Resources for Caregivers

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

**What are a caregiver’s legal responsibilities?**

If a person decides to become a caregiver for a loved one, their duty to care for the other person and the extent of the duty will depend on each situation. While caregiving duties can vary dramatically from person to person, common caregiving duties can include helping with personal care, preparing meals, making sure the patient is taking his or her medication accordingly, helping the patient move around their home, making medical appointments, and transporting their loved one from place to place. Simply put, the caregiver has the duty to provide assistance to the patient according to his or her needs.

- **Are parents required to take care of their adult children?**

  A parent’s duty to take care of their child ends when their child reaches the age of majority (usually age 18) in their state. However, many states have laws that require a parent to continue their parental care after their child reaches the age of majority, if the child has a disability that causes him or her to be unable to take care of themselves. That being said, if an adult develops cancer later in life and his or her parents are still alive, his or her parents are usually not legally required to take care of their adult child.

- **Are adults required to take care of their aging parents?**

  Adult children are generally not legally bound to take care of their aging parents, but some states have “filial responsibility” laws that require adult children to financially support an aging parent in need of financial or general support, or to potentially reimburse the state for services used by the aging parent. Although these laws exist in many states, they are rarely enforced. For questions about filial responsibility laws in your state, contact the CLRC.

**What are a caregiver’s financial responsibilities?**

Generally, a person does not take on financial responsibilities for their loved one when he or she chooses to become a caregiver, but there are certain circumstances where a caregiver is responsible for a patient’s expenses. For example, a caregiver would be financially responsible for the debts of the person he or she cares for if the caregiver co-signed a credit card or loan with
the patient or signed other forms at the doctor’s office or hospital agreeing to be financially responsible for any expenses not covered by insurance.

For people who are married, some states follow a rule called the “doctrine of necessaries.” In those states, the doctrine of necessaries makes a spouse liable for his or her spouse’s necessary expenses that are related to their health and well-being, such as medical bills, utility bills, rent, food, and clothing. Under the doctrine of necessaries, if one spouse accumulates medical debt, his or her spouse may be responsible for helping to pay off that debt, even if the caregiving spouse did not sign for or authorize the treatment, and even if the spouse who was sick dies. To learn about whether the doctrine of necessaries applies in your state, contact the CLRC. If a person dies with debt and there is no one legally bound to pay off their debt, the debt of the person who died will be paid off from their estate (whatever money and property they left behind). This may impact how much money and property is left over to distribute to the heirs of the person who died.

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 (all 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 (located within a 75-mile radius of where the employee reports to work) in order for their employees to qualify for FMLA leave. To qualify for leave, an employee must have worked at that employer for 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. As of July 2019, California, New Jersey, New York, Rhode Island, and Washington (effective January 2020) offer paid family leave.
Can I hire someone to provide caregiving services for my loved one, or to help me in my role as a caregiver?

Caregiving can be challenging, but there are different resources that a caregiver can turn to when they need help or time off. There are respite care services, state programs, care insurance programs, and consumer directed programs that are available to caregivers when they need to take time for themselves.

- **Respite Care**: Respite care services allow caregivers to take time off from their role as a caregiver while someone else cares for the patient. Respite care services can be arranged according to the caregivers needs. For example, the caregiver might arrange for an afternoon off or for several weeks off. The services also vary as the patient can be transferred to a healthcare facility to be looked after or services can be arranged to be performed in the patient’s home. People usually pay for respite care out of pocket, but Medicare, Medicaid, and some long-term care insurance plans might cover the costs associated with respite care.

- **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 an insurance agent to explain benefits and conditions before purchasing a plan, or read over your loved-one’s policy to know whether he or she has coverage. Keep in mind that usually long-term care insurance carriers can discriminate based on pre-existing conditions, so if your loved one does not have a policy before he or she becomes ill, it may not be possible (or may be very expensive) to obtain a policy.

- **Consumer-Directed Programs**: Many state Medicaid programs offer services where a chronically ill or physically disabled Medicaid enrollee can hire someone to help perform every day activities (sometimes called In Home Supportive Services). If the enrollee/patient wishes for a family member or friend to be the person that provides care to them, 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 at [www.medicaid.gov/about-us/contact-us/contact-state-page.html](http://www.medicaid.gov/about-us/contact-us/contact-state-page.html) for more information.

- **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 regulations, Medicaid requirements (if necessary), and is approved by all interested parties (For more information see Publication 926, Household Employer’s Tax Guide [www.irs.gov/pub/irs-pdf/p926.pdf](http://www.irs.gov/pub/irs-pdf/p926.pdf) and I-9 Employment Eligibility Verification at [www.uscis.gov/i-9](http://www.uscis.gov/i-9). Also, 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. For a general overview of Employment Taxes for Household Employees visit [www.irs.gov/taxtopics/tc756](http://www.irs.gov/taxtopics/tc756).

**What kinds of legal documents can be helpful to a caregiver?**
Having difficult conversations early is important so that a patient can create valid legal documents while he or she has the ability to understand and make informed decisions about who will get their property and valuables after they are gone or about who will make decisions about their health care if they are not able to do so. Check to make sure existing documents, like wills and trusts, are up to date, and that they follow current state laws. It can be helpful to talk to an estate planning 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 himself 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, and accessing bank accounts. A power of attorney may be revoked, but most states require written notice of revocation to the person named to act for you.

Medical Records Access – written permission is needed for a caregiver (who is not a parent or guardian) to access medical records. The Health Insurance Portability and Accountability Act (HIPAA) enables individuals to decide how their health information and medical records may be used and who can access them. Visit [www.hhs.gov/hipaa/for-individuals/index.html](http://www.hhs.gov/hipaa/for-individuals/index.html) to learn about rights under HIPAA, how information may be used or shared, and how to file a complaint if you think rights were violated.

**For more information and assistance regarding caregivers:**

**American Cancer Society**  
(800) 227-2345  
(Pamphlets, self-care, and caregiving tips)

**Cancer Fighters**  
[www.cancerfighter.com/get-support/caregiver-support/](http://www.cancerfighter.com/get-support/caregiver-support/)  
(Provides emotional support, and resources for caregivers and their families.)

**LIVESTRONG**  
(1-855) 220-7777  
[www.livestrong.org/we-can-help/caregiver-support](http://www.livestrong.org/we-can-help/caregiver-support)  
(Matches caregivers with other caregivers by cancer type, experience with specific cancer treatment, gender and location to talk about their experiences.)
Cancer Support Community  
(888) 793-9355  
www.cancersupportcommunity.org/caregivers  
(Tips, educational information, trainings, nationwide classes, and 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  
http://www.cancercare.org/tagged/caregiving  
(Podcasts, telephone and group support, publications, financial assistance)

Caregiver Action Network  
(202) 454-3970  
https://caregiveraction.org/  
(Educational information, peer support)

Family Caregiver Alliance  
(800) 445-8106  
www.caregiver.org  
(Resources, caregiver education, information, and trainings)

Lotsa Helping Hands  
www.lotsahelpinghands.com  
(Online community coordinates caregiving tasks among family members and friends)

My Cancer Circle  
mycancercircle.lotsahelpinghands.com/caregiving/home/  
(Online support community for caregivers that provides private spaces for support and coordinating volunteer activities)

National Alliance for Caregiving  
(301) 718-8444  
www.caregiving.org  
(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, and education)

National Caregivers Library  
(804) 327-1111  
www.caregiverslibrary.org  
(Articles, forms, and checklists)

Cancer Hope Network  
(877) 467-3638  
www.cancerhopenetwork.org/what-we-do/caregiver-support.html  
(Matches family members and caregivers with trained volunteer caregivers)

Help for Cancer Caregivers  
www.helpforcancercaregivers.org/  
(Creates Personal Care Guides to help caregivers with their well-being)

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