-GettingOrganized).
- For more information about estate planning: [TriageCancer.org/EstatePlanning](https://TriageCancer.org/EstatePlanning).

Additionally, as an agent you should make sure that you know where important documents (e.g., the advance health care directive or will), are kept as well as how to access accounts, safety deposit boxes, and storage units. Compiling information in one place, like the Triage Cancer Financial Big Picture document may be useful ([TriageCancer.org/FinancialBigPicture](https://TriageCancer.org/FinancialBigPicture)).

If you are not married, it may be necessary to have a signed Authorization for Use or Disclosure of Protected Health Information (i.e., a HIPAA release form) so that you are able to obtain their medical information should you need to make decisions on their behalf.

Almost all estate planning documents require that the person creating the document be of "sound mind." Which means that the person must have the mental capacity to understand what they are doing.

Therefore, it is important for estate planning documents to be created before one's health deteriorates. Caregivers may have to bring up the subject of estate planning with their loved one. If you are struggling with this task, a social worker or other mental health professional might be able to help you have these conversations. Although not required to create an estate plan, some people prefer to work with an attorney. For information about finding an attorney: [TriageCancer.org/QuickGuide-LegalAssistance](https://TriageCancer.org/QuickGuide-LegalAssistance).

**Respite Care:** Caregivers may sometimes need help with or need a break from their caregiving responsibilities. Consider asking other family members, friends, neighbors, or other members of your support community to help. Professional respite services can also be provided through in-home care agencies, adult day services, facilities that allow short-term stays, and individuals you hire directly. There may also be retreats or meetings in your area to support caregivers. Help may be available from organizations, such as:

- Family Caregiver Support Program (FCSP) - Area Agency on Aging: [eldercare.acl.gov](https://eldercare.acl.gov)
- Caregiver Action Network: [www.caregiveraction.org](http://www.caregiveraction.org)
- Family Caregiver Alliance: [www.caregiver.org](http://www.caregiver.org)
- Arch National Respite Network and Resource Center: [www.archrespite.org](http://www.archrespite.org)

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