



Cancer Legal  
Resource Center  
A DRLC PROGRAM



## Patient Legal Handbook

### Telephone

(866) THE-CLRC (843-2572)

### Website

[cancerlegalresources.org](http://cancerlegalresources.org)

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# A Letter from Our Director

Dear friends,

When thinking about cancer, we often consider only the medical buzzwords: prevention, screening, treatment, and side effects. However, as you may already know, cancer can take a significant toll on many aspects of a patient's life, including finances, employment, insurance, and housing, not to mention the toll it can take on the family. Although it should not require legal assistance or information to access health care or preserve one's job, it too often does.

The Cancer Legal Resource Center (CLRC) was established in 1997 as a program of the Disability Rights Legal Center in Los Angeles, California, as a way of addressing the unique legal issues faced by people with cancer throughout the United States. We believe that a little knowledge about common legal issues faced by those with cancer can go a long way in preventing significant legal or financial difficulties down the road and can empower patients to enforce their rights themselves, hopefully before they even need to hire an attorney. Our program primarily focuses on patient and provider education, and we maintain a panel of attorneys throughout the country for referrals for more complicated matters.

Over the last seven years, I have listened to the stories of thousands of patients, caregivers, and family members. One of the most heartbreaking things that I hear from survivors is that they wish they had known about the Cancer Legal Resource Center and the legal information we provide when they were first diagnosed. As a result, we have created this handbook to highlight many of the common questions we hear from patients and their families. We hope to one day ensure that all people who are newly diagnosed with cancer have access to this handbook and are aware that there are resources available to provide assistance.

Since our founding, we have provided information and resources to over 500,000 caregivers, survivors, health care providers, and people living with cancer through our outreach events, workshops, webinars, conferences, national telephone assistance line, and print materials. If you have additional questions that are not answered in this handbook, please reach out to us by submitting your cancer-related legal questions online at [www.clrcintake.org](http://www.clrcintake.org) or by leaving us a message at 866-THE-CLRC. If you have an urgent or complicated legal issue, please contact an attorney, or legal aid organization in your area. Please also visit [www.cancerlegalresources.org](http://www.cancerlegalresources.org) to explore our free online library of handouts and webinars for more in-depth information.

We look forward to continuing to serve the cancer community and hope that you find this resource helpful.

Sincerely,



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Stephanie A. Fajuri, Esq.  
Director, Cancer Legal Resource Center



*This handbook is intended to provide general information that will not necessarily apply to every individual patient, and does not and cannot serve as legal or medical advice. If you have an urgent or complicated legal issue, please contact an attorney, legal aid organization in your area, or visit [www.cancerlegalresources.org](http://www.cancerlegalresources.org) to explore our free online library of handouts and webinars for more in-depth information. You may also submit your cancer-related legal questions online at [www.clrcintake.org](http://www.clrcintake.org) or leave us a message at 866-THE-CLRC.*

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# Work



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# Taking Time Off Work

The Family and Medical Leave Act (FMLA) gives eligible employees the right to take up to 12 weeks of unpaid, job- and health benefit-protected leave per year. This leave may be taken all at once or in smaller increments. FMLA applies to all public employers, and to private employers with 50 or more employees. A worker may be eligible if all of the following conditions apply:

- The employee has worked for his/her employer at least 12 months, and
- The employee has worked at least 1,250 hours within the past 12 months, and
- The employee has worked at a company location with 50 or more employees within a 75-mile radius.



## PRACTICAL TIP

Disclosing your cancer diagnosis to your employer is a personal decision. If you do not wish to disclose your diagnosis to your employer, ask a doctor other than your oncologist to certify your need for medical leave, sharing just enough information to make it clear that you are unable to work because you have a serious health condition.

A worker is eligible to receive up to 12 weeks of unpaid leave each year for any of the following reasons:

- The arrival of a new child in the family, whether by birth, adoption, or foster care
- Caregiving for an immediate family member, such as spouse, child, or parent, with a serious health condition requiring a doctor's care,
- Employee inability to work due to a serious health condition.

Follow these rules to request FMLA leave:

- Give at least 30 days' notice or notice as soon as possible,
- Provide enough information to justify the need for FMLA leave, with its expected time and duration,
- If required by employer, fill out the FMLA Medical Certification Form or other medical certification form. The healthcare provider may need to complete a certification form to verify the employee's health condition.

If you do not qualify for FMLA, you may still be entitled to medical leave under state law or your employer's rules. Check with the CLRC or your HR representative.

For more information, call (202) 693-0066 to speak with the Department of Labor, Family Medical Leave Act, or visit [www.dol.gov](http://www.dol.gov). Federal employees should contact the Office of Personnel Management (OPM) for questions related to FMLA at [www.opm.gov](http://www.opm.gov) or (202) 606-7400.

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# Staying Employed During and After Medical Treatment

While some people continue working during cancer treatments, others need time off or flexible schedules. Depending on employer size, a worker with cancer may be entitled to protection under both the Americans with Disabilities Act (ADA) and FMLA. Also, most states have fair employment laws that provide protection for employees with disabilities at very small businesses.



## PRACTICAL TIP

If you are eligible for reasonable accommodations at work, it is important to request them before your work performance is affected. If your employer does not know about your need for an accommodation and your work suffers, your employer may be able to take negative actions against you, including write-ups and even job termination.

The ADA applies to businesses with 15 or more workers and requires employers to make reasonable work environment or work policy changes (called accommodations) so an employee with a disability (like cancer) can perform the essential functions of his/her job. This applies as long as the accommodations do not create an undue hardship for the employer by being too expensive, inconvenient, or fundamentally changing the employee's job functions. Reasonable accommodations can include flextime, work from home, use of special equipment, or time off, but what is considered "reasonable" varies depending on the accommodation requested, the nature of the employee's job, the employer's size/resources, and other factors.

Keep records of all employer and/or human resource conversations regarding accommodation requests. Employer/employee discussions (called the "interactive process") may be necessary regarding what kind of accommodation is "reasonable" and will best fit the needs of both parties. For more information about ADA, contact the Equal Employment Opportunity Commission (EEOC) at (800) 669-4000 or visit [www.eeoc.gov](http://www.eeoc.gov). For additional information about reasonable accommodations, visit [www.askjan.org](http://www.askjan.org).

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## Exhausting Medical Leave or Sick Time

Sometimes the medical leave offered by an employer or protected by FMLA is not enough to cover treatment needs. If an employee exhausts his/her 12-week FMLA leave and needs additional time off, or is not eligible for FMLA leave to begin with, it is possible to ask for a medical leave extension or to request time off as a reasonable accommodation under ADA or state fair employment law.

Remember that employers do not have to grant indefinite leave extensions or accommodation requests if the accommodation would be an undue hardship to the employer. It may be an undue hardship for an employer to keep your job open indefinitely. A leave extension is more likely to be granted if your doctor can specify a return-to-work date, such as a few extra days or a few additional weeks. For more information about ADA, contact the EEOC at (800) 669-4000 or visit [www.eeoc.gov](http://www.eeoc.gov).

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## Applying for a Job with a History of Cancer

The ADA and state fair employment laws generally prohibit employers from discriminating against people with disabilities at all stages of the employment process, which includes hiring. Employers are not allowed to ask a person if they have or have ever had cancer when applying for a job, and you are not required to disclose this information when applying for a job or once you are hired. However, if you need accommodations to apply for a job, to attend an interview, or to perform essential job functions, you may need to tell the employer that you have a disability in order to receive an accommodation.

Employers are only required to provide reasonable accommodations if they know or should have known about accommodation needs. They do not have to make accommodations for a person who is not otherwise qualified for the job. Employers do not have to remove essential functions, create new jobs, or lower production standards to accommodate a person with disabilities.

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### PRACTICAL TIP

You are not required to tell a new or prospective employer that you currently have or previously had cancer.

Generally speaking, employers cannot make applicants take a medical exam before being offered a job. However, if all employees in similar jobs at the company are required to pass a medical exam, an applicant may be given a conditional job offer, pending the outcome of the medical exam. An employer cannot reject an applicant due to information the medical exam reveals about his/her disability, unless reasons for doing so are job-related and necessary to conduct business.

For more information, visit the EEOC frequently asked questions page at [eeoc.custhelp.com/app/answers/list](http://eeoc.custhelp.com/app/answers/list) or call (800) 669-4000.



# Health Coverage

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# Understanding Health Plan Coverage

A health insurance policy is an agreement between the purchaser and the insurance company. It lists medical benefits, such as tests, drugs, and treatment the insurance company agrees to cover in terms of a percentage (usually 100, 90 or 50) or a dollar amount. It also lists services not covered. Read the policy carefully to understand fully the coverage agreement. Call the insurance company or speak to a licensed insurance representative with any questions or concerns.

The Affordable Care Act (ACA) requires all new medical health insurance plans to offer “minimum essential coverage” by covering the following 10 essential health benefits: emergency services; hospitalization; lab work; maternity and newborn care; mental health and substance use disorder services; outpatient services; prescription drugs; rehabilitative and habilitative services and devices; preventive and wellness services, chronic disease management; and pediatric services.



## PRACTICAL TIP

It is your responsibility to understand your healthcare coverage. Find and read your policy, and do not be afraid to ask questions!

To verify plan coverage, review the summary plan description, evidence of coverage booklet available online, or call the insurance company and ask them to mail you a hard copy of your policy. If you are participating in an employer group health plan, ask Human Resources for a description of covered benefits. You should become familiar with your health coverage before you need it, to avoid surprises and additional costs later on.

Keep in mind that insurance laws and regulations are constantly changing, so check with the CLRC or your state’s department of insurance for up-to-date information.

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## Appealing Health Plan Claim Denials

If you have private health insurance and your insurance company denies a claim payment or terminates health coverage, options to appeal do exist. When an insurance company receives a request, it is required to review and to explain its decision. It must also let you know how to appeal its decision. Insurance laws require this process to occur in a timely manner. Below are two ways to appeal a health plan claim denial:

### 1. Internal Appeal

You have the right to an internal appeal if a claim is denied. Ask the insurance company to conduct a full and fair review of its

decision. If the claim is urgent, the insurance company must expedite this process and generally has to respond within 72 hours. To file an internal appeal, complete all forms required by the health insurer, or write a letter to the insurer. Be sure to include your name, claim number, and health insurance ID number. Submit any additional, relevant information, such as doctors' letters. The process for internal appeals may vary depending on the carrier and type of insurance policy.

## **2. External Review**

If an internal appeal fails, ask for an independent medical review or external appeal by a third party. In urgent situations, request an external review even if the internal appeals process has not been completed. External review requests must be in writing and may need to be filed within 60 days, depending on your state's process. The notice sent by the health plan should provide a timeline for requesting this review. During the external review process, a reviewer who is independent from the insurance company reviews the information and makes a binding decision regarding coverage and/or payment. Contact your state's insurance department for more information on the external review process at [www.naic.org/state\\_web\\_map.htm](http://www.naic.org/state_web_map.htm).

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## **Options When You Are Unhappy with Your Care**

You may wish to express your disappointment with the care (or lack of care) that you received from your doctor or other health care providers in order to prevent similar mishaps from affecting others. You may also feel that professionals you believe injured you should be held accountable. There are several ways you can follow up on your complaints:

### **Informal Communications:**

- You may want to talk to your doctor about your complaint. Most physicians want to hear about a patient's dissatisfaction directly from the patient.
- You can seek additional medical opinions ("second opinion") from different doctors. However, the costs for a second opinion are not always covered by your insurance.

### **Medical Board Complaint:**

- Contact your state's medical or other licensing board, which oversees the licensing and regulation of doctors, surgeons, nurses, and other healthcare professionals, to file a complaint.

- Be as clear as possible in your complaint. You will usually be required to sign a release of medical information for the board to review the relevant medical records.
- An analyst, investigator and/or professional reviewer will investigate your complaint. If the board feels you were treated in a way that is an extreme departure from community standards (such as reckless, unethical, or dangerous care) then the matter is usually forwarded to the state attorney general who will file a formal administrative complaint.
- If you file a complaint with a medical board, you will likely not recover any medical expenses or receive a monetary award, but you may help prevent harm to other patients.
- For a directory of state medical boards, please visit the Federation of State Medical Boards' website: [www.fsmb.org/state-medical-boards/contacts](http://www.fsmb.org/state-medical-boards/contacts).

## Medical Malpractice Lawsuit:

- There are various forms of lawsuits that can be filed to seek a monetary award from a healthcare provider you or your loved ones believe caused harm. There are strict time limits for filing complaints (called statutes of limitations).
- **Medical Malpractice:**
  - Medical malpractice lawsuits claim that a healthcare provider failed to treat a patient with the kind of caution and expertise used by most practitioners in the same or similar circumstances, causing harm to the patient.
  - To be successful in a medical malpractice lawsuit, the patient must have an expert opinion to support his/her claim and prove a substantial damage.
- **Elder Abuse:**
  - Many states have laws that permit lawsuits against healthcare providers who, in the course of their professional care, neglect the basic needs of the elderly.
  - These suits can continue even after your death, and can be prosecuted by survivors.
- **Wrongful Death:**
  - When a person dies because of someone else's negligence, surviving family members can file a complaint for wrongful death to seek a monetary award, as compensation for the loss of support, loss of income that the loved one would have been able to share had he/she survived, and to compensate for other financial injuries.



### PRACTICAL TIP

If you think your doctor made a mistake and you want to file a lawsuit, contact a medical malpractice attorney as soon as possible so that you do not miss the filing deadline in your state.

- The elements of proof for wrongful death are essentially the same as in medical malpractice. These claims are often filed together.

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## Knowing How a Cancer Diagnosis or Genetic Information Affects Insurance

Federal laws that protect against genetic discrimination are explained below:

- Genetic Information Nondiscrimination Act (GINA) prohibits genetic discrimination in both employment and health insurance. GINA defines genetic information as family medical history, one's genetic test results or that of a family member, and use of genetic services.

A person's current health status or diseases and conditions he/she has developed are not genetic information. Health insurance companies are not allowed to deny or reduce coverage or charge more based on genetic information. GINA does not apply to Veterans Health Administration (VA), Indian Health Service (IHS), TRICARE military health system or Federal Employees Health Benefits Program, although other laws provide protection. GINA also does not apply to life, long term care, or disability insurance.

- Health Insurance Portability and Accountability Act (HIPAA) prohibits group and individual health insurance plans from using genetic information to determine insurance eligibility.
- Affordable Care Act (ACA) prohibits health insurance companies from basing coverage decisions on medical history or pre-existing conditions, and protects against genetic discrimination during eligibility review.

State laws regulate supplemental or voluntary insurance like life, disability and long-term care insurance, and many states also prohibit genetic discrimination in these supplemental policies. For additional information, contact your state's department of insurance. For more information about genetics and cancer more generally, visit [www.cancer.org/cancer/cancer-causes/genetics.html](http://www.cancer.org/cancer/cancer-causes/genetics.html).

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## Learning About Clinical Trials

If you are interested in participating in clinical trials or other experimental treatments, the first step is to speak with your doctor. He/she may be able to recommend specific trials based on your condition and the treatments you have already received. Additionally, several organizations have developed online

systems to match patients with studies they may qualify or be eligible for. Some services also allow people to subscribe to mailing lists, which alert subscribers when new studies open.

- The American Cancer Society can help you learn more about what happens during a clinical trial so you can decide if participating is right for you. Visit [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials) or call 1-800-227-2345 for information.
- EmergingMed provides free, confidential matching and referral services at [www.emergingmed.com](http://www.emergingmed.com) or call (877) 601-8601.

Clinical trials lists provide names and descriptions of new treatment clinical trials. They will often include a description of each study, criteria for patient eligibility, and contact person. The following are some sources for clinical trials lists:



## PRACTICAL TIP

Clinical trial eligibility can be confusing. Talk to your doctor to learn about whether participating in a trial might be right for you.

- National Cancer Institute (NCI) sponsors most government-funded cancer clinical trials. NCI has a list of active studies (those currently enrolling patients), as well as some privately funded studies. Find the list on their website at [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials) or by calling 1-800-4-CANCER (1-800-422-6237).
- National Institutes of Health (NIH) has an even larger database of clinical trials at [www.clinicaltrials.gov](http://www.clinicaltrials.gov).
- Center Watch ([www.centerwatch.com](http://www.centerwatch.com)) is a publishing and information services company that keeps a list of both industry-sponsored and government-funded clinical trials for cancer and other diseases.
- Private companies, such as pharmaceutical or biotechnology firms, may list studies they sponsor on their websites or offer toll-free numbers to call. Some of these firms also offer matching systems for studies they sponsor. This can be helpful if you are interested in research on a particular experimental treatment and know which company is developing it.

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## Accessing Prescription Medications

Under the Affordable Care Act, most private health insurance plans are required to cover prescription drugs. Medicaid and Medicare also offer prescription drug benefits.

The amount you pay for your prescriptions depends on whether the drug is on your insurance policy's list of approved medications (called a formulary), and which tier of coverage the medication falls into. If your doctor prescribes medication that is expensive or not on your

policy's formulary, you can share the formulary with your doctor's office. He/she may be able to prescribe an alternative that would be covered at a lower cost to you. Doctors are not always familiar with their patients' drug formularies or financial situations.

Some insurance companies require prior authorization before they will pay for a medication. Your doctor may need to contact your insurance company and get permission (prior authorization) before prescribing the drug. Review your insurance policy for information about prior authorization requirements.

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## **PRACTICAL TIP**

A "formulary" is the list of prescription drugs covered by your health plan and/or prescription drug plan.

"Step therapy" is another hurdle you might encounter. Before your health plan will pay for you to use a new, expensive, or name brand drug, you may be required to first try taking a less expensive alternative. You may then have to demonstrate that the less expensive drug does not treat your illness or symptom in order for your plan to cover the newer or more expensive medication.

If your health plan refuses to cover a medicine your doctor has prescribed, you have the right to ask your insurance company to reconsider this decision in an appeal. You can ask your doctor to help with this by writing a letter explaining why a specific drug is medically necessary for you. You may also be able to ask your doctor for free samples of the medication, contact the pharmaceutical company that makes your medication for coupons or discounts, or ask your pharmacy about discount cards. Contact the CLRC or your insurance carrier for more information.

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## **Obtaining New Health Insurance**

If you are unable to obtain employer-provided health insurance, have recently stopped working or had some other major life change, and/or do not qualify for Medicaid or Medicare, you may be able to purchase a new health insurance policy through an insurance company or broker, or through the state or federal health insurance marketplace. Under the Affordable Care Act, insurance companies cannot ask about or consider pre-existing conditions when deciding how much to charge you or whether to offer you coverage.

Purchasing marketplace health coverage is the only way to receive tax credits to lower monthly premiums, if you qualify based on household income. Income changes during the year should be reported and may impact your eligibility for or the amount of your tax credits. Apply for marketplace health coverage during open enrollment each fall.

Outside the annual Open Enrollment Period, you can enroll in coverage only if you are eligible for a 60-day Special Enrollment Period due to a “qualifying event” (such as leaving your job, getting married/divorced, moving, or other major changes), or if you become ineligible for Medicaid or the Children’s Health Insurance Program (CHIP). Below are the four ways to apply for marketplace health coverage:

1. Apply online. Create an account; fill out a marketplace application, and view eligibility results online. Visit [www.healthcare.gov/get-coverage](http://www.healthcare.gov/get-coverage) for more information.
2. Apply by phone. A customer service representative will help choose a plan, fill out an application and review eligibility. Call (800) 318-2596 to apply.
3. Apply with in-person help. An assister can meet in-person, help you choose a plan, and fill out an online or paper application, and review eligibility. Visit [localhelp.healthcare.gov](http://localhelp.healthcare.gov) for people and organizations that can help.
4. Apply by mail. You also have the option to fill out and mail in a paper application. Eligibility results will come in the mail. If possible, either create a marketplace account online or contact the marketplace Call Center to choose a plan and enroll. Visit [marketplace.cms.gov/applications-and-forms/marketplace-application-for-family.pdf](http://marketplace.cms.gov/applications-and-forms/marketplace-application-for-family.pdf) for an application and [marketplace.cms.gov/applications-and-forms/marketplace-application-for-family-instructions.pdf](http://marketplace.cms.gov/applications-and-forms/marketplace-application-for-family-instructions.pdf) for instructions.

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## Understanding Medicare Health Coverage Options



### PRACTICAL TIP

Health insurance companies cannot charge more or deny coverage based on a pre-existing condition such as cancer.

Medicare is health care coverage for people 65 years or older, people who are under 65 but have been eligible for/receiving SSDI benefits for 2 years or more, or anyone with End-Stage Renal Disease. Medicare has several parts:

- Part A helps cover inpatient hospital care. It also includes coverage in hospice or skilled nursing facilities for a limited time, but not long-term care.

Medicare beneficiaries do not usually pay a monthly premium for Part A coverage if they or their spouse paid Medicare taxes for at least 10 years while working.



- Part B helps cover medically necessary services like doctors' services, outpatient care, and medical services Part A does not cover, such as many preventive services. If you enroll in Part B, the premium is usually taken from your monthly SSDI or Social Security retirement check. If you are enrolled in Medicare but are not receiving SSDI or Social Security Retirement payments, Medicare sends a monthly bill for the Part B premium.
- Part C: Medicare Advantage Plans provide coverage through private insurance companies that have contracted with Medicare. Options often include preferred provider organizations (PPO) or health maintenance organizations (HMO), which may be similar to private insurance that you had when you were still working. Part C includes all benefits and services covered under Parts A and B, and Medicare prescription drug coverage (Part D) as part of the plan.
- Part D provides prescription drug coverage through Medicare-approved private insurance companies.

Keep in mind that Medicare usually only covers 80 percent of health care costs, which is why many people purchase supplemental insurance (often called Medigap) to help cover the remaining costs, or you may also be eligible for Medicaid as supplemental coverage. For more information about Medicare, visit [www.medicare.gov](http://www.medicare.gov) or contact the State Health Insurance Assistance Program (SHIP) in your state here: [www.shiptacenter.org](http://www.shiptacenter.org).

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## Obtaining Health Coverage for Low Income Households

Medicaid is a state-run federal program that provides health care coverage for people with low income and limited resources. Each state has different rules about eligibility and how to apply for Medicaid. More than half of U.S. states have chosen to expand their Medicaid programs to cover all people who earn less than 138 percent of the Federal Poverty Line (about \$16,000 per year for an individual).

In states that have not expanded Medicaid coverage, a person may qualify for Medicaid if he/she has limited income and resources and is one or more of the following: 65 years or older; under 19 years; pregnant; living with a disability; a parent or adult caring for a child; an adult without dependent children (in certain states); or an eligible immigrant.

Medicaid provides all of the services that private health insurance offers, as well as additional services such as long-term or nursing home care, in-home supportive services, and dental care for adults, depending on where you live.

For more information about state Medicaid programs and how to qualify, visit [www.HealthCare.gov/do-i-qualify-for-medicaid](http://www.HealthCare.gov/do-i-qualify-for-medicaid).

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## Keeping Health Insurance After Terminating Employment

Keeping work-based health insurance may be important in covering cancer care costs once employment stops, especially if you are currently going through treatment and/or you like your doctors/network. Upon termination of employment, a person may be eligible for a Special Enrollment Period to purchase a new insurance policy. See [page 12](#) to learn more.

The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a federal law that allows workers to temporarily keep their employer's health coverage after a "qualifying event," such as reducing work hours, or leaving or losing their job. COBRA is not a separate insurance plan to sign up for; it simply allows workers to keep the same policy they had while they were working, for up to 18 months.

COBRA applies to employers with 20 or more employees. Some states have mini-COBRA laws that may apply to employers with fewer than 20 employees. Contact your state's department of insurance to learn more.



### PRACTICAL TIP

If COBRA is too expensive, you may find more affordable insurance options on the state or federal marketplace. Check [healthcare.gov](http://healthcare.gov) for more information.

If eligible for COBRA, follow these steps to maintain coverage:

1. Confirm that your employer has notified the employer's health plan of the qualifying event;
2. Choose COBRA within 60 days of terminating employment;
3. Pay the first premium within 45 days of choosing COBRA;
4. Pay the monthly premiums on time.

The monthly premium becomes your responsibility and can be as much as 102 percent of what your employer was paying. If a person is eligible for COBRA and Medicaid, he/she may also be eligible for a state Health Insurance Premium Payment Program (HIPP). Contact your state's department of insurance to find out whether it has a HIPP program and how to qualify. For questions about COBRA, contact the U.S. Department of Labor, Employee Benefits Security Administration, at (866) 444-3272 or visit [www.dol.gov/ebsa](http://www.dol.gov/ebsa).

# Finances



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# Paying Bills When Unable to Work

Several government programs provide financial benefits/income replacement to individuals and families. The Social Security Administration (SSA) runs two such programs: Supplemental Security Income and Social Security Disability Insurance. Eligibility for Supplemental Security Income (SSI) is based on financial need and is designed to help people who are aged, blind, or disabled and who have little or no income. It provides cash to meet basic needs for food, clothing and shelter.

Social Security Disability Insurance (SSDI) pays disability benefits to workers and certain family members if they work long enough and have a medical condition that prevents them from working, or is expected to prevent them from working, for at least 12 months or end in death. Keep in mind that eligibility for these programs may vary depending on your immigration status.

- SSI. Income and resources are used to determine a person's eligibility to meet the program's financial requirements. For 2018, the SSI monthly maximum Federal benefit amount is \$750 for an eligible individual and \$1125 for an eligible individual with an eligible spouse. Some states supplement the fixed amount, and the program usually provides annual cost-of-living adjustments (COLA).
- SSDI. Benefits are based on lifetime work history and how much money the worker has paid into the system through Social Security taxes. The monthly disability benefit is based on average lifetime earnings. The average monthly SSDI benefit amount is around \$1200, and there is a five-month waiting period from the day your disability began until the SSA starts paying benefits. To find out how much you would receive if approved for SSDI, create an account on the Social Security website, or call the Social Security Administration.



## PRACTICAL TIP

If you receive government benefits or are receiving charitable health care from your doctor or hospital, be sure that any cash gifts or awards will not be counted as income and interfere with your eligibility for those programs. Talk to a lawyer or call the CLRC for more information.

In addition to SSI and SSDI, some employers offer private disability benefits. Individuals can also purchase private disability insurance before they get sick. If applicable, check your policy to see what the eligibility requirements are to collect benefits. Also, some states have short-term disability programs, usually called State Disability Insurance (SDI).

For other forms of financial assistance, check with local service

organizations like Kiwanis, Rotary Club or Lions Club; 211 and the Area Agency on Aging; private financial assistance programs like Salvation Army, Lutheran Social Services, Jewish Social Services and Catholic Charities; non-profit organizations like American Cancer Society and Patient Advocate Foundation; and cancer-specific programs that focus on assisting patients with certain types of cancer like Leukemia and Lymphoma Society, American Kidney Fund, and The Pink Fund. Online fundraisers have also become quite popular in recent years.

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## Managing Debt

Cancer care is expensive. Below are some strategies that can help you to deal with expenses and debts that you may owe:

- Review medical bills for errors: Simple billing mistakes can cost patients a lot of money. It is a good idea to review your bills to ensure that you are not being charged for services you did not receive, and to look for other errors. You may also hire a professional bill reviewer.
- Negotiate medical bills: If you cannot afford to pay your medical bills, try to negotiate with the billing department at your doctor's office or hospital. Although they may not be required to do so, hospitals will often agree to a payment plan or to accept a smaller amount than the total amount owed. It is important to try to work out a payment plan before the bill is sent to collections so that it does not negatively impact your credit. Additionally, try to avoid using credit cards to pay medical bills. It is more difficult to negotiate with a credit card company than a hospital or doctor's office.
- Prioritize debt/expenses: Medical debt is "unsecured" debt, and should generally not be paid before "secured" debt or living expenses such as food, housing, utilities, or car payments. Secured debt is something that is tied to collateral, such as a car loan or a mortgage. If you fail to make payments on your secured debt, the lender can repossess your car or foreclose on your home.
- Bankruptcy: Bankruptcy is a legal procedure in a federal court to relieve a person of certain debts that he/she is no longer able pay. The primary purposes of bankruptcy are: (1) to give an

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### PRACTICAL TIP

For more information on consumer debt/creditors, visit [www.DebtAdvice.org](http://www.DebtAdvice.org)

honest debtor a “fresh start” by relieving the debtor of most debts, and (2) to repay creditors in an orderly manner to the extent that the debtor has the ability to make payments. Talk to a bankruptcy attorney to determine if this option is right for you.

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## Understanding Housing Rights

Having a clean, safe place to live is especially important for those who are coping with cancer. Housing laws vary from state to state. For landlord/tenant disputes (including eviction notices), contact an attorney who works in landlord/tenant law, or a legal aid organization. Tenants who try to sue their landlords without representation by an attorney are at a huge disadvantage.

A few things to keep in mind regarding your housing rights:

- If you cannot afford to pay your rent, you should talk to your landlord as soon as possible. If you do not pay your rent, your landlord can start eviction proceedings against you, even if you have cancer. You may be able to negotiate a deal with your landlord or move out early. You may be required to give written notice 30 or 60 days before moving out, and/or pay a penalty.
- Your landlord (or Homeowners Association, if you own your residence) may be required to make reasonable accommodations or modifications to your unit or common areas, if your disability requires them. Possible housing accommodations include: an assigned, accessible parking space; moving into a different, available unit; or modifying policies regarding pets to allow for service animals. Your landlord may also be required to allow you to make modifications to your unit, at your expense, such as installing grab bars in the bathtub, widening doorways, or installing a ramp. If you live in federally subsidized housing, your housing must be made accessible at no expense to you.

Landlords are required to maintain rental units and common areas in a livable condition. If your landlord refuses to make repairs to your apartment and your health is suffering as a result, you may be able to move out, call a local city inspector, repair the problem yourself and deduct the cost from your rent, withhold rent, or sue for damages. However, before resorting to these options, please consult with an attorney experienced in landlord/tenant law.

# End of Life Issues



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## Understanding End of Life Options for Those with Terminal Illness

If best efforts to cure or manage cancer as a chronic condition fail, and the doctor says the cancer is terminal, patients have a range of available options. Excellent pain and symptom management (referred to as “palliative care” or “comfort care”) should be the goal (though you do not need to have a terminal illness to benefit from palliative care). If there is any doubt as to whether your current health care team is skilled in palliative care, ask for referral to a palliative care specialist or to hospice. Hospice care, which focuses on pain management, comfort, and support (instead of curative treatment), can be provided on an inpatient basis, but it is most often provided in-home with hospice nurses visiting on a regular basis.

A patient has the right to accept or to reject any life prolonging treatment, including medication, artificial food/fluid and respiratory support like a ventilator. Decisions about accepting or forgoing life-prolonging treatment may change the timing of death and should be discussed fully and openly with the doctor and/or hospice team. A patient can also choose to stop ingesting food and fluid while receiving supportive palliative care and advance the time of death in this way. If pain and other distressing symptoms cannot be well-managed even with good palliative care, a patient may want to consider palliative sedation. Palliative sedation is a process whereby sedating medication is given to make a person unconscious and not aware of his/her symptoms, and food/fluid are withheld until death arrives.

Individuals have a right to all of the above choices in every state. In some states a patient may also be able to ask for a prescription for medication he/she can ingest to achieve a peaceful death if the dying process is unbearable. This choice is known as “aid in dying” (also referred to as “death with dignity”) and is openly available to mentally competent, terminally ill patients in some states, including Oregon, Washington, Vermont, Montana, and California. The law in this area is rapidly evolving, so check with CLRC for details about whether this option is available in your particular state.

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## Planning for Loved Ones After Death

Speaking with an estate planning lawyer is an important starting point to make sure loved ones are provided for after a person’s death. The lawyer may recommend a will, which is a legal document that directs who will receive a person’s property after he/she dies. It can also be used to name a guardian for minor children and their assets.



Below are several ways to create a will:

- **Holographic or Handwritten Will.** Some states allow a holographic will, which is completely written in the person's own handwriting, signed, and dated. It expresses how property is to be distributed. It is not necessary to have this will notarized or signed by witnesses, and any typed material may invalidate the will. Check with an attorney or the CLRC to see whether a holographic will is valid in your state.
- **Statutory Will.** These fill-in-the-blank will forms are available in some states and may work well if the person does not have a large or complicated estate or assets.
- **Lawyer-Prepared Will.** Estate planning lawyers make sure wills follow state law. They can also offer suggestions about estate planning options, explain potential tax benefits, and provide information on ways in which property can be transferred.

For more complicated estates, a trust may be a better option than a will. A trust is a written agreement naming beneficiaries who will be given, or who will inherit, property. The person who owns assets (trustor) names a person to manage assets held in trust (trustee). Depending on the type of trust, it may be revocable or changed during the asset holder's lifetime. After he/she passes away, the trust cannot be changed.

Once a person creates a trust, he/she must transfer assets from his/her name to the name of the trust. Several types of trusts exist, but the most common is a "living trust." This type is created while the asset holder is alive, and it allows the person to act as his/her own trustee until death, when another trustee takes over.

One major difference between a will and a trust is that a will usually needs to go through an administrative process called "probate," while a trust avoids the probate process. If you do not plan ahead and die "intestate" (without a will), the state will decide who gets your property. For more information about advance planning, contact your state's bar association or Cancer Legal Resource Center (CLRC).

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## Ensuring Wishes Are Carried Out

Adults have the right to make decisions about their healthcare. However, when patients are not able to express their wishes, physicians will follow instructions from a surrogate decision maker. There are several different ways to establish your surrogate decision maker (also called your "agent"). **The Advance Health Care Directive (AHCD)**, also known as a medical directive or advance directive,

is a set of written instructions communicating a person's wishes about medical care should he/she be unable to make decisions. State laws and definitions of incapacity vary by state. AHCD forms are available online and can contain several parts, depending on your state's rules:



## PRACTICAL TIP

Make sure you talk to the person you want to name as your surrogate decision maker to make sure that he/she is willing and able to carry out your wishes.

- Power of Attorney for Health Care names someone (called an “agent,” “proxy,” or “surrogate”) to make *medical* decisions for a person who has become unable to make decisions for him or herself, or “incapacitated.” Make sure you speak with your agent to confirm that he/she understands your wishes and is willing to carry them out.
- Living Will provides instructions about life-sustaining medical treatment. This is where you can give specific instructions for your agent to follow, if you want to.
- Organ Donation expresses a person's wishes about specific organ and/or tissue donation.
- An AHCD usually needs to be signed and witnessed, and/or notarized.

**POLST/MOLST (“Physician/Medical Order for Life Sustaining Treatment”)** is a document used by seriously ill or frail patients in most states to instruct physicians as to whether treatments like CPR or other life support measures should be used if the patient's heart and/or breathing stops. It is similar to a Do Not Resuscitate order, but is completed after consultation with the patient's health care provider and is included in the patient's medical record. The instructions in the POLST document can (and should) echo the instructions provided elsewhere, such as an advance health care directive.

Without written instructions regarding your health care wishes, health care providers will be guided by laws (state and federal) and standard practices to determine the proper surrogate decision maker (such as a spouse, adult child, or parent).

**Power of Attorney for financial and business matters** allows a person (principal) to appoint someone (agent) to make financial or business decisions if he/she is unable to do so. In most states, it must be signed and notarized. A power of attorney ends at death when a will or trust takes effect.

There are a few different ways to set up your power of attorney for health or financial/business affairs:

- Durable Power of Attorney becomes effective at signing and can last through incapacity. This means that a person can ask

their agent to make decisions on his or her behalf regardless of whether he/she is still able to make such decisions. This can be useful for someone who may not want to focus on daily affairs and trusts their agent to make decisions if he/she is unable to do so.

- Non-durable Power of Attorney becomes effective at signing, but the agent will lose power if the person becomes incapacitated. This may be useful if a person wants to designate one person to help while competent and a different person to help while incapacitated.
- Springing Power of Attorney goes into effect when a certain condition or event occurs, such as when a person becomes incapacitated. A durable springing power of attorney is the most common type of Power of Attorney.

For questions, talk to an estate planning attorney. The National Academy of Elder Law Attorneys lists attorneys with special expertise in this area by state. Or, contact CLRC for more information.

# Miscellaneous



## Resources for Caregivers

Caregiving for someone with cancer can be extremely challenging, both physically and emotionally. However, there are some resources available that can help.

- Some laws provide protections for caregivers under certain circumstances. The Americans with Disabilities Act (ADA) prohibits discrimination against employees based on their relationship to or association with a person with a disability at companies with 15 or more employees. However, unlike the ADA's protections for people with disabilities, caregivers are not entitled to reasonable accommodations.
- Additionally, the Family and Medical Leave Act (FMLA) provides eligible caregivers with the right to take up to 12 weeks of unpaid leave from work to take care of a parent, spouse, or child with a serious medical condition. See [page 4](#) for more information about the ADA and FMLA.
- A few states (including California, New Jersey, New York, and Rhode Island) have paid family leave programs, which provide some income replacement for 4, 6, or even 12 weeks while a covered family member is off work providing caregiving services for a family member. These programs are generally run through the state's short-term disability insurance program.

- Other organizations that provide caregiving resources include the Caregiver Action Network ([www.caregiveraction.org](http://www.caregiveraction.org)), Family Care Alliance ([www.caregiver.org](http://www.caregiver.org)), and support organizations like the American Cancer Society ([www.cancer.org/caregivers](http://www.cancer.org/caregivers)), Cancer Support Community, and CancerCare.

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## Concerns and Benefits for Non-U.S. Citizens

Non-citizens may qualify for government benefits, including income replacement and healthcare, in certain circumstances. However, when you apply to become a citizen (naturalization), the government reviews your financial situation to make sure that you are not likely to become reliant on the government for financial support (called becoming a “public charge”). If you are not a U.S. Citizen and are considering a change in naturalization status in the future, there are a few things you should know before applying for certain government benefits.

- Supplemental Security Income (SSI): Accepting Supplemental Security Income (SSI) benefits may negatively impact a naturalization application. SSI and other means-tested income replacement benefits are cash payments and may be considered in determining whether you might become a “public charge.”
- Medicaid: If you qualify for Medicaid (state-run health coverage for people who have low incomes), these benefits would probably not be considered in a public charge determination. However, if you need long term care or institutionalization paid for by Medicaid, the use of those services may later be taken into consideration in determining public charge.

These are not the only factors that the government considers when trying to determine whether you will become a public charge. Factors affecting review of your application are best discussed with an experienced immigration attorney. For a more detailed explanation of “public charge” in naturalization applications: [www.uscis.gov/greencard/public-charge](http://www.uscis.gov/greencard/public-charge).

For more information about Social Security benefits for non-citizens: [www.ssa.gov/ssi/spotlights/spot-non-citizens.htm](http://www.ssa.gov/ssi/spotlights/spot-non-citizens.htm).

For more information about Medicaid benefits for non-citizens: [www.healthcare.gov/immigrants/lawfully-present-immigrants](http://www.healthcare.gov/immigrants/lawfully-present-immigrants).

*Your feedback is important to us. Please take a few minutes to let us know what you thought of the Cancer Legal Resource Center's Patient Legal Handbook: [cancerlegalresources.org/plh-survey](http://cancerlegalresources.org/plh-survey).*

**Thank you to our Professional Panel members, for your ongoing support of the CLRC and for all that you have done for those that have been touched by cancer:**

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**For more information:**

[www.cancerlegalresources.org](http://www.cancerlegalresources.org)  
866-THE-CLRC

# NO ONE SHOULD HAVE TO FIGHT CANCER ALONE.



In 2005, Amgen founded *Breakaway from Cancer*® out of the belief that it takes a team to beat cancer. The nationwide initiative aims to increase awareness of the important resources available to people affected by cancer – from prevention through survivorship.

*Breakaway from Cancer* is a collaboration between Amgen and four nonprofit organizations that play leading roles in several aspects of cancer care, complementing the services provided by healthcare professionals. Services of the independent nonprofit organizations include advice from cancer survivors, links to research and clinical trials, information on cancer prevention, cancer education, emotional support, help with financial issues, and access to care.

The resources provided by these organizations, as well as information from more than 100 additional cancer websites, are compiled on the *Breakaway from Cancer* website. Designed to address the many questions a patient may have, the website features a navigator tool that allows users to customize a search specific to their needs.

To learn more, visit [www.breakawayfromcancer.com](http://www.breakawayfromcancer.com)



**Prevent Cancer Foundation** is a national organization focused on educating the public about how to prevent cancer, as well as the importance of screening and early detection.



Uniting The Wellness Community and Gilda's Club Worldwide, **Cancer Support Community** is an international, nonprofit organization dedicated to providing support, education and hope to people affected by cancer.



**Patient Advocate Foundation** is a national nonprofit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability relative to their diagnosis of life threatening or debilitating diseases.



The oldest survivor-led advocacy organization in the country, **National Coalition for Cancer Survivorship** advocates for quality cancer care for all Americans and provides tools that empower people affected by cancer to advocate for themselves.

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## **For More Information:**

**Tel: (866) THE-CLRC (843-2572)**  
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