Public Counsel

CANCER JUSTICE HANDBOOK

KNOW YOUR RIGHTS: A LEGAL GUIDE FOR PATIENTS AND FAMILIES FACING CANCER

Why Cancer Justice?

A cancer diagnosis is life-changing medically, financially, and legally. While many people associate cancer with medical terms like diagnosis, chemotherapy, radiation, or remission, cancer extends far beyond physical health. A cancer diagnosis can have strong impacts on employment, health insurance, housing stability, finances, access to public benefits, caregiving responsibilities, and long-term planning. It can feel overwhelming.

A cancer diagnosis can also impact families and communities including spouses, partners, parents, children, siblings, and close friends. Families and friends often step into caregiving roles by adjusting work schedules, coordinating medical appointments, managing insurance issues, and providing emotional and financial support. Caregivers may face their own employment disruptions, income loss, and legal questions while trying to support someone they love.

Cancer Justice is a resource to help you understand and manage complex legal concerns while navigating your or your loved one's medical treatment. This Cancer Justice Handbook is designed to help you advocate. Access to clear, reliable legal information can prevent serious legal and financial hardship and empower individuals and families to protect their rights.

Cancer Justice, formerly the Cancer Legal Resource Center (CLRC), was founded in 1997 to help people and families work through the consequences of a cancer diagnosis. Since then, we have provided legal information and resources to more than 500,000 patients, caregivers, survivors, health care professionals, and advocates nationwide. Now at Public Counsel, one of the nation's largest pro bono public interest law firms, Cancer Justice continues and expands that mission: to ensure that no one faces the legal and financial fallout of cancer alone. This Handbook is inspired by the questions, concerns, and patterns we hear through our national helpline, including:

- What are my employment rights and medical leave protections?
- How do I understand my health insurance coverage?
- What can I do if a claim is denied?
- How can I manage medical debt?
- What housing protections exist after a cancer diagnosis?
- What public benefits programs might I qualify for?
- What legal protections are available for caregivers?
- What advance planning and end-of-life decisions should I consider?
- What should non-citizens know when facing cancer?

We will answer these and many more questions. We hope this Cancer Justice Handbook is helpful and provides clarity, confidence, and support during a difficult time.[1] If you need

[1]*This Guide offers general information intended to help individuals understand common legal rights and protections related to cancer. It is not legal or medical advice. Because laws vary by*

additional guidance or are unsure where to turn, we are here to help. We are honored to serve you.

You can reach out to our Cancer Justice Helpline at:

213-736-1455 | 866-843-2572
[Insert Public Counsel QR code or intake website link]
[Insert Public Counsel mailing address]

With respect and solidarity,

The Cancer Justice Team

state and every situation is unique, if you are facing an urgent or complex legal issue, we encourage you to contact an attorney or a legal aid organization in your area.

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What Are My Employment Rights?

Protecting Your Job During and After a Cancer Diagnosis

People are diagnosed with cancer during their working years while also building careers, raising families, paying mortgages, and relying on health insurance through their jobs. Cancer treatment, fatigue, and other side effects can make it difficult to work. Family members and caregivers may also need to reduce their work hours or take time away from work to care for a loved one with cancer.

When health and work responsibilities overlap, it is important to understand your rights. Federal, state, and local laws may help protect your job, allow you to take leave from work, provide workplace accommodations, and protect you from discrimination because of a medical condition.

When work and health collide, these laws may also help protect your income and health insurance. The protections available to you will depend on where you live, where you work, and the size of your employer. In the sections that follow, we explain how federal laws, such as the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA), work and how state and local laws may provide additional protections. These protections may include broader coverage, expanded family leave, or wage replacement benefits. Understanding these laws can help you identify the rights, benefits, and options that may be available to you.

What Is the Americans with Disabilities Act (ADA) and How Can It Protect My Job?

The ADA may help protect your employment after a cancer diagnosis. Cancer, including a history of cancer or cancer in remission, will often qualify as a disability under the ADA because it affects normal cell growth and may limit daily activities.

The ADA prohibits discrimination against people with disabilities and may provide important workplace protections. The ADA defines a disability as a physical impairment that "substantially limits one or more major life activities." These activities may include working, concentrating, caring for yourself, or how your body normally functions.

While some people continue working during cancer treatment, others may need adjustments, time off, or a flexible schedule while receiving treatment or managing side effects. The ADA may help if you work for an employer with 15 or more employees. It requires employers to provide reasonable changes at work, called ***accommodations***, that allow an employee with a disability, such as cancer, to perform their job.

These accommodations can be very helpful, and employers must provide them unless doing so would create an "undue hardship." An undue hardship generally means the accommodation would be too expensive, too difficult to provide, or would fundamentally change the nature of the job or the employer's operations. In California, once a reasonable accommodation is identified, the employer must provide it unless the employer can show that doing so would create an undue hardship.

The goal of the ADA is to help people with disabilities stay employed. For individuals affected by cancer, reasonable accommodations may make it possible to continue working while undergoing treatment or managing its effects.

How Do I Request Workplace Accommodations?

When treatment, fatigue, medical appointments, or recovery begin to affect your ability to work in the usual way, you have the right to ask for ***accommodations***. Your employer must work with you in what is called an "***interactive process***" when you ask for accommodations. The interactive process means your employer should work with you in ***good faith*** to find ways that let you do your job.

Accommodations are individualized, meaning that they need to fit your needs. Examples of accommodations during and after cancer treatment may include:

- Flexible or less hours.
- Being able to work remotely or hybrid.
- Temporary reassignment of non-essential duties, meaning tasks that are not central to your position.
- More breaks during the workday.
- Change workspace or equipment.
- Time off for medical appointments.
- Short-term or extended unpaid leave.

TIP: Employers do not have to approve leave requests that do not have an expected return date. An employer may deny a leave request if it would create an undue hardship for the business. For example, if you ask your employer to hold your job open for an unknown amount of time, they may decide that is too difficult. However, if your doctor can provide an estimated return-to-work date, your request for additional leave may be more likely to be considered reasonable.

Practical Tips When Asking for Accommodations:

- Asking for accommodations before treatment or side effects affect your work performance. Asking early may help prevent misunderstandings about attendance or productivity.
- Make all accommodation requests in writing. If your HR representative or supervisor calls you, follow up with an email or other written record of the conversation.
- Be specific about the changes you need.
- Provide a doctor's note if your employer asks for one.
- Keep copies of all communications, including emails, letters, messages, memos, and other documents.
- • If your request is denied, follow up in writing.

What Is the FMLA and How Does It Protect My Job During Cancer Treatment?
The Family and Medical Leave Act (FMLA) may help if you need time away from work during cancer treatment or recovery. The FMLA is a federal law that gives eligible employees up to 12 weeks of unpaid, job-protected leave each year. During FMLA leave, you can generally keep your employer-sponsored health insurance coverage, which may help ensure continued access to your doctors, treatment, and cancer care.

Employees may be eligible for up to 12 weeks of leave during a 12-month period if they have not already used their available leave. Employers may calculate this 12-month period in different ways. For example, they may use the calendar year, the year beginning when leave first starts, a rolling period measured backward from the date leave is taken, or another fixed 12-month period, such as a fiscal year.

Employers must choose one method and apply it consistently. If an employer does not clearly identify the method it uses, the method that is most favorable to the employee may apply.

Eligible employees may use up to 12 weeks of FMLA leave each year if:

- Your own serious health condition prevents you from doing the essential functions of your job.
- You are caring for a spouse, child, or parent who has a serious health condition.
- You have a child, and you need time to care for the newborn within the first year after birth.
- You have a child placed with you for adoption or foster care, and you need time to care for the newly placed child within the first year after placement.
- You need to take leave to help your spouse, child, or parent serving on covered active military duty.

Although FMLA leave is unpaid, it gives you two important protections. First, you have job protected status while you are on leave. Second, your employer must keep your employer-sponsored health insurance under the same terms as if you were working.

Some people take all 12 weeks off at once. Others break it up, and, for example, may take a few days off each week during chemotherapy. This is called ***intermittent leave***, and it may be available if medically necessary. How leave is used often depends on the individual's treatment plan, recovery needs, and medical guidance.

How Do I Know If I Am Eligible for FMLA?

You may qualify for FMLA if:

1. You work for a public employer.
    - This includes jobs with the federal or state government, a local government agency, a public school district, or a city or county department.
2. You work for a private employer with at least 50 employees within 75 miles of your worksite, and
    - You have worked with that employer for at least 12 months
    - You have worked with that employer at least 1,250 hours in the past 12 months.

How Do I Request FMLA Leave?

1. If possible, give your employer at least 30 days' notice before your leave begins. If you suddenly need leave, let your employer know as soon as possible. It is best to make your request for FMLA leave in writing.
2. Provide enough information to explain why you need FMLA leave, including when and how long you expect to be on leave.

> **Practical Tip:** You can decide whether to tell your employer that you have cancer. If you prefer to keep your diagnosis private, you may ask a doctor other than your oncologist to certify that you need medical leave because of a serious health condition.

3. Your employer may ask for a medical certification form to show that you have a qualifying serious health condition. To complete this form, it usually must be filled out by a licensed healthcare provider involved in your care.
4. Be sure to turn in the paperwork your employer needs on time.

For more information about the Family and Medical Leave Act, FMLA, contact the U.S. Department of Labor at 202-693-0066 or visit www.dol.gov/agencies/whd/fmla. The Department of Labor website helps explain FMLA rights, what makes you eligible, medical certification guidance, and how to file a complaint.

Federal employees should contact the Office of Personnel Management, OPM, at 202-606-7400 or visit www.opm.gov for information about how FMLA works for federal workers and what to do to take time off for medical leave.

What If I Have Used All My Leave or Do Not Qualify for FMLA?

If your cancer treatment and recovery last more than 12 weeks, or if you do not meet the requirements for FMLA, you may still have options. Other laws, like the ADA, may protect your job or let you take time off as a reasonable accommodation. You may also have the right to take leave under state laws, your work contract, a union agreement, or your employer's rules.

Check with your Human Resources representative or Cancer Justice to help you understand your protections. You can also contact the U.S. Equal Employment Opportunity Commission (EEOC). The EEOC is a federal agency that makes it illegal for employers to discriminate because of your disability, including cancer. On its website, www.eeoc.gov, you can learn about your rights under the ADA. You can also find out how to ask for reasonable accommodations or file a discrimination charge on time. The site also has sample forms, answers to common questions, and step-by-step instructions to help you decide if you want to file a complaint. You may also call the EEOC at 800-669-4000.

For more information about reasonable accommodations under the ADA, visit the Job Accommodation Network (JAN) at www.askjan.org. JAN is a free service funded by the U.S. Department of Labor.

JAN can help you identify accommodations based on your cancer, medical condition, job duties, symptoms, or treatment side effects. The website also has sample language for accommodation requests and practical guidance for employees and employers. JAN can be a helpful resource when considering workplace changes or looking for accommodation options that may help you continue working.

What Additional Rights Do State and Local Laws Provide?

Many states offer additional rights and benefits on top of the federal laws For example, some state laws help employees who work in smaller offices. This means you may still be protected even if your employer is too small to be covered by the ADA or FMLA. Some states also use a broader definition of "family member," which may allow you to take time off work to care for more relatives and loved ones.

State and local laws may provide additional protections related to leave from work, job protection, and income. For example, some states allow employees to take more job-protected medical leave than federal law provides. Others offer programs that replace part of your income while you are unable to work. Some states and local governments also provide paid family leave or paid sick leave.

In addition, some states use a broader definition of "disability" and specifically protect people who have had cancer in the past or who are currently in remission.

Because these laws vary from state to state, it is important to review the laws where you live so you can better understand your rights and available protections.

For example, in California, there is a law called the Fair Employment and Housing Act (FEHA). FEHA applies to employers with as few as five workers. It also protects people with current disabilities, a history of disability, or perceived disabilities. California also recognizes cancer as a protected medical condition. California also has the California Family Rights Act (CFRA), which applies to smaller workplaces than the FMLA. It also allows employees to take time off to care for more types of loved ones, including close, family-like relationships. California also provides partial income replacement through State Disability Insurance (SDI) and Paid Family Leave (PFL).

What Should I Know About Applying for Jobs During or After Treatment?

If you are applying for a job during or after cancer treatment, you do not have to tell an employer that you have or had cancer. Employers may not ask about medical conditions before making a job offer. It is also possible to ask for reasonable accommodations during the hiring process. This includes accommodations like scheduling flexibility, additional test-taking time, or a remote interview option. You may request one without sharing your specific diagnosis.

An employer may require a medical examination only after making a conditional job offer, and only if all applicants for the same or similar positions must take that same test. Any medical information they get must be kept confidential.

An employer may not withdraw a job offer because of a disability, including cancer or a history of cancer, unless the condition would prevent you from performing the essential functions of the job and no reasonable accommodation would allow you to perform those functions safely. Before they can go back on a job offer, and rescind it, an employer must see whether a reasonable accommodation would help you to do the job.

Protecting Your Privacy During a Job Search

Employers cannot ask about your medical history before making a job offer. However, many may search online for information about job applicants. If you have shared information about your cancer diagnosis online or if friends or family have shared it publicly, an employer may see it through social media posts, fundraising pages, news articles, or professional networking websites.

Employers must follow anti-discrimination laws and cannot refuse to hire someone because of a disability. If you want to keep your diagnosis private, you may want to check what information about you is public online and change your privacy settings.

Sharing your story can be powerful and meaningful. This guidance is simply meant to help you stay in control of what information about you is public.

What If Workplace Protections Are Limited or Hard to Use?

Not all workers are covered by federal employment laws. Gig workers, independent contractors, day laborers, and employees of very small businesses may not qualify for protections under federal laws like the ADA or FMLA.

Even when legal protections exist, using them can feel risky. Many people worry about retaliation, reduced hours, job loss, immigration problems, or losing income they urgently need. It might not be financially possible for some, including workers in low-wage, part-time, or unstable jobs, to take unpaid leave, even if the law allows it.

These challenges do not affect everyone equally. People in communities of color, immigrant communities, workers with limited English proficiency, and those working in the gig or informal economy often face greater barriers to accessing workplace protections.

If you feel unsure or afraid to speak up, you are not alone. This information is meant to provide a starting point, but employment rights depend on the specific details of your job, your employer, and your state. Even small differences in circumstances can affect what protections are available.

What Workplace Protections Exist for Caregivers?

Caring for someone with cancer can be physically and emotionally demanding. There are resources that may help support you during this time.

- The FMLA allows eligible workers to use up to 12 weeks of unpaid, job-protected leave to care for a spouse, child, or parent with a serious health condition.
- Some states offer Paid Family Leave (PFL), which provides partial income replacement while you take time off to care for a loved one. These programs are available in states such as California, New York, New Jersey, and Rhode Island. The length of leave and amount of pay vary by state. In California, for example, eligible caregivers may receive partial wage replacement for up to 8 weeks.

You are not alone in navigating these issues. In addition to Cancer Justice, the following organizations provide support, education, and resources for caregivers:

- Caregiver Action Network - caregiveraction.org
- Family Caregiver Alliance - caregiver.org
- American Cancer Society - cancer.org/caregivers
- Cancer Support Community - cancersupportcommunity.org
- Cancer Care - cancercare.org

What Are My Health Insurance Rights and Options?

Navigating health insurance while managing a serious illness can be confusing and stressful. Knowing your rights and what options are available can help you make informed decisions and maintain uninterrupted care.

Patients often face questions about:

- keeping coverage
- understanding benefits
- obtaining treatment approvals
- appealing denials
- managing costs.

Knowing your rights and available options can help you make informed decisions and reduce interruptions in care.

This section explains key parts of health insurance coverage. This includes provider networks, prior authorization requirements, prescription drug coverage, and the appeals process if insurance denies coverage for treatment or medication. This is also an overview of common health insurance options. This includes employer-sponsored insurance, Medicare, Medicaid, and marketplace health plans. In addition, this section discusses medical billing and debt concerns, patient rights related to quality of care, and situations where seeking legal or professional assistance may be helpful.

Why Does Health Insurance Matter During Cancer Care?

Your health insurance policy is a contract between you and the insurance company. It explains the medical services the insurance company agrees to cover, and it also describes the costs you must pay. These services can include tests, medications, and treatment. What your insurance company pays, known as coverage, may be provided as a percentage (for example, 100%, 90%, or 50%) or as a specific dollar amount. Your policy will also list services that are not covered.

Health insurance can be a critical resource when you are facing cancer, but it often does not cover everything you need. Some health insurance plans limit access to specialists, out-of-network providers, or high-cost medications. Other plans may require prior authorizations, set high deductibles or copayments, or place restrictions on certain services. These plan types and terms are discussed in detail below.

What Type of Health Plan Do I Have?

Your type of health plan affects how you can access doctors, hospitals, and specialists. Knowing your plan type may help you understand whether you need a referral before seeing a specialist, whether you can go to an out-of-network center, and what your costs may look like. If you are not sure what type of plan you have, check your insurance card, your Summary of Benefits and Coverage, or call your insurance company.

There are three common types of health plans:

- **Health Maintenance Organization (HMO)**: An HMO usually requires you to choose a primary care doctor, also known as a primary care provider (PCP). If you need to see a specialist, your primary care doctor generally must give you a referral first. Typically, an HMO covers only care from in-network providers, who are a part of your HMO's plan, except in emergencies. HMOs often have lower monthly premiums and out-of-pocket costs, but they offer less flexibility in choosing your providers. This means you will generally need to receive treatment at hospitals and from doctors who are part of your HMO's network. If you want to receive care from someone not in your network, like a certain cancer center or a specialist, you may need to ask your plan for an exception or authorization. You also may need to consider switching plans during an open enrollment period or a qualifying life event.
- **Preferred Provider Organization (PPO)**: A PPO allows you to see any doctor or specialist without needing a referral from a primary care doctor. You will pay less when you use providers in your plan's network, but you can also go outside the network for an additional cost. Out-of-network care can sometimes be significantly more expensive. A PPO may make it easier to see specialists at different hospitals or seek a second opinion without needing permission from your plan first.
- **Exclusive Provider Organization (EPO)**: An EPO is like an HMO in that you generally must use providers within the plan's network for your care to be covered, except in emergencies. However, unlike most HMOs, an EPO usually does not require you to get a referral from a primary care doctor before seeing a specialist. An EPO is a more flexible option, like a PPO. This means you can typically see an in-network oncologist or specialist directly, without an extra step.

As explained below, a referral and a prior authorization are not the same thing.

- A referral is when your primary care doctor sends you to a specialist.
- Prior authorization is when your insurance company must approve a specific treatment, test, or medication before you receive it.

Even in a PPO or EPO plan that does not require referrals, your insurance company may still require prior authorization for certain services. These services can include advanced imaging, surgery, or specialty medications. Your doctor's office can usually help you determine whether prior authorization is needed.

How Do I Understand My Health Insurance Coverage?

The Affordable Care Act (ACA) is a federal law that expanded access to health insurance and set a minimum standard of quality for any level of coverage. Under the ACA, most individual and small-group health insurance plans must cover a core set of essential health benefits. These benefits include hospitalization, outpatient care, prescription drugs, laboratory services, preventive care, and mental health services. The ACA also stops insurance companies from setting yearly or lifetime dollar limits on coverage of these essential health benefits. This means

that even if your treatment costs a large sum, your ACA-compliant plan cannot limit the total amount it will pay for covered services.

ACA protections apply to certain health plans, like those purchased through the Health Insurance Marketplace or most employer-sponsored plans. Some products marketed as "health insurance," such as short-term limited-duration plans, are not required to follow ACA rules. These plans that do not follow ACA rules may deny coverage for pre-existing conditions, impose annual or lifetime limits, or exclude cancer treatment.

To understand what your insurance covers, review your *Summary of Benefits and Coverage* (SBC) or *Evidence of Coverage* booklet. Your insurance company or your employer's Human Resources department is available to answer any questions you may have about your benefits. Understanding your health insurance coverage can help you access care, avoid unnecessary delays, and better manage the financial impact of treatment.

Health insurance uses many specialized terms that can be confusing. Understanding a few key concepts can help you work with your plan and avoid unexpected costs or delays in care.

- **Provider Network**: A group of doctors, hospitals, pharmacies, and other health care providers that have agreed to work with your insurance company at set payment rates. When you use providers in your network, your costs are usually lower.
- **Out-of-Network**: A provider that does not have a contract with your insurance company. Your plan may charge higher costs for this care or may not cover it at all.
- **Prior Authorization**: A rule that your insurance company must approve a service, procedure, or medication before you receive it. In most cases, your doctor's office handles the prior authorization process on your behalf. However, you can also call your insurance company directly to ask whether a prior authorization is required before scheduling a procedure or starting a new treatment.
- **Premium**: The monthly amount you pay to keep your health insurance.
- **Deductible**: The amount you must pay each year before your insurance starts paying for services.
- **Copayment (Copay) / Coinsurance**: The part of the cost you must pay for services even after you meet your deductible.
- **Out-of-Pocket Maximum (also called an Out-of-Pocket Limit)**: The most you will have to pay for covered services in a plan year. Once you reach this amount, including your deductible, copayments, and coinsurance, your insurance plan pays 100% of covered services for the rest of the year.

How Does Prescription Drug Coverage Work?

Prescription medications are often an essential part of cancer treatment. Understanding how much your insurance covers for your medications can help you manage costs and avoid delays in treatment. Your health insurance plan has a list of medications it covers, called a *prescription formulary*. The *formulary* may include different coverage levels, costs, and rules, such as prior authorization or step therapy requirements. Medications are often organized into cost levels called tiers. Lower tiers typically include generic medications with lower costs, while higher tiers

may include brand-name or specialty medications with higher copayments or coinsurance. Many cancer treatments fall within specialty drug tiers.

A *brand-name drug* is a medication sold under a specific brand name by the company that developed it. A *generic drug* contains the same active ingredients and works in the same way, but it usually costs less. Some plans require *prior authorization* before they cover certain medications. Plans may also require *step therapy*, which means you may need to try a lower-cost medication before your insurance company will approve a more expensive treatment. If your doctor prescribes a medication that is not on your plan's formulary, your doctor may be able to request an exception or identify a similar medication that your insurance plan covers.

What Happens If I Do Not Have Health Insurance or Lose Coverage?

If you do not have health insurance, or if you lose coverage through your job, you may still have several options for getting health coverage. Depending on your circumstances, you may be able to continue your current insurance plan, purchase a new private plan, or qualify for public health insurance programs.

Losing job-based coverage is generally considered a "qualifying life event". A qualifying life event is a life change that allows you to enroll in new health coverage or continue existing coverage outside the normal enrollment period.

This includes circumstances like:

- losing a job
- a reduction in work hours
- divorce
- aging out of a parent's health insurance plan (typically at age 26)

Options for Continuing or Purchasing Private Health Insurance

COBRA and Continuation Coverage

COBRA is a federal law that may allow you to continue your employer-sponsored health insurance for a limited time after leaving your job or experiencing another qualifying life event. COBRA coverage typically lasts up to 18 months, although some states offer additional continuation coverage programs, often called "mini-COBRA," that may extend coverage for a longer period.

For example, California's Cal-COBRA law may let you continue coverage for a longer period than the federal COBRA period. While COBRA lets you keep your existing health insurance plan, you are usually responsible for paying the full monthly premium yourself, including the amount your employer previously paid toward your coverage.

Health Insurance Marketplace Plans

If COBRA coverage is too expensive, or if you do not qualify for COBRA, you may be able to purchase health insurance through the federal or state Health Insurance Marketplace.

Depending on your income and household size, you may also qualify for financial assistance to reduce the cost of coverage. There are two types of financial assistance available through the Marketplace: premium tax credits and cost-sharing reductions. Premium tax credits work by lowering your monthly premium. Cost-sharing reductions work by lowering your deductible, copayments, and out-of-pocket costs.

For more information about Marketplace coverage, visit www.healthcare.gov or call 1-800-318-2596. California residents can also visit www.healthforcalifornia.com.

Other Sources of Private Coverage

Some individuals may also have access to health coverage through other sources. Check if you have access to health coverage through your spouse's employers, unions, professional organizations, or religious groups. Each plan may have different eligibility requirements, costs, provider networks, and covered services.

Public Health Insurance Programs

You may also qualify for public health insurance programs depending on:

- your age
- income
- disability status
- military service

These programs can provide important health coverage if you do not have access to private insurance or need more affordable coverage options. As explained below, there are 4 main types.

1. **Medicare** is a federal health insurance program primarily for people age 65 or older. Those under the age 65 may also qualify if they have received Social Security Disability Insurance (SSDI) benefits for at least two years or have certain serious medical conditions, such as End-Stage Renal Disease. Medicare generally covers many healthcare services, but patients are often still responsible for deductibles, copayments, coinsurance, and other out-of-pocket costs. To help cover these expenses, some individuals purchase supplemental insurance, often called Medigap coverage.

To learn more about Medicare, visit www.medicare.gov or locate your state's State Health Insurance Assistance Program (SHIP) through www.shiphelp.org. California residents may also find assistance through www.healthconsumer.org or healthcarerights.org.

2. **Medicaid** provides health coverage to individuals with limited income and resources. While it is a joint federal and state program, eligibility rules and program names vary by state. Medicaid may cover many of the same healthcare services offered through private insurance

plans. It also may provide coverage for services that private insurance does not typically cover, such as certain long-term care or in-home supportive services.

In California, Medicaid is called Medi-Cal. You can learn more about Medi-Cal eligibility, benefits, and enrollment through the California Department of Health Care Services website at https://www.dhcs.ca.gov/services/medi-cal. You can also explore coverage options through Covered California at https://www.coveredca.com.

3. **VA Health Care** provides medical services to eligible veterans through hospitals, clinics, and other healthcare facilities operated by the Department of Veterans Affairs. For more information about eligibility, enrollment, and available services, visit: https://www.va.gov/health-care/eligibility

4. **TRICARE** is a health insurance program for Active-Duty service members, National Guard and Reserve members, military retirees, and eligible family members, including spouses and children. Depending on the specific TRICARE plan, coverage may include care from both military and civilian healthcare providers. Some TRICARE plans require you to use approved provider networks or obtain referrals before seeing specialists. It is important to review your plan carefully to understand where you can receive care and what costs may apply. For more information, visit: https://www.tricare.mil/

Will My Cancer Diagnosis Affect My Insurance Eligibility?

The Affordable Care Act makes it illegal for health insurance companies to deny coverage or charge higher premiums because of pre-existing conditions, including cancer.

Employer-sponsored health plans cannot use your health status to decide whether you are eligible for coverage. Public programs like Medicare and Medicaid also do not deny coverage based on a cancer diagnosis. Eligibility is based on things like age, disability status, or income.

This is not necessarily true for other types of insurance. Some types of insurance, like life insurance, disability insurance, or long-term care insurance, may consider your medical history when deciding whether to offer coverage.

What Is the Genetic Information Nondiscrimination Act (GINA)?

GINA, as federal law, protects genetic information. The Genetic Information Nondiscrimination Act (GINA) generally does not allow health insurers and employers to use genetic information to make decisions about coverage, eligibility, or employment. Types of protected genetic information include family medical history and genetic test results.

This means two things: health insurers cannot use genetic information to deny coverage or increase costs, and employers cannot use genetic information in hiring, firing, or promotion decisions. Please note that GINA does not apply to life insurance, disability insurance, or long-term care insurance.

For more information about GINA, visit: https://www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/resource-center/publications/genetic-information-health-plan-protections.pdf

What Can I Do If My Insurance Denies Coverage?

If your health insurance company denies coverage for a treatment, medication, or medical service, it can feel frustrating and confusing. The good news is that you have the right to challenge that decision. Today, many insurance companies use automated systems or artificial intelligence (AI) to review claims and prior authorization requests. These tools process requests quickly, but that can lead to faster denials because AI relies on limited medical information or on rules that do not carefully review requests. Because of these concerns, some states have started regulating how insurance companies use AI.

For example, California passed legislation (Senate Bill 1120), which requires that decisions about whether care is medically necessary must be made or reviewed by a licensed physician or qualified health professional. AI tools may help with the review process, but they cannot be the ones to deny or delay care on their own.

When appealing an insurance denial:

If your insurance company denies treatment or medication, you can appeal the decision and ask whether a licensed physician reviewed your case. You may also ask if your doctor can request a "peer-to-peer review" with the insurance company. A peer-to-peer review is when your doctor speaks directly with a physician who works for the insurance company to explain why the treatment is medically necessary. This is often the fastest way to resolve a denial, because it allows your doctor to provide clinical details and answer questions in real time.

There is also a federal law called the "No Surprises Act" to protect you. The No Surprises Act protects patients from "surprise" medical bills in certain situations. You are protected if you receive emergency care, or if you are treated by an out-of-network provider at an in-network hospital or facility without your advance consent. This law generally limits what you can be billed to the amount you would pay for in-network care. This protection is especially helpful for patients who may receive care from multiple providers during a hospital stay or surgical procedure (such as an out-of-network anesthesiologist or radiologist) without choosing or even knowing the provider was out-of-network.

How Does the Appeal Process Work?

Step 1: Review the Denial Notice

Carefully read the denial notice from your insurance company. The notice should explain:

- why the claim was denied.
- how you can appeal the decision.
- the deadline to submit your appeal.

Pay close attention to the appeal deadlines listed in the notice. Missing a deadline can make it harder to challenge the decision. Keep copies of the denial letter and any documents you receive from your insurance company.

Some denial letters say that the treatment was "not medically necessary." This means the company has determined that the treatment does not meet its standard for being appropriate and needed for your condition based on accepted medical guidelines. However, this does not necessarily mean the treatment is wrong for you. To appeal the denial and possibly receive this type of treatment, your insurance company needs more information or disagrees with your doctor's recommendation. If this happens, your doctor may be able to give them medical information explaining why you need the treatment for your condition.

Step 2: File an Internal Appeal

You have the right to ask your insurance company to reconsider its decision. This is called an internal appeal. When you file an appeal, it can help to include additional information that supports your claim. This may include:

- a letter from your doctor explaining why the treatment is medically necessary.
- medical records.
- a treatment plan or other documentation from your healthcare provider.

Sometimes your doctor can ask for a peer-to-peer review. That is when your doctor speaks directly with a doctor who works for the insurance company to explain why the treatment is medically necessary. This can resolve the denial without going through the full appeals process. Your doctor's office may help you gather and submit the information needed for an appeal.

Step 3: Request an External Review

If your insurance company denies your internal appeal, you may ask for an external review, where an independent medical reviewer, who does not work for the insurance company, evaluates whether the treatment should be covered. The insurance company usually must do what the reviewer decides. An external review is a right under federal law and is available in every state.

IMPORTANT: If your medical situation is urgent, you can request an expedited external review. Under federal law, the independent reviewer must issue a decision within 72 hours for expedited cases.

In California, this process is called an "Independent Medical Review" (IMR) and is handled by the California Department of Managed Health Care or the California Department of Insurance, depending on your type of health plan.

If you need help, you can also contact your state insurance department. Many insurance denials are overturned at this stage. For example, the California Department of Managed Health Care has shown that more than half of IMR cases are decided in favor of patients, making it an important step not to skip.

Where to Get Help With Denials and Appeals?

California Department of Managed Health Care (DMHC): 1-888-466-2219 or www.dmhc.ca.gov

California Department of Insurance (CDI): 1-800-927-4357 or www.insurance.ca.gov
Your state's insurance department (for residents outside California)

What Happens If My Health Insurance Is Canceled?

If your health insurance coverage is terminated, your insurance company must explain in writing why they are terminating you and tell you about your right to appeal the decision. You may challenge the termination by filing an internal appeal with your insurance company.

If the appeal is unsuccessful, you may ask for an external review by an independent reviewer. While your appeal is pending, you may also want to look into other coverage options, such as COBRA continuation coverage, Medicaid, or a health plan offered through the Health Insurance Marketplace.

What Are My Rights During Medical Treatment?

As a patient, you have important rights when it comes to your medical care.

You have the right to:

- Receive clear information about your diagnosis and treatment options to make informed decisions about your care.
- Ask questions.
- Talk about alternatives.
- Give or deny consent before a treatment or procedure is performed.
- Get a second opinion from another doctor.
- Choose to transfer your care to a different provider.

Second opinions can be very helpful. A second opinion can help confirm a diagnosis, clarify treatment options, or provide reassurance about your care. Before getting a second opinion, you may want to check with your insurance company because some insurance plans do not always cover the cost of a second opinion, especially if the doctor is outside your insurance network.

Health Insurance Portability and Accountability Act (HIPAA)

You also have the right to access your medical records. As federal law, the Health Insurance Portability and Accountability Act (HIPAA) allows patients to review and get copies of their medical records. Some state laws provide even faster access. For example, in California, healthcare providers must let you review your records within five business days and provide copies within fifteen days. That is faster than the 30-days allowed under federal law.

Finally, you have the right to raise concerns about your care and file complaints without fear. If you believe you received unsafe care or were treated unfairly, you may report your concerns to the healthcare facility, a licensing board, or another appropriate authority. If you experience retaliation for reporting concerns such as denial of care, discharge from treatment, or intimidation, this may be unlawful.

Speaking up about your healthcare can feel difficult, especially during treatment, but patients generally have the right to ask questions, report concerns, and advocate for safe and appropriate care.

How Do I Raise Concerns About My Care?

In many situations, the first step is simply to talk with your healthcare provider. You may want to speak directly with your doctor about your concerns, send a message through your patient portal, or contact the hospital's patient advocate or patient relations office. Many doctors want to hear directly from patients and may be willing to explain what happened or address your concerns.

How Do I File a Complaint With a Licensing Board?

If you believe a healthcare provider acted improperly or provided unsafe care, you may also file a complaint with your state medical board or another licensing board. When filing a complaint, try to be as clear and detailed as possible about what happened, including the dates of care, the names of the providers involved, and a clear description of the issue or concern. In many cases, you will be asked to sign a medical records release so that the board can review the medical records as part of its investigation.

To find contact information for your state medical board, you can visit the Federation of State Medical Boards website at www.fsmb.org/state-medical-boards/contacts. A licensing board may investigate the complaint and take disciplinary action if it finds that a provider violated professional standards.

When Can Poor Medical Care Lead to Legal Claims? In some situations, you or your family may consider legal action if you believe that serious harm occurred because of medical care. This may include situations involving medical malpractice, elder abuse, or wrongful death.

What Is Medical Malpractice? Medical malpractice occurs when a healthcare provider fails to meet the accepted standard of care and that failure is what causes the patient harm. These cases

usually require expert medical testimony and careful review of medical records to determine whether the provider's actions fell below the standard expected of similar medical professionals.

What Is Elder Abuse? Some states allow lawsuits when healthcare providers or caregivers neglect the basic needs of an elderly patient. This may include failing to provide necessary medical care, supervision, medication, or assistance with basic daily needs.

What Is Wrongful Death? If a patient dies because of negligent medical care, certain family members may have the right to file a lawsuit to bring a wrongful death claim to get compensation for the harm caused by the loss of their loved one.

These types of lawsuits have strict deadlines called statutes of limitations. Because these deadlines vary by state, it may help to speak with an attorney as soon as possible if you believe serious harm occurred.

How Can I Find and Participate in a Clinical Trial?

If you are interested in participating in a clinical trial or other experimental treatment, speak with your doctor first. Your doctor may be able to recommend trials based on your condition and the treatments you have already received. As a second step, you can also use online tools that match patients with clinical trials and provide alerts when new studies become available. The American Cancer Society provides information about what to expect during a clinical trial at https://www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html. The EmergingMed Clinical Trial Navigation Service also offers free, confidential trial matching and referral services. Cancer-specific nonprofits may also have information about clinical trials and new therapies on their websites.

When looking at clinical trials, their listings typically include:

- a summary of the study
- eligibility requirements
- contact information for the research team

Several organizations maintain searchable databases of clinical trials. The National Cancer Institute lists government-funded and some privately funded cancer trials. The National Institutes of Health has a large database at ClinicalTrials.gov. CenterWatch (CenterWatch Homepage - Clinical Trial Listing Database & Insights |) also has information about industry-sponsored and government-funded studies. Pharmaceutical and biotechnology companies may also list trials they sponsor and offer matching tools for patients interested in specific treatments.

Clinical trials must follow federal laws that protect participants. These protections come from research regulations, including the Federal Policy for the Protection of Human Subjects, also known as the Common Rule, or oversight by the U.S. Food and Drug Administration. Every clinical trial must also be reviewed and monitored by an independent group called an Institutional Review Board (IRB). The IRB reviews study plans before a trial begins and monitors the study through the end. Its role is to help ensure that the research is ethical, risks are minimized, and participants are treated fairly and safely.

As a third step, before joining a clinical trial, you must go through an informed consent process. During this process, researchers must provide clear and complete information so that you can decide whether to participate. This includes what will happen during the study, the possible risks or side effects, and the potential benefits. Participation in a clinical trial is always voluntary. You have the right to leave a study at any time and for any reason, and choosing to leave will not affect your access to regular medical care. Your doctors can help you safely transition out of the study if needed.

It is important to know that participation in a clinical trial may also affect how your medical care is covered and what costs you may be responsible for. Be sure to understand how your health insurance applies to clinical trial participation, what services are covered, and whether prior approval may be required.

What Are My Housing Rights During Cancer Treatment?

A cancer diagnosis can affect many parts of your life, including your housing. Treatment, changes in income, or new physical needs may make it harder to stay safely in your home. Federal law, including the Fair Housing Act (FHA), helps protect you from unfair treatment and allows you to ask for changes or support. These protections apply to both renters and homeowners, and state laws may offer more protections. The sections below explain your rights and options if you face housing problems during treatment.

What Are My Rights as a Renter?

Because cancer can qualify as a disability, you are protected from housing discrimination under federal law. Landlords, property managers, and homeowners' associations (HOAs) cannot refuse to rent to you or evict you because of your diagnosis.

By law, you are not required to disclose your cancer diagnosis to your landlord or HOA. However, to request legal protections such as reasonable accommodations, you may need to let them know that you have a disability. This does not mean you need to give them detailed medical information. Once a housing or financial issue arises, it is often best to communicate as early as possible. Early and effective communication can help prevent more serious problems

Accommodations and Modifications

You have the right to request reasonable accommodations and modifications that allow you to safely live in your home. Accommodations are changes to rules or policies. This includes letting a caregiver to stay with you, giving a reserved parking space, or changing certain policies. Reasonable accommodations may also include giving you flexibility with how and when rent is paid. It also can allow a third-party charity or assistance program to pay rent on your behalf or adjust the rent due date to match when you get disability or other benefit payments. Modifications are different from accommodations, but they can be just as helpful. Modifications are physical changes, like installing grab bars, adding a ramp, or widening doorways. Renters are typically responsible for modification costs unless they live in federally funded housing.

If you are discriminated against, you can file a complaint with the U.S. Department of Housing and Urban Development (HUD) within one year or contact a local fair housing agency or legal aid organization for support.

If cancer treatment affects your ability to pay rent, it is important to let your landlord know as early as possible, preferably in writing. You may be able to ask for a payment plan, temporary rent reduction/delay, or talk about ending your lease early. **If you get an eviction notice, act quickly - legal aid and rental assistance programs may still help.**

Landlords must maintain safe and livable housing, including essential services. If repairs are not made, you may have options depending on state law, but it is important to keep detailed records of all requests and conditions.

By law, you should have access to:

- heating
- plumbing
- electricity
- the ability to address unsafe conditions, such as mold or pests

What Are My Rights as a Homeowner?

Federal law also protects homeowners from housing discrimination. You have the right to safely live in and use your home during cancer treatment. This is still true even when dealing with homeowners' associations (HOAs) and mortgage lenders.

You are not required to tell them about your cancer diagnosis to your HOA or mortgage lender. To ask for legal protections or financial assistance, you may need to say that you have a disability, without providing detailed medical information. It is important to communicate early because it can help you find out what options you have and avoid serious financial or housing issues.

You have the right to make reasonable, medically necessary changes to your home, such as installing ramps, adding handrails, widening doorways, or modifying entrances or bathrooms. HOAs cannot deny these changes because of appearance rules, although they may ask for some proof and require compliance with local permits.

If cancer treatment affects your ability to pay your mortgage, lenders cannot treat you unfairly because of your diagnosis. You may qualify for options such as a loan modification, forbearance, repayment plans, or other hardship programs.

Protections may also apply under the Equal Credit Opportunity Act (ECOA), a federal law that helps ensure lenders treat you fairly and do not deny or limit assistance because of a disability or health condition.

Practical Tip: Be careful when working with third party mortgage intermediaries offering help with a loan modification. While some help, others may be scams.

How Can I Take Action to Protect My Housing?

Housing laws vary by state. Contact a local legal aid or fair housing organization if you need help. Taking action early can help protect you and your housing. You have the right to remain safely in your home during cancer treatment.

HUD-approved housing counselors can help you understand your options for free or low-cost. Their counselors can explain options like loan modification, forbearance, or repayment plans. They can also help with budgeting, paperwork, and talking to your lender. HUD counselors can also help you identify potential scams.

You can find a HUD-approved housing counselor near you through the Consumer Financial Protection Bureau at https://www.consumerfinance.gov/find-a-housing-counselor/ or by calling (800) 569-4287.

What Are My Rights in Housing Court and How Can I Get Help?

Courts across the United States must provide disability accommodations under the Americans with Disabilities Act (ADA). **If you need an accommodation in a housing court case, you can ask the court for help.** Accommodations are changes that affect how the judge runs the courtroom. In most courts, **you must ask for these by making a formal request or filing a motion.**

Examples of accommodations you may need include:

- More time to meet court deadlines.
- A new court date if you cannot attend because of treatment or your condition.
- The option to show up remotely instead of in person because of your health condition.
- If you do not have an attorney, you can ask to bring someone to help you understand what happens in court.
- More or longer breaks during court.

Remember to ask for accommodations as early as possible. The judge may ask for some information about what you need, but it should not ask for more medical details than what the judge really needs to decide on how to accommodate you.

How Can I Protect My Finances During Treatment?

How Do I Pay Bills When I Cannot Work?

A cancer diagnosis can affect more than your health. It can also create serious financial stress. Many people experience something that is called “financial toxicity.” Financial toxicity is the

overwhelming economic burden of medical care. The high cost of care plus making less or no money is hard when you are also dealing with cancer. This financial distress can make it hard to pay all the bills. You may be facing medical bills, insurance issues, or changes in your ability to work. If you cannot work or your income has changed, there are programs and resources to help replace lost income and help you manage your key expenses.

What Public Disability Benefits Are Available?

The Social Security Administration (SSA) offers two main programs that give financial support to people with disabilities, including those who cannot work because of cancer:

1. **Supplemental Security Income (SSI)**:

   SSI is a need-based program for people who are aged, blind, or disabled, who have limited income and resources. It gives monthly cash payments to help cover basic needs such as food, clothing, and shelter. As of 2025, the maximum federal benefit is $967 per month for a single person, $1,450 for a couple, and $484 for an essential person (someone who lives with and provides necessary care to the recipient). Some states add extra payments, and benefits are usually adjusted each year for the cost of living.

2. **Social Security Disability Insurance (SSDI):**

   SSDI is for people who have worked and paid into Social Security through payroll taxes. To qualify, you must have a medical condition expected to keep you from working for at least 12 months or that results in death. Monthly benefits are based on your work history and earnings. Average payments are around $1,200. There is a five-month waiting period from when your disability begins before payments start. You can check your estimated benefit at **www.ssa.gov** or by contacting SSA directly.

What Other Financial Assistance Is Available?

Beyond government programs, you may also get financial help from community and nonprofit organizations. Local civic groups and faith-based organizations, like the Salvation Army and Catholic Charities, may help. National groups like the American Cancer Society and Patient Advocate Foundation, the Leukemia & Lymphoma Society, and other cancer-specific organizations may also help.

Some programs like Angel Flight help you get to your doctor's appointments. They may offer free or low-cost flights to medical appointments. You may also consider online platforms like GoFundMe to help cover medical and daily living expenses.

What Should I Know About Crowdfunding?

Crowdfunding can help raise money for medical bills and everyday expenses during cancer treatment. It is important to plan. Understand how getting money this way may affect your finances and privacy. Sharing your story can help others understand what you need\s, but it is

important to think carefully about how much personal or medical information you are comfortable making public or having another person share about you.

Most platforms charge small fees to process donations. This may reduce the total amount you get. Funds raised may also affect whether you can get certain public benefits, such as SSI, Medicaid, or food assistance. Sometimes, financial planning tools like special needs trusts or ABLE accounts may help protect your eligibility for these benefits. Donations are often flexible and can be used many types of expenses, including medical care, housing, transportation, and daily needs.

How Do I Manage Medical Debt?

Cancer care can lead to large medical bills. The following steps can help you manage costs and avoid financial distress:

What Steps Can I Take?

- **Check Bills Carefully:** Review your medical bills for errors. Look out for duplicate charges or services you did not get. If something looks wrong, contact the billing office and ask for an itemized bill.
- **Ask About Financial Assistance:** Many hospitals offer free or reduced-cost care for patients who qualify. These programs may be available even if you have insurance. Look for a financial assistance or charity care policy on the hospital's website or ask the billing office for an application.
- **Try to Negotiate:** If you cannot pay your bill in full, contact the provider early. You may be able to set up a payment plan or request a discount. It is usually easier to negotiate terms before the bill is sent to collections.
- **Focus on Essential Expenses First:** Prioritize housing, food, utilities, and secured debts, such as your mortgage or car loan. Medical debt is usually unsecured, meaning it does not put your property at immediate risk if you do not pay it.
- **Get Help if You Need It:** You do not have to manage medical bills alone. There are many resources to help you. Organizations like the Patient Advocate Foundation can help you organize bills, fight charges, and understand your insurance. The American Cancer Society may also connect you with services to help you deal with your finances. These services can be help you figure out complex bills and explore your options.

In some states, people with very limited income and assets may be considered "collection proof," meaning creditors may not be able to collect money from them even if they owe money. This depends on your individual circumstances, and debts may still be sent to collections or appear on your credit report.

What Financial Assistance Is Available for Medical Bills?

Cancer treatment can be expensive. Many people worry about how they will pay their medical bills. If you are struggling with medical costs, you are not alone. Many nonprofit hospitals offer financial assistance programs, sometimes called charity care. Under federal law, nonprofit hospitals must make these programs available to eligible patients (26 U.S.C. § 501(r)).

Depending on your income and financial situation, these programs may cut your bill or eliminate it. Hospitals may also offer payment plans that allow you to pay your bills over time instead of all at once. This can be helpful to balance other costs. If you receive a bill you cannot afford, it is often helpful to contact the hospital's billing department as soon as possible to ask them what options they must help.

It is also important to review your medical bills carefully because billing errors can happen. If something on your bill does not look right, you can contact the provider's billing department and ask for an explanation of the charges. Billing staff may be able to correct mistakes, clarify charges, or talk to you about payment options. Many hospitals also have financial counselors or patient navigators who can help you understand your bills and apply for financial assistance programs.

Some nonprofit organizations may also help patients with hospital financial assistance applications. For example, DollarFor.org is a free nonprofit resource that helps patients figure out whether they qualify for hospital charity care and help fill out the application.

How Is Medical Debt Handled in California?

California law provides extra protections that may help reduce or manage medical debt. Medical debt includes any money owed for hospital care, doctor visits, dental care, and/or other health services. It may also include debt on medical credit cards or regular credit cards used to pay for treatment.

California hospitals usually have to offer financial assistance, sometimes called charity care, to patients who qualify. This help may include free care or discounted care that lowers your medical bills. For example, in 2026, this type of help was for individuals earning approximately $63,840 per year or a family of four earning approximately $132,000 per year or less.

Patients may qualify if they are:

- uninsured
- have high out-of-pocket medical costs
- have household incomes at or below 400 percent of the federal poverty level

Hospitals must also offer reasonable payment plans based on your ability to pay. You can ask for a financial assistance application from the hospital billing department or website and ask hospital staff or patient navigators for help complete the paperwork and the process. Some nonprofit organizations, such as www.DollarFor.org may also help patients apply for hospital financial assistance programs.

California law also limits how medical debt is handled. Medical debt owed directly to hospitals, doctors, or dentists generally does not show up on consumer credit reports in California. But, if you use a credit card or medical credit card to pay for care, that debt may be reported to credit agencies and may affect your credit score if you miss your payments.

If you receive a medical bill you cannot afford, consider these steps:

- ask for an itemized bill
- double check that your insurance was billed correctly
- apply for financial assistance as soon as possible

If you believe a hospital has not followed California financial assistance laws, you may file a complaint with the California Department of Health Care Access and Information.

Under California law, hospitals usually have to give you information about financial assistance before sending eligible medical debt to collections. You may apply for financial assistance at any time, even after you get a bill or paid some of it. Some patients may be able to get refunds for overpayments. Hospitals generally cannot require you to disclose your immigration status to apply for financial assistance and must provide notices in multiple languages. Many patients do not know they may get help even if they have health insurance.

When Should I Consider Bankruptcy?

Bankruptcy may help get rid of certain debts and give you a fresh start if you feel overwhelmed. It is a serious decision with long-term effects, so it is important to speak with a lawyer. Cancer Justice is housed at Public Counsel, which has a Bankruptcy Clinic that gives free legal guidance. If you have debt related questions, you can reach out to Cancer Justice for more information and support.

Estate Planning and Planning Ahead

A cancer diagnosis can raise difficult questions about the future, including how to protect yourself, your loved ones, and your finances. While these conversations can feel overwhelming, planning can help provide clarity and peace of mind during an uncertain time.

Estate planning allows you to put important wishes in writing before a medical emergency happens. These documents can help you choose who can make medical or financial decisions for you, who will care for your children, and how your property and belongings should be handled.

Many people focus on the estate part of the term estate planning, but no matter your finances, planning may help reduce stress, delays, costs, and confusion for your loved ones. In some situations, it may also help protect access to important public benefits, including Medicaid, called Medi-Cal in California. If you do not have a plan in place, state law may determine who can make decisions for you and who receives your property.

What Are the Key Estate Planning Tools?

There are several common estate planning tools that can help you communicate your wishes and make important decisions easier for your loved ones during a difficult time.

An **Advance Health Care Directive** (AHCD) allows you to choose someone to make medical decisions for you if you cannot speak for yourself. It also allows you to explain your wishes

about your potential future medical care. It may also allow you to include information about your treatment preferences and values.

It is highly important to speak openly with the person you choose. This individual should understand your wishes and feel prepared to advocate for you if needed. Your AHCD can also set out your wishes for whether you want life-sustaining treatments continued indefinitely, what your organ donation wishes are, and many other instructions. Setting out these wishes ahead of time in an AHCD can help your chosen person act in your stead if it becomes necessary.

Some patients may need to complete medical planning forms. For example, a **Do Not Resuscitate** (DNR) order tells medical providers whether you want attempts made to restart your heart or breathing. A **Physician Orders for Life-Sustaining Treatment** (POLST) form is a medical order that is completed with a doctor to explain your wishes about certain treatments, such as CPR, feeding tubes, or hospitalization.

These forms are often used by individuals with serious or advanced illness with no other planning in place. A hospital social worker or healthcare provider may be able to help you understand and complete these documents.

A **Power of Attorney** (POA) allows someone you trust to help manage financial matters, such as paying bills or handling bank accounts, if you are unable to do so yourself. Without a POA, your loved ones may need to go through a court process to manage your finances.

A **Will** explains who should receive your property after your death and allows you to nominate a guardian for your children. Some people may be able to create a simple Will online using tools such as FreeWill (freewill.com). FreeWill is a free service that helps individuals prepare basic estate planning documents. While these tools may be helpful for simpler situations, more complex circumstances may still require legal advice.

A **Living Trust** allows property to pass to loved ones without going through Probate, which is a court process that can take time and cost money. In some states, including California, Probate can be lengthy and expensive. It can also help avoid a situation where any property passing to your children is overseen by the court until they are 18.

A **HIPAA Authorization** allows people you have specified to speak to your medical professionals about your condition. This can be helpful so they can determine whether the documents above need to be put into effect. Without such a waiver, some providers will not speak with your loved ones.

Other tools, such as **Transfer-on-Death** (TOD) or **Payable-on-Death** (POD) designations, allow certain assets, including bank accounts or property, to transfer directly to a named person.

It is also important to review beneficiary designations for retirement accounts, pensions, and life insurance policies. These forms control who receives those assets, no matter what your Will or Living Trust says. Naming family members who have passed away, ex-spouses, or people you haven’t spoken to in years can make things complicated or frustrate your wishes.

In some situations, a **Special Needs Trust** may help protect important public benefits, such as Supplemental Security Income (SSI) or Medicaid, if you receive money from a settlement or inheritance or if you are leaving money to a child who receives public benefits.

How Do I Plan for My Children's Care?

If you have children, it is important to think about who could help care for them during treatment or in an emergency. At times, treatment or side effects may make it harder to manage daily responsibilities such as school pickups, meals, transportation, or medical appointments. Identifying trusted support in advance can help provide stability for your children during an uncertain time.

To allow another adult to care for your child, you may need certain legal documents. Without written permission, schools or medical providers may not allow another adult to pick up your child or make decisions on your behalf. Some states allow temporary caregiving forms that give another adult limited authority to help care for a child.

As an example, California has a Caregiver's Authorization Affidavit that may allow a trusted adult to enroll your child in school and consent to certain medical care without going to court. For longer-term planning, you may also choose to nominate a guardian for your children in your Will. While a judge ultimately appoints a guardian, a parent's nomination carries a great deal of weight. It can also help ensure that different sides of the family do not argue about who will take responsibility, since you will have already made your wishes clear as to who you trust to take responsibility for them if you are not able. Planning ahead can help reduce stress and provide greater clarity for your loved ones.

How Could Estate Recovery Affect My Benefits?

If you receive Medicaid, the state may seek repayment through certain assets after your death. This process is commonly called "Estate Recovery." It often applies to individuals who are age 55 or older. Estate Recovery rules vary by state.

In California, for example, Medi-Cal Estate Recovery is generally limited to assets that are subject to Probate. Planning ahead may help protect your home and other assets. In some situations, using tools like Living Trusts or Transfer-on-Death Deeds may help avoid Probate.

Because these rules can be complicated and may affect your family or property, you may want to speak with a lawyer if you receive Medicaid or Medi-Cal benefits.

What Are the Important Legal Considerations?

Estate planning documents must usually be properly signed to be considered legally valid. Depending on the type of document and the laws of your state, you may need witnesses or a notary. Without these documents, loved ones may need to go through a court process to make decisions on your behalf. Even if you are healthy, planning documents can still be important in case of an emergency.

Because laws vary by state, it is important to understand the rules that apply where you live.

What Happens When a Child with Cancer Turns 18?

When a child turns 18, they are legally considered an adult in most states. This means parents may no longer automatically have the right to access medical information, speak with doctors, make healthcare decisions, or manage financial matters for their child, even if the child is still undergoing treatment.

Because of this, families may want to consider whether to sign certain legal documents before or after the child turns 18. These may include an Advance Health Care Directive (AHCD), which allows the young adult to identify someone to make medical decisions if they become unable to do so, a HIPAA authorization form, which allows healthcare providers to share medical information with parents or caregivers, and a Power of Attorney (POA), which may allow a parent or trusted adult to assist with financial or legal matters.

If the young adult is unable to make decisions independently because of cognitive, developmental, or medical limitations, families may also want to speak with a lawyer about conservatorship options. Depending on the state, a court may appoint someone to make medical, financial, or personal decisions on behalf of an adult who cannot safely make those decisions independently.

In California, additional information about conservatorship is available through the California Courts Self-Help Guide at https://www.selfhelp.courts.ca.gov/start-limited-conservatorship-case.

How Do I Plan Ahead for Medical Decisions?

If you are facing a serious illness, you generally have the right to make decisions about your medical care, including whether you want to accept or refuse treatment. Not all treatments have the same goal. Some treatments may focus on extending life. Others may focus on comfort, symptom management, and quality of life. Thinking about your goals and values ahead of time can help you communicate the type of care you want to receive.

Palliative Care focuses on managing pain, symptoms, and stress related to serious illness. It can be provided at any stage of illness, including while you are still receiving treatment. Hospice Care is generally for individuals who are no longer seeking treatment to cure their illness. Hospice focuses on comfort, support, and quality of life and is often provided at home. Planning for medical decisions may also help reduce stress and uncertainty for loved ones during a medical emergency.

When Should I Seek Legal Help?

Estate planning may become more complicated in circumstances like:

- if you own a home
- receive public benefits
- have children

- have significant assets
- co-own property with your spouse, partner, family members, or others

In these situations, speaking with a lawyer or legal aid organization may help ensure your documents are completed correctly and reflect your wishes. Because laws vary by state, you may also want to speak with a local attorney about the rules that apply where you live. Cancer Justice may be able to provide legal information, resources, and referrals.

For individuals with simpler situations, it may be possible to create basic estate planning documents online using tools such as FreeWill (freewill.com), a free step-by-step platform that helps individuals prepare documents such as a Will, Advance Health Care Directive (AHCD), and Power of Attorney (POA). FreeWill has partnered with Public Counsel to help expand access to estate planning resources. However, if your situation is more complex, it is important to seek legal advice.

What Should Non-U.S. Citizens Know?

Many immigrants can receive health care and other benefits. The rules can be complex, but receiving benefits will not affect everyone in the same way. In many cases, it is safe to get care and support. Getting medical care for cancer treatment is generally safe and should not prevent you from getting help.

How Could Benefits Affect My Immigration Status?

If you apply for a green card or certain immigration statuses, the government may look at whether you are likely to depend mainly on cash assistance. This is called the **"public charge"** test. Not all benefits are treated the same. In general, getting medical care or short-term help does not make someone a public charge. Having a disability or serious illness does not, by itself, make someone a public charge.

Some benefits may be considered in a public charge review. These generally include:

- Supplemental Security Income (SSI), which provides monthly cash support.
- Long-term institutional care paid for by Medicaid (such as nursing home care).

Many other benefits do not count against you. These generally include:

- Health coverage, including Medicaid for most medical care.
- The Children's Health Insurance Program (CHIP).
- Marketplace insurance under the Affordable Care Act, even if you receive financial help.
- Food assistance (SNAP).
- Housing assistance.

Who Is Exempt?

Some immigrants are not subject to public charge rules at all. This includes:

- Refugees and asylees.
- Survivors of domestic violence or trafficking.
- People with Temporary Protected Status (TPS).
- Certain children and special immigrant groups.

Public charge decisions are based on your overall situation. This includes factors like your income, health, and family support. Just because you get a benefit does not mean you are a public charge. Because these rules can be complex and change, get advice before applying for benefits or making changes to your immigration status.

What Health Coverage Is Available for Immigrants?

Some states offer health coverage regardless of immigration status. In California, for example, many low-income residents can qualify for Medi-Cal, even if they are undocumented.

Federal programs have different rules. Some immigrants lawfully in the US must wait before qualifying. Undocumented immigrants are not eligible for most federally funded programs. But there are exceptions. In some states, children and pregnant women may qualify for coverage more easily, even under federal programs.

Can Hospitals Ask About Immigration Status?

Hospitals and clinics may ask for personal information for billing, insurance, or eligibility purposes. This can sometimes include questions about residency or eligibility for certain programs. However, **you do not have to answer questions about your immigration status to receive emergency medical care.**

Under the Emergency Medical Treatment and Labor Act (EMTALA), **hospitals must provide emergency care regardless of immigration status, insurance status, or ability to pay.** This includes care in emergency rooms.

For non-emergency services, hospitals or clinics may ask for information to see if you are eligible for programs like Medicaid or Medi-Cal, or to set up payment plans or financial assistance. In these cases, you can ask why they need the information and what happens if you choose not to answer those questions.

How Is My Privacy Protected?

Hospitals must protect your personal information under HIPAA. This means your medical information is private, and **hospitals do not share your information with immigration enforcement as a routine practice.**

What Are My Key Rights?

You can still seek care even if you are undocumented. Emergency care cannot be denied. Being asked for information does not mean it will be shared with immigration authorities. If you are unsure, you can ask to speak with a social worker or patient advocate.

If you are not a U.S. citizen and are worried about how benefits may affect your immigration status, talk to an immigration attorney or a trusted legal aid organization before applying. Cancer Justice may also be able to provide legal information, education, and referrals to help you understand your options.

You Are Not Alone on Your Cancer Journey

A cancer diagnosis can bring many legal, financial, and personal challenges. You may not have all the answers to your employment, health insurance, medical debt, housing, public benefits, and estate planning questions. But you are not alone. That is why Cancer Justice is here for you.

This Cancer Justice Handbook offers a starting point to help you understand your rights and options. When you have questions not covered in this handbook or when need help working through issues that came up or became harder after a cancer diagnosis, we encourage you to reach out to us. Taking that first step can make a meaningful difference. Juntos Podemos. Together we can.

The Cancer Justice Helpline is here for you.

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