

Resources for Caregivers

Caregiving for someone with cancer can be extremely challenging, both physically and emotionally. Caregivers are individuals who regularly assist someone else. Each situation is different, and a caregiver's role may change depending on the needs of the patient over time. Caregivers may live with the person they are caring for, share caregiving responsibilities with family and friends, or provide long distance care through phone and email. There are resources available to help caregivers understand their rights and responsibilities, as well as to provide support.

What are a caregiver's legal responsibilities?

There is generally no legal requirement to become a caregiver, regardless of whether the person who is ill is a family member or a close friend. A person can take on responsibility for a patient's health, which can create a duty of care. Whether a caregiver has taken on a duty to care for another person and the extent of the duty will depend on each situation.

What types of legal protections do caregivers have?

It is important to **check individual state laws and services**, which may provide additional coverage or benefits.

- **Discrimination:** The **Americans with Disabilities Act (ADA)** prohibits private employers with 15 or more employees from excluding/denying equal jobs or benefits because of an individual's *relationship or association* with an individual who has a disability (which can include cancer or the effects of cancer). Although caregivers are protected against job discrimination due to their associations with a person with cancer, they are not entitled to reasonable accommodations, such as a reduction of work hours or modification of the workplace (unlike a person with a disability, who may be eligible for accommodations).
- **Unpaid Family Leave:** The **Family and Medical Leave Act (FMLA)** allows qualified employees to take up to 12 weeks of unpaid leave (at once or in shorter blocks of days or even a few hours) within a 12 month period. This law applies to patients *and* caregivers of a spouse, child, or parent with a "serious health condition." Employers must have at least 50 employees within a 75-mile radius in order for their employees to qualify for FMLA leave. Employees at those companies must have worked at least 1250 hours in the past 12 months, and must have worked for the employer for at least a total of 12 months in the last 7 years. Medical certification from a health care professional is often required, stating that the caregiver's services are needed.
- **Paid Family Leave:** Paid family leave is only available in certain states, so it is important to check with your local government agency to see whether it is an option in your state. The states that do have the program provide partial wage replacement during leave for a limited period of time. Paid Family Leave programs are usually run through the state's short term disability insurance program.

Is professional caregiving assistance available?

- **State Programs:** Many state or local health departments have licensed home care agencies. Services can include visits by nurses or social workers, medicine delivery, and help with daily tasks. Clients can pay privately or through private insurance coverage. These agencies may also contract to provide services to patients on Medicare and Medicaid.
- **Private long-term care insurance:** Private long-term care insurance may cover some home care. Ask the insurance agent to explain benefits and conditions, or read over your loved-one's policy to know whether he or she has coverage.
- **Consumer-Directed Programs:** Some states have consumer/patient-directed programs which would pay a family member or friend in certain circumstances. Strict rules and waiting lists may apply. Contact your local Medicaid office or the National Resource Center for Participant-Directed Services (www.bc.edu/nrcpds/ or (617) 552-6582).
- **Hiring a Private Professional or Friend:** Formal care contracts may set up a payment arrangement between patient and caregiver. It is important to consult a lawyer if possible to make sure the contract meets tax (see Publication 926, Household Employer's Tax Guide and I-9 Employment Eligibility Verification at www.IRS.gov or (800) 829-3676) and Medicaid requirements (if necessary) and is approved by all interested parties. Check to see if household insurance (renter's or homeowner's) covers household employees in case of an accident. If hiring a friend, do not forget to consider potentially serious emotional pitfalls.

What documents can provide assistance with caregiving?

Having difficult conversations early is important so that the patient can create valid legal documents while he or she has the ability to understand and make informed decisions. Check to make sure existing documents are up to date, that they follow current state laws, assets are all covered, and the correct beneficiaries are named. It can be helpful to talk to an attorney to avoid common mistakes which could result in making the documents invalid.

1. **Living Will** – gives instructions regarding medical care if the patient is unable to speak for him- or herself. May include information regarding life prolonging treatment at the end of life, food and water, palliative care (pain relief), and Do Not Resuscitate (DNR) orders. Some states only recognize living wills as part of an Advance Health Care Directive.
2. **Advance Health Care Directive/Durable Power of Attorney** – allows the patient to name another person to oversee healthcare wishes and make necessary medical decisions in case the patient becomes unable to act for him or herself. It is possible to give as much or as little authority as desired. May include types of treatment that should or should not be used -includes a Do Not Resuscitate (DNR) order if desired.
 - a. Hospital Visitation Directive – states who may or may not visit in the hospital. May sometimes be included with the Durable Power of Attorney for healthcare or a separate document.
3. **Power of Attorney for Financial Affairs** – allows a patient to name another person to handle financial matters for him or herself, including paying bills, signing/depositing checks, accessing bank accounts.
4. **Medical Records Access** – written permission is needed for a caregiver (who is not a parent or guardian) to access medical records.

For more information and assistance regarding caregivers:



DIRECT LINE: 866-THE-CLRC (866-843-2572)
ONLINE INTAKE FORM : www.CLRCintake.org
EMAIL: CLRC@DRLCenter.org
Fax : 213-736-1428
Video Relay Phone : 213-908-1079
www.CancerLegalResourceCenter.org

American Cancer Society

(800) 227-2345

www.cancer.org/treatment/caregivers/

(Pamphlets, self care, & caregiving tips)

Cancer Support Community

(888) 793-9355 www.cancersupportcommunity.org

(Tips, educational information, trainings, nationwide classes, & support groups)

Cancer.net (888) 273-3508 www.cancer.net/coping/caregiving

(Tips, self care, caregiver assistance, home and long distance care information)

CancerCare

(800) 813-4673 www.cancer.org/tagged/caregiving

(Podcasts, telephone & group support, publications, financial assistance)

Caregiver Action Network

(301) 942-6430 www.caregiveraction.org

(Educational information, peer support)

Family Care Alliance

(800) 445-8106 www.caregiver.org

(State by state guide to resources, caregiver education, information, & trainings)

Lotsa Helping Hands <http://www.lotsahelpinghands.com/>

(This online community helps you coordinate caregiving tasks among family members and friends)

National Alliance for Caregiving

<http://www.caregiving.org/>

(A non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation and advocacy)

National Cancer Institute

(800) 422-6237 www.cancer.gov/cancertopics/coping/caring-for-the-caregiver/page1

(Pain management, clinical trials, caregiver resources, & education)



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DRLCenter.org



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National Caregivers Library

(804) 327-1111 www.caregiverslibrary.org

(Articles, forms, checklists)

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