

TRIAGE CANCER

A Practical Guide to Cancer Rights for Caregivers



Navigating Employment, Insurance, & Finances

A guide to the legal and practical issues that may impact the caregivers of individuals diagnosed with cancer.

TRIGE CANCER

Everyone should have access to the resources they need to manage their life beyond diagnosis, regardless of their type of cancer, where they live, or their financial situation.



Triage Cancer is a national, nonprofit organization that provides free education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through free events, materials, and resources.



As long as there are questions, we'll have answers.

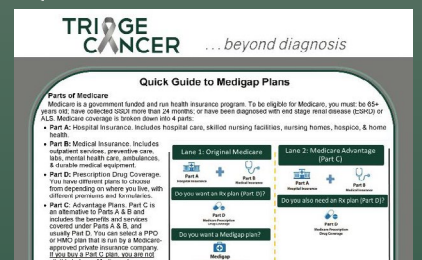
Educational Events



Animated Videos



Quick Guides & Checklists



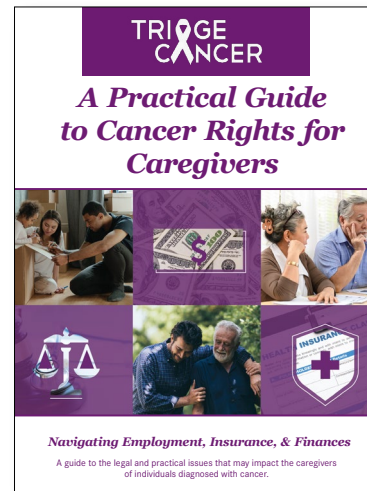
CancerFinances.org



All of these resources and more can be found at TriageCancer.org.

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What is Cancer Rights Law?

Cancer rights law includes a number of separate areas of law, including employment, insurance, government benefits, consumer rights, and estate planning.

Some of the topics discussed in this guide are not even thought of as legal issues by most people, such as health insurance. But, getting health insurance coverage, consumer protections in the use of coverage, and the right to appeal denials of coverage are all rooted in laws. Lack of awareness of the law and failure to recognize its power to help people, can keep people from getting their needs met, and contributes to the financial burden of a cancer diagnosis.

An understanding of your rights as a caregiver can improve your quality of life, reduce stress and anxiety, and can mean the difference between losing your job, your health insurance, or even your home.

This guide is meant to serve as an introduction to some of the cancer rights law topics that most people have to deal with in some way after a cancer diagnosis: employment, insurance, and finances.

The details about these laws and programs may change frequently. The most up-to-date information about these topics and many others can be found at [TriageCancer.org](https://www.TriageCancer.org).

Disclaimer: This guide is intended to provide general information on the topics presented. It is provided with the understanding that Triage Cancer is not engaged in rendering any legal, medical, or professional services by its publication or distribution. Although this content was reviewed by a professional, it should not be used as a substitute for professional services. ©TriageCancer

A Practical Guide to Cancer Rights for Caregivers: Navigating Employment, Insurance, & Finances

Your Rights at Work

If you are a caregiver for someone with cancer, you may need to figure out how to continue working, take time off, return to work, or even retire. Understanding employment laws may help you navigate these options and make decisions.

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal law that provides eligible individuals with disabilities protection against discrimination. Title I of the ADA protects individuals with disabilities and caregivers from discrimination at work and gives individuals with disabilities access to reasonable accommodations.

Employers Covered by Title I of the ADA

- Private employers with 15 or more employees.
- Employment agencies, labor organizations, and joint labor-management committees.
- State and local governments of any size.
- Employees of the federal legislative branch (e.g., employees of the Senate, House of Representatives, and agencies that support Congress).
 - Employees of the federal executive branch (e.g., United States Postal Service, federal agencies, etc.) are covered by the Rehabilitation Act of 1973 (similar to ADA).

Employees Eligible for Protection Under the ADA

- Individuals who are “qualified” (i.e., they can perform essential functions of the job, with or without reasonable accommodations)

- Individuals who currently have a physical or mental impairment that substantially limits one or more major life activities*, as well as those who have a history of having a disability, or are regarded as having a disability by their employer
- Individuals who “associate with an individual with a disability” (i.e., caregivers)

*Major life activities, according to the ADA, are “activities that an average person can perform with little or no difficulty.” Activities include physical functions (breathing, hearing, seeing, talking, walking, other motor movements), mental functions (concentrating and learning), and social/professional functions (working or caring for oneself).

When Are You Protected by the ADA?

The ADA provides protections during all phases of employment (including during the job application process) and when all employment-related decisions are being made, including hiring, firing, pay, benefits, promotions, job assignments, bonuses, training opportunities, and leaves of absence.

What Are Reasonable Accommodations?

According to the ADA, “an accommodation is any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities.” Reasonable accommodations are anything that can help you continue to do your job or return to work, such as:

- Changing work schedule (e.g., flex time, additional breaks).
- Changing workspace (e.g., telecommuting, ergonomic chair, hand controls on cars, a different office).



- Using technology (e.g., tablet, smart phone, screen reading software, speak-type software).
- Changing workplace policies (e.g., allowing an employee with a scar to wear a scarf or hat, allowing more breaks).
- Shifting nonessential job duties to other employees.
- Moving to a vacant position, if one is available (Note: employers are not required to create a new position for an employee with a disability, but you still may make a request).

Are Caregivers Eligible for Reasonable Accommodations?

Employers are not legally required to provide reasonable accommodations to employees who are acting as caregivers. However, many employers recognize the benefit of keeping a valued employee and avoiding the costs associated with finding a replacement. Therefore, many of the strategies discussed above can be useful options for caregivers as well. Caregivers can consider asking their employers for accommodations so that they can continue to effectively perform their job.

State Fair Employment Laws

Most states have a state fair employment law. Many provide similar protections to the ADA, but some provide more extensive coverage and options for employees looking for accommodations than the ADA might give them. Some do so by broadening the definition of disability, and some cover private employers with fewer than 15 employees, unlike the ADA. Below is a chart that lists the states that cover employers with fewer than 15 employees, as well as how many employees the state requires them to have to be covered. If a state is not listed here, the state law is the same as the ADA and requires an employer to have 15 or more employees.

1	2	3	4	5	6	8	9	12
AK	CO	CT	IA	CA	MA	KY	AR*	WV
HI	WY		KS	ID	MO	TN		
IL			NM		NH	WA		
ME			NY		OR			
MI			OH					
MN			PA					
MT			RI					
NJ								
ND								
SD								
VT								
VA								
WI								

*But 15 for Reasonable Accommodations

Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) is a federal law that allows eligible employees to take up to a total of 12 weeks of unpaid, job-protected, and health insurance-protected leave per year:

- For their own serious medical condition.
- For the care of a parent, child, or spouse with a serious medical condition.
- For the birth of a son or daughter, and for bonding time with that child.
- For placement of a child with the employee for adoption or foster care, and for bonding time with that child.

- For any qualifying exigency (such as deployment) when a spouse, son, daughter, or parent is a military member on covered active duty or call to covered active-duty status.
- For any combination of the qualifying reasons above.

The FMLA can be flexible. An employee is not required to use all 12 weeks of leave consecutively. For example, an employee may be able to take off of work in increments as little as a few hours at a time to take a family member to a medical appointment.

Employers Covered by the FMLA

- Private employers that have or had 50 or more employees during 20 or more workweeks in the current or preceding calendar year.
- Public agencies, including local, state, or federal agencies, regardless of number of employees.
- Public or private elementary or secondary schools, regardless of the number of employees.

Employees Eligible for Leave Under the FMLA

- Work for an employer that has at least 50 employees within 75 miles of the employee's worksite **and**

- Have worked for a covered employer for at least 12 months in the last seven years (note: the 12 months don't have to be in a row) **and**
- Have worked at least 1,250 hours for the employer during the 12 months immediately before taking leave.

What Activities Count as Caregiving Under the FMLA?

Caregiving can include helping with activities of daily living, such as providing basic medical, hygienic, nutritional or safety needs; transportation to and from medical appointments; providing psychological comfort; assisting with housework or paperwork; organizing prescription medication or grocery shopping; and assisting in chores.

What Happens to Your Health Insurance if You Take Time Off Under the FMLA?

If you receive health insurance coverage from your employer, your employer must continue to offer you that coverage, under the same terms and conditions that were in place before taking leave. For example, if your employer pays 50% of your monthly premium while you are working, they must continue to do so while you are on FMLA leave.

When Should You Ask for FMLA Leave?

Generally, employees should request FMLA leave as soon as they know they need time off work. If the need for leave is foreseeable, employees must provide employers with at least 30 days' notice. If the need for leave is unforeseeable, employees must provide employers with notice "as soon as practicable," usually within one to two days of when the need for leave arises. You should follow your employer's rules for absences unless you are receiving emergency medical care.

How Do You Ask for FMLA Leave?

Check your employee handbook to see if your employer has a process for requesting FMLA leave. Your request for leave does not necessarily have to specifically mention the cancer diagnosis of the person you are caring for, but does need to contain enough information so the employer can determine if you are eligible for FMLA leave.



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If you are eligible for FMLA leave, your employer cannot interfere with your right to take leave. An employer cannot retaliate against you because you are taking FMLA leave. An employer cannot use your FMLA leave against you in decisions related to your job, such as attendance policies, promotion, or discipline.

How Does the FMLA Work With Other Types of Leave?

The ways that federal laws, state laws, and employer policies work together are similar to puzzle pieces fitting together. Except that everyone's puzzle looks different, depending on which laws apply to you, which state you live in, and what benefits are offered by your employer.

When thinking about taking time off work, you may have multiple options available to you.

- Some states have passed leave laws, which may offer more protection than the FMLA.
- Your employer can require you to substitute unpaid leave under the FMLA with paid leave that you have available. Even if your employer does not require that you use your paid time off at the same time as the FMLA, you have the option to do so.

What Can You Expect When You Return to Work from FMLA Leave?

When you return from FMLA leave, your employer must reinstate you to the same or an "equivalent" job. An equivalent job is one with the same responsibilities, pay, and benefits as the original job.

Your employer can require a medical certification that you are able to return to work, as long as that requirement would be applied to any employee in a similar situation. If at the end of 12 weeks of FMLA leave you are not ready to return to work, you may be able to request additional time off as a reasonable accommodation under the ADA.

Medical Certification Forms

Your employer is entitled to medical certification from a health care provider to show you are eligible for FMLA leave. However, your employer doesn't necessarily need to know about the details of the cancer diagnosis of the person whom you are caring for, if you don't want to

share that information. The FMLA certification form only needs to include enough information that explains why you need FMLA leave.

Employers may contact the health care provider who completed the medical certification form, as long as the employee's direct supervisor is not the one contacting the health care provider. But, the employer is only allowed to ask the health care provider for clarification (e.g., what does line two say) or authentication (e.g., did you sign the form) of the certification form. The employer is not entitled to additional information than what is included on the certification form.

Be careful of medical certification forms created by employers, which may request more information than what they are entitled to, such as a specific diagnosis. The U.S. Department of Labor has model forms that can be used for guidance as to what information an employer can request. Note that even the model form asks for the specialization of the health care provider completing the form. So, if you prefer to keep the cancer diagnosis of the person who you are caring for confidential, you may not want to have an oncologist complete the form. Under the FMLA, there are multiple health care providers who can complete the form, including primary care physicians or clinical social workers.

Paid Leave Options for Caregivers

Kin Care Laws

Kin care laws are state laws requiring that if an employer provides accrued paid leave, it must allow the employee to take it for certain covered reasons. For example, if an employee has access to paid sick leave from the employer, then they must be allowed to use that time off to care for a family member. Details of state laws vary, but typically require that the paid leave must also be job-protected leave. States with kin care laws include California, Georgia, Illinois, Maine, Maryland, Massachusetts, Minnesota, Nevada, New Mexico, Texas, Vermont, and Washington.

General Paid Leave Laws

Paid leave laws are state laws that require employers to provide paid leave to their employees to be used for any reason. States with paid leave laws include Maine and Nevada. For information about your state, visit [TriageCancer.org/StateResources](https://www.triagecancer.org/state-resources).



Paid Family and Medical Leave Laws

By 2024, 10 states and Washington, D.C. will have Paid Family and Medical Leave programs in effect. These programs are statutory insurance programs that are administered by either the state or an insurance company. The programs cover family member care and bonding and employee illness, although some might go about it in different ways. Below is a summary of the programs of each state that currently has a program or will have one in the near future:

■ California

The California Paid Family Leave (PFL) program began in 2004, and covers all private sector employers as well as some public sector employers. To qualify, an employee must have paid into the State Disability Insurance (SDI) program during the previous 18 months. An employee must have earned at least \$300 in gross wages during the base period from which SDI deductions were taken. The program does not have a waiting period, but the employer may require that you use up to 2 weeks of vacation time or other paid time off before getting PFL benefits. The program does not provide job protection, but you may be covered by other laws that provide protection.

- Effective July 2004
- Length: up to 8 weeks per 12-month period
- Benefit: 60-70% of pay, depending on income
- Website: edd.ca.gov/disability/paid-family-leave/

■ Colorado

The Colorado Paid Family and Medical Leave program is scheduled to begin on January 1, 2024. It covers any employer with one or more employees during each of 20 or more calendar workweeks during the year. It excludes federal government employers, and local government employers may opt out. However, self-employed persons and local government employees may choose to pay into the program. To qualify, an employee must have earned at least \$2,500 in wages during the base year or year prior. The program requires continuation of health insurance benefits, as well as reinstatement to the previous or equivalent position if employed at least 180 days before taking leave. An employee can choose to supplement leave through this program with earned paid time off (PTO). If the employee chooses to take leave intermittently, it must be in no greater than 1-hour increments, payable once 8 hours has accumulated.

- Effective January 2024
- Length: 12 weeks (16 if disability is pregnancy-related)
- Benefit: up to 90% of the state average weekly wage
- Website: famli.colorado.gov

■ Connecticut

The Connecticut Paid Family and Medical Leave program began January 1, 2022, and covers all employers, but private plans must be approved by the state. To qualify, employees must work in the state, have earned at least \$2,325 during the highest earning quarter within the base period, and be either presently employed or have been employed in the previous 12 weeks by an employer. This program does not offer job protection.

- Effective January 2022
- Length: 12 weeks (14 if disability is pregnancy-related)
- Benefit: 95% of their weekly wage, on a sliding scale
- Website: ctdol.state.ct.us/

■ Delaware

The Healthy Delaware Families Act will begin January 1, 2026. Individuals who work for an employer with 10 or more employees will have access to parental leave during the first year after a child's birth, adoption, or foster care placement. Individuals who work for an employer with 25+ employees will have access to leave to care for a family member with a serious health condition or their own serious health condition. Employees must work for their employer for one year and at least 1,250 hours in the past 12 months to be eligible.

Individuals may receive up to 80% of their average weekly wage. Includes continuation of health benefits, and reinstatement to previous position, or an equivalent one, after leave. Qualified individuals will receive up to twelve weeks of leave.

- Effective January 2026
- Length: up to 12 weeks
- Benefit: up to 80% of state average weekly wage
- Website: jacksonlewis.com/sites/default/files/docs/HealthyDelawareFamiliesActEngrossment.pdf

■ Maryland

The Time to Care Act will begin January 1, 2025. Leave can be taken to care for a family member, or your own, serious medical condition. Individuals will be eligible if they have worked 680 hours in the past 12 months. Self-employed individuals can opt in. Individuals can receive up to 12 weeks of paid leave. Benefits will range from \$100 to \$1,000 per week. Beginning October 1, 2023, employees and employers with 15 or more employees must start paying into the fund.

- Effective January 2025
- Length: up to 12 weeks
- Benefit: \$100 to \$1,000 per week
- Website: mgaleg.maryland.gov/mgaweb/legislation/details/sb0275

■ Massachusetts

The Massachusetts Paid Family and Medical Leave program began in January of 2021 and covers all employers. Employers may use the state plan or a state-approved private plan. Self-employed individuals may choose coverage under certain conditions. If you have earned at least \$5,700 during the last 4 completed calendar quarters, and at least 30 times more than how much you are eligible to get each week in benefits, you qualify for benefits. You can use a calculator on the program website to see if you qualify. Employers covered by this program must provide continuation of health insurance benefits, and reinstatement to an employee's previous or equivalent position.

- Effective January 2021
- Length: 12 weeks (family leave); 20 weeks (medical leave); 26 weeks (military caregiver leave)
- Benefit: 80% of income, up to 50% of state average weekly wage, then 50% of their wages above that amount
- Website: mass.gov/orgs/department-of-family-and-medical-leave

■ New Hampshire

The New Hampshire Family and Medical Leave Insurance program began in July of 2021, and covers state employers. However, private employers may opt in. Even if they don't, if the employer has more than 50 employees, the employees may still opt in. If an employer does opt in, they will receive a tax credit of 50% of the premium paid, and employees will receive job protection. The program has a 7-month waiting period, a one-week elimination period, and a 60-day annual open enrollment period.

- Effective January 2023
- Length: up to 6 weeks
- Benefit: 60% of wages
- Website: governor.nh.gov/sites/g/files/ehbemt336/files/documents/family-leave.pdf

■ New Jersey

The New Jersey Family Leave Insurance program started in 2009, and covers all employers. Employers can use the state plan or a state-approved private plan. To qualify in 2022, an employee must have either (1) worked 20 calendar weeks in New Jersey in the base year, earning \$240 or more each week; or (2) earned \$12,000 or more in the last year prior to the start of family leave. There is no waiting period for this program. An employee may choose to (but an employer cannot require them to) use vacation/paid time off at 100% of pay instead of receiving benefits through this program. This program provides job protection.

- Effective July 2009
- Length: up to 12 weeks (56) days or until benefits equal 1/3 of total wages during the year, whichever is less
- Benefit: 85% of their average weekly wage, up to the maximum amount
- Website: nj.gov/labor/myleavebenefits/worker/fli

■ New York

The New York Paid Family Leave (PFL) program began in 2018, and covers all employers. To qualify, an employee must be scheduled 20+ average hours per week for 26 consecutive weeks, or if scheduled for less than 20 average hours per week, must show 175 days worked. Employee must be located in New York and contribute to the PFL fund. This program has no waiting period and does not cover partial intermittent absences. It does provide job protection.

- Effective January 2018
- Length: 12 weeks

- Benefit: 67% of employee’s or state average weekly wage, whichever is less
- Website: paidfamilyleave.ny.gov/paid-family-leave-family-care

■ Oregon

The Oregon Paid Family and Medical Leave (PFML) program is scheduled to begin September 3, 2023, and covers any employer with one or more employees working in the state (excludes federal government employers). Tribal governments and self-employed workers may opt in. To qualify, an employee must have contributed to the PFML Insurance Fund during the base year (4 of the last 5 quarters worked) and have earned at least \$1,000 in wages during the base year or the prior year. This program requires the continuation of the employee’s health insurance benefits and reinstatement to their previous or equivalent position, if employed at least 90 days before taking leave. The employee can choose to supplement this program with earned paid time off.

- Effective September 2023
- Length: 12 weeks (14 if disability is pregnancy-related)
- Benefit: up to 100% of average weekly wage on a sliding scale
- Website: paidleave.oregon.gov

■ Rhode Island

The Rhode Island Temporary Caregiver Insurance (TCI) program began in 2014, and covers all private employees and some public employees. To qualify, the employee (1) must have been paid wages in Rhode Island and have paid into the TCI fund; and (2) must have been paid at least \$12,600 in the base period or earned at least \$2,100 in one quarter with total taxable wages at least 1.5x of the highest quarter of earnings and base period taxable wages equal to at least \$4,200. This program requires maintenance of health benefits while on leave and provides job protection. Leave must last for 7 or more consecutive days to be eligible for benefits.

- Effective January 2014
- Length: 5 weeks (2022); 6 weeks (2023)
- Benefit: 4.62% of wages paid in highest base period quarter
- Website: ripaidleave.net

■ Washington

The Washington Paid Family Medical Leave program began in 2020, and covers all employers. Self-insured workers may opt in. To qualify for the state plan,

an employee must have been employed for at least 820 hours in the qualifying period. To qualify for the voluntary plan, an employee must have worked 340 hours in the last 12 months. There is a one-week waiting period, except for bonding and qualifying exigency leaves. The state plan provides job protection and health insurance protection for employees who have worked at least 12 months, and worked 1,250 hours in the 12 months immediately preceding leave, and work for an employer who has 50+ employees. The voluntary plan provides job protection for employees who have worked at least 9 months and worked 965 hours in the 12 months preceding leave. Under the voluntary plan, employers must maintain health benefits for employees.

- Effective January 2020
- Length: 12 weeks (family leave); 12-16 weeks (family and medical leave)
- Benefit: 90% of average weekly wage up to state average, then 50% of average weekly wage exceeding that
- Website: paidleave.wa.gov

■ Washington, D.C.

The Washington D.C. Universal Paid Leave program began in 2020, and covers all private employers, unless they are exempt from D.C. taxes by federal law or treaty. A self-employed individual may opt in. To qualify, an employee must work more than 50% of the time in D.C. in the 52 calendar weeks immediately preceding leave or regularly spend a substantial amount of time working in D.C. without spending more than 50% of their work time in another jurisdiction. There is a 1-week waiting period for this program. This program does not provide job protection.

- Effective July 2020
- Length: 6 weeks (family caregiver leave); 2 weeks (medical leave); 8 weeks (parental leave)
- Benefit: 90% of average weekly wage up to 150% of DC minimum wage, then 50% of average weekly wage exceeding that
- Website: dchr.dc.gov/page/paid-family-leave

For additional resources, visit:
TriageCancer.org/Employment
TriageCancer.org/Caregiving

- Quick Guides & Checklists
- Animated videos
- Chart of state laws
- State resources
- Webinars
- CancerFinances.org



Health Insurance Basics

Health insurance can be confusing. To understand options for you and your family and find coverage that is most appropriate for you, there are some health insurance basics that are helpful to know.

Types of Health Insurance Plans

There are two main payment systems when you receive medical care:

- **Fee for service:** A health care provider is paid a fee for each service provided. With these plans, you can go to any provider willing to see you. You pay for a portion of your care and the insurer pays the rest.
- **Managed care:** Health care providers contract with a health insurance company to be a part of its network. If you go to a provider in the network, the provider has agreed to a certain payment rate for treating you (i.e., allowed amount). Regardless of what the provider bills, it's that "allowed amount" that will determine your final cost. You typically pay a portion of the allowed amount, depending on your plan.

Common types of managed care plans are:

- **Health Maintenance Organizations (HMOs):** Your health care services start with your primary care physician, and you usually need a referral to see another health care provider, except in an emergency. For example, if you have a skin rash, you first go to your primary

care physician. If needed, that physician will refer you to a dermatologist in your network. Generally, HMOs have smaller networks of providers, and providers outside of your network will not be covered by your HMO. While you may have less choice in providers, HMOs are often less expensive.

- **Exclusive Provider Organizations (EPOs):** Generally, you do not need to start with your primary care physician. Typically, EPOs have larger provider networks than HMOs, but will not pay for any services obtained outside of the network.
- **Preferred Provider Organizations (PPOs):** These plans have the largest network of providers, and generally you do not need to start with your primary care physician. While most PPOs have some out-of-network coverage, staying inside your network means lower out-of-pocket costs. Typically, PPOs cost more than HMOs, but you have more choice and control.

When choosing a plan, you should consider your personal needs and the options available in your area.

Health Insurance Cost Terms

Here are terms related to the cost of health insurance that you should understand. First, there are the costs you pay for coverage.

- **Monthly premium:** This is what you pay each month to have coverage; you pay these costs even if you never receive medical care. It's similar to paying for car insurance all year but never filing a claim.

Then there are costs that you have to pay when you receive medical care, often called "out-of-pocket" costs. The specific amount of those costs will depend on your plan.

- **Annual deductible:** This is the amount you have to pay out-of-pocket each year before your health insurance policy kicks in. This fixed dollar amount could be any amount, such as \$500 to \$5,000. Some plans have a \$0 deductible.

Example: Out-of-pocket Maximums

Mark was in an accident. He went to the emergency room and then spent a week in the hospital that is in his plan's network. Mark ends up with a \$102,000 hospital bill. His health insurance plan has an emergency room co-payment of \$250, a deductible of \$2,000, an 80/20 co-insurance, and an out-of-pocket maximum of \$4,000. How much of that does Mark actually have to pay?

- Mark pays his co-payment of \$250 at the time of his emergency room visit, which leaves \$101,750.
- Then he has to pay the rest of his \$2,000 deductible ($\$2,000 - \$250 = \$1,750$), which leaves \$100,000.
- Then the insurer will pay 80% of the bill. Mark is responsible for 20% of \$100,000, which is \$20,000.

However, Mark's plan has an out-of-pocket maximum of \$4,000. Because he has already paid his \$2,000 deductible out-of-pocket, Mark only needs to pay another \$2,000 to reach his \$4,000 out-of-pocket maximum and the health insurance company will pay the rest.



- **Co-payment:** A fixed dollar amount you pay when you get medical care. For example, when you visit the doctor's office, you might have a \$20 co-payment; if you go to see a specialist, you might have a \$40 co-payment. You usually pay your co-payment at the time you receive care.
- **Co-insurance (aka cost-share):** A percentage difference in what the insurance company pays for your medical expenses and what you pay for your medical expenses. For example, if you have an 80/20 plan, the insurance company pays 80% of your medical expenses and you are responsible for 20% of your medical expenses after paying your deductible.
- **Out-of-pocket maximum:** A fixed dollar amount that is the most that you will have to pay for your medical expenses out-of-pocket during the year. Your out-of-pocket maximum will depend on your plan. It is a very important thing to find out! Generally, you reach your out-of-pocket maximum by paying your deductible, plus any co-payments that you make during the year, plus any co-insurance payments you make. So, it's everything that you pay, except your monthly premiums. Once you reach your out-of-pocket maximum, your

insurance pays 100% of your medical expenses for the rest of the year. Most insurance companies only count expenses toward the out-of-pocket maximum that are from in-network providers. Also, some employer-sponsored plans may carve out expenses from the out-of-pocket maximum (e.g., co-payments won't count toward your out-of-pocket maximum).

Prescription Drug Terms

Here are some helpful terms to understand prescription drug coverage:

- **Brand-name drugs:** A prescription drug with a specific name from the company that sells the drug. A generic version of a drug may be available and sold by other companies, usually after a patent expires.
- **Generic drugs:** A prescription drug that contains the same chemical substance as a brand-name drug.
- **Specialty drugs:** Prescription drugs that have a high cost, high complexity and/or require a high touch. Many drugs for cancer are considered specialty drugs.

Example: Prescription Drug Costs

Noah's Plan:

- Deductible = \$1,000
- Co-payment = \$50
- Co-insurance = 70/30 plan
- Out-of-pocket maximum = \$1,500

If Noah has a prescription for a drug that costs \$10,000, how much does he pay?

- His co-payment of \$50: $\$10,000 - \$50 = \$9,950$ left
- His remaining deductible of \$950: $\$9,950 - \$950 = \$9,000$ left
- His co-insurance amount of 30%: $30\% \text{ of } \$9,000 = \$2,700$

But his out-of-pocket maximum is only \$1,500. So, after paying the \$50 co-payment and the remaining \$950 of the deductible, he has paid \$1,000 in out-of-pocket expenses and only needs to pay another \$500 of the \$2,700 co-insurance amount to reach his \$1,500 out-of-pocket maximum. His plan will pick up the rest of the costs.

- What does Noah pay next month for his prescription? \$0

- **Formulary:** A list of prescription drugs that a health plan will cover and for how much. Using a plan's formulary will help you save money on medications. Some plans have formularies with two or more cost levels, known as tiers. A drug on a higher tier will have higher out-of-pocket costs for you. The highest tier in most formularies is the "specialty" tier, which includes many cancer drugs. The co-payment and co-insurance amounts will depend on the tier of the prescription drug you are taking. For example, a tier 1 drug may have a \$10 co-payment, while a specialty tier drug may have a 30% co-insurance amount.

- **Step therapy:** When an insurance company requires patients to try a generic or lower cost drug before getting a brand-name or more expensive drug. If the lower cost drug doesn't work or causes a bad reaction, the patient would be allowed to "step up" to another medication. If your insurance company uses step therapy, it is important to work with your health care team to show that taking a specific drug is medically necessary for you and why the insurance company should make an exception to its process.

Generally, if a drug isn't on formulary the insurance company will not cover it. But you may be able to file an appeal called an "exception request" based on medical necessity. There are different types of exception requests:

- **Nonformulary drug exception:** A request to cover a nonformulary drug.
- **Tier exception:** A request to treat a drug as if it were in a lower tier, reducing your out-of-pocket costs.
- **Brand exception:** A request to cover a higher-cost brand name drug even if a generic is available.

Picking a Health Insurance Plan

Finding the right health insurance plan can feel overwhelming. There are a few key things to consider when picking a health insurance plan:

- What will the plan actually cost me?
- Are my health care providers and facilities included in the plan's network?
- Does the plan cover my prescription drugs and the pharmacies I use?

When comparing plans, it can be tempting to just choose the one with the lowest monthly premium. But to figure out the total cost for the year in a worst-case scenario, including your out-of-pocket expenses, you have to do some math:

$$\text{(Plan's monthly premium x 12 months) + Plan's out-of-pocket maximum = Total annual cost}$$

Choosing health insurance is not a one-time activity. You should review your options every year to ensure your plan meets your needs. A plan that met your needs in the past may not meet your needs in the future as your health changes over time. Open enrollment is the time of the year when you can change plans without penalty. The dates for open enrollment will depend on what type of health insurance coverage you have. For example, if you have an employer plan, it will vary, but many employers have open enrollment in the fall for the plan year to start on January 1.

Health Insurance Options

The health insurance options available to you depend on where you live, your age, your employment, your income level, and a number of other factors. Here are some of the main options for health insurance coverage.

Health Insurance Marketplaces

The Patient Protection and Affordable Care Act (ACA) created a new way to find and buy private health insurance coverage for individuals and families: state health insurance marketplaces. Originally called “exchanges,” the term “marketplace” refers to a place where you can find health insurance options from private insurance companies. These marketplaces have been compared to an insurance shopping mall. The marketplaces for most states are operated by the federal government at [HealthCare.gov](https://www.healthcare.gov). Some states run their own marketplaces.

There are real benefits to shopping for coverage through the marketplace.

- **Out-of-pocket maximum cap:** There is a cap on the out-of-pocket maximum for plans sold through the marketplace, which is often lower than some employer plans. Also, out-of-pocket maximums for all marketplace plans must include everything you spend for deductibles, co-payments, and co-insurance for in-network providers.
- **Standardized plans:** Plans sold through the marketplace are standardized by their level of cost-sharing:

Example: Picking a Plan

- *Plan A* is an HMO with a monthly premium of \$25, an annual deductible of \$2,500, a 70/30 co-insurance and an out-of-pocket maximum of \$7,000.
- *Plan B* is a PPO with a monthly premium of \$100, an annual deductible of \$1,500, an 80/20 co-insurance and an out-of-pocket maximum of \$4,000.

At first glance, it may seem that *Plan A* is less expensive because of its low monthly premium. But you have to do the math!

- *Plan A:* (\$25 premium x 12 months = \$300) + out-of-pocket maximum of \$7,000 = Total cost of \$7,300.
- *Plan B:* (\$100 premium x 12 months = \$1,200) + out-of-pocket maximum of \$4,000 = Total cost of \$5,200.

After doing the math, *Plan B* is actually the more affordable plan if your medical expenses reach the out-of-pocket maximum.



- **Bronze plans** have a 60/40 cost-share, meaning that the insurance company pays for 60% of your medical expenses and you are responsible for 40% of your medical expenses. Bronze plans generally have lower monthly premiums but higher out-of-pocket costs.
- **Silver plans** have a 70/30 cost-share.
- **Gold plans** have an 80/20 cost-share.
- **Platinum plans** have a 90/10 cost-share, with higher monthly premiums but lower out-of-pocket costs.

- **Financial assistance:** Based on your household income level, you may qualify for one or both forms of financial assistance. You may receive “premium tax credits,” which lower your monthly premium based on the plan you choose. And “cost sharing subsidies” can lower co-payment amounts, deductibles, and co-insurance amounts.

The marketplace open enrollment period is usually from November 1 through January 15. The earliest plans will begin is January 1. States that run their own marketplaces may have open enrollment periods that last longer.

If you lose coverage or have a life-changing event, you may qualify to enroll during a special enrollment period.

You can enroll in a marketplace plan through a 60-day special enrollment period for reasons that include:

- Loss of health insurance (including coverage through work; end of COBRA; or loss of eligibility for Medicaid, Medicare, or Children’s Health Insurance Program).
- Loss of coverage through a family member.
- Change in residence (e.g., moving to a new ZIP code or county).
- Move to/from school.
- Changes in household.
- Marriage (choose plan by last day of month and coverage will start first day of next month).
- Birth of a baby, adoption of a child, or placement of a child in foster care (coverage starts day of event, even if you enroll in plan up to 60 days later).
- Divorce or legal separation (if this results in losing health insurance).
- Death of someone on your marketplace plan.

If you lose employer-sponsored coverage, you may have a number of options for comprehensive health insurance coverage, even if you have a pre-existing medical condition such as cancer. These options include a marketplace plan, COBRA, another group health plan, Medicaid, or Medicare. Because you may be eligible for more than one of these options, it is important to compare your options to determine which plan is best for you.

COBRA

COBRA is a federal law that allows eligible employees to keep their existing employer-sponsored health insurance plan after experiencing a “qualifying event.” **Table 1** lists the qualifying events that may entitle you to continue coverage under COBRA and the maximum length of time you can keep your plan.

COBRA applies to private employers with 20 or more employees and to state and local governments. Federal employees have similar protections under a different law. Many states also have a COBRA law that covers employers with two to 19 employees.

A main barrier to COBRA coverage is cost. Typically, you pay 100% of what your employer was paying for your coverage, plus a possible 2% administrative fee (for a total of 102%). But there may be some benefits to COBRA. For example, if you are in the middle of treatment, with COBRA coverage, you wouldn’t have to find a new insurance plan that has the same coverage for your doctors, hospitals, and prescription drugs.

TABLE 1. Qualifying Events for COBRA Coverage

COBRA Qualifying Event	Maximum COBRA Coverage*
Employment ends or hours reduced	18 months
Loss of dependent child status (i.e., turning 26)	36 months
Covered employee enrolls in Medicare	36 months
Divorce or legal separation from covered employee	36 months
Death of covered employee	36 months

*There are two times when you may be able to extend COBRA coverage. There are also a few times when COBRA coverage may end early, such as when an employer stops offering health insurance coverage to all employees or when an employer goes out of business.

Also, if you have already met your out-of-pocket maximum or deductible for the year, it may be less expensive to pay the higher COBRA premiums and not have any out-of-pocket costs for the rest of the year. You should do the math to figure out which option would cost you less.

You must choose COBRA within 60 days of your qualifying event. If you wait until the 59th day, you may have to back pay the premiums for the two prior months, but any medical care that you received during that time should be paid for by your COBRA plan. If you need financial assistance to pay your COBRA premiums, Medicaid’s Health Insurance Premium Payment Program may help. If you qualify for Medicaid but have access to a group plan through an employer (e.g., COBRA), Medicaid may pay your monthly premium for the group plan.

Another Group Health Plan

You may be eligible for a special enrollment period to move to a group plan that is available to you through another job that you might have, your spouse’s group plan, or a parent’s group plan (if you are under 26). Check the other employer’s plan for additional rules.

Medicaid

You may be eligible for Medicaid in your state. Medicaid is a federal health insurance program that provides coverage to individuals with a low income level. If you live in a state that expanded its Medicaid program under the

Affordable Care Act and you have a household income under 138% of the federal poverty level (FPL), you may be eligible for Medicaid. If you live in a state that has not expanded Medicaid, eligibility is based on having a low income level, having a low resource level (e.g., assets), and meeting another category of eligibility, such as receiving SSI. Currently, 39 states and Washington, D.C., have expanded their programs and 11 states have not. Medicaid applications are accepted year-round.

Qualifying for Medicaid Coverage Based on Income Level

If you live in a state (or Washington, D.C.) **with expanded Medicaid**, and your household income is:

- Up to 138% of the FPL: You have access to Medicaid.
- Between 138% and 250% FPL: You have access to marketplace premium tax credits and cost-sharing subsidies (if you pick a silver health insurance plan).
- Between 250% and 400% FPL: You have access to marketplace premium tax credits.
- Above 400% FPL: You can buy a marketplace plan, but you do not qualify for financial assistance in most states. Some states provide additional assistance. For example, in California you can qualify for premium tax credits up to 600% FPL.

TABLE 2. Benefits Available by Household Income in States With Expanded Medicaid

Benefits Available by FPL			
100% FPL	138% FPL	250% FPL	400% FPL
	Cost-Sharing Subsidies (Silver Plans Only) → → →		
Medicaid → →	Premium Tax Credits → → → → → →		

FPL, federal poverty level.

TABLE 3. Benefits Available by Household Income in States Without Expanded Medicaid

Benefits Available by FPL			
100% FPL	138% FPL	250% FPL	400% FPL
Cost-Sharing Subsidies (Silver Plans Only) → → → → → →			
Medicaid → →	Premium Tax Credits → → → → → →		

FPL, federal poverty level.

If you live in a state **without expanded Medicaid**, and your household income is:

- Between 100% and 138% FPL: You have access to marketplace cost-sharing subsidies (if you pick a silver health insurance plan).
- Between 138% and 250% FPL: You have access to marketplace premium tax credits and cost-sharing subsidies (if you pick a silver health insurance plan).
- Between 250% and 400% FPL: You have access to marketplace premium tax credits.
- Above 400% FPL: You can buy a marketplace plan but do not qualify for financial assistance.

Note: Under the American Rescue Plan Act, if your household income is above 400% FPL, you may qualify for marketplace premium tax credits to lower your health insurance costs to 8.5% of your

household income. This additional benefit is set to expire December 31, 2025.

Note that the FPL numbers for the current year are used to determine Medicaid eligibility. The FPL numbers for the previous years are used to determine marketplace financial assistance. Refer to **Table 2** and **Table 3** to determine available benefits.

Medicare

Medicare is a government health insurance program. To be eligible you must be 65 or older, have collected SSDI for more than 24 months, or have been diagnosed with end-stage renal disease or amyotrophic lateral sclerosis. There are currently about 62 million Americans enrolled in Medicare.

Medicare coverage is broken down into four parts:

- **Part A: Hospital Insurance.** Includes hospital care, skilled nursing facilities, nursing homes, hospice, and home health care.
- **Part B: Medical Insurance.** Includes outpatient care from doctors, preventive care, lab tests, mental health care, ambulances, and durable medical equipment.
- **Part D: Prescription Drug Coverage.** Plans have options depending on where you live, with different premiums and formularies offered by private insurance companies.
- **Part C: Advantage Plans.** An alternative to Parts A and B, it includes the benefits and services covered under Parts A and B, and usually Part D. You can select a PPO or HMO plan that is run by a Medicare-approved private insurance company.

Parts A and B together are referred to as Original Medicare.

Medicare Costs

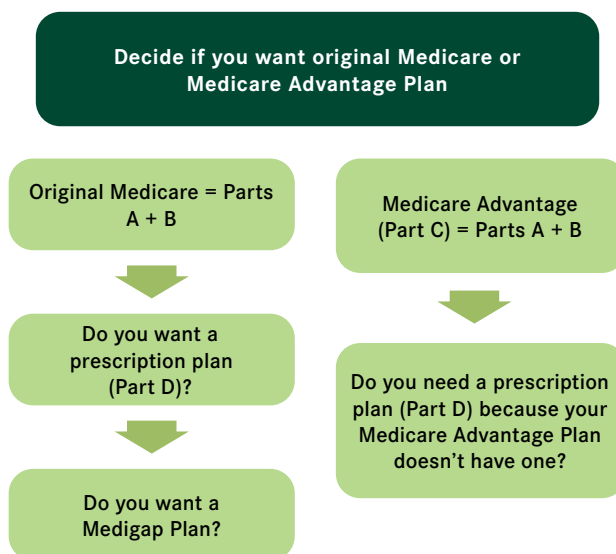
- **Part A:** If you have paid into Medicare while working over your lifetime, the monthly premium is free. If you didn't pay into the system, you will pay a monthly premium. There is an annual deductible. You may also be responsible for paying a cost-share amount depending on the number of days spent in a hospital.
- **Part B:** There is an annual deductible plus a monthly premium that is based on your income. The cost-share for Part B coverage is 80/20, which means that once you have paid your deductible, Medicare will cover 80% of your health care costs and you will be responsible for 20%. With Part B coverage, there is not an out-of-pocket maximum. If you enroll in Part B late, there will be a 10% penalty for each year you wait to enroll. (Example: Phil's initial enrollment period ended December 1, 2018, but he waited until December 1, 2020, to sign up for Part B. His Part B penalty is 20%). You also may have to wait until the general enrollment period to sign up.
- **Part C:** The premiums for this plan are usually at

least the same as Part B or more, but they vary based on the plan you choose. The deductibles, cost-share, and out-of-pocket maximums will vary.

- **Part D:** The premiums for prescription drug coverage vary by plan and are higher for those with higher income levels. After paying the annual deductible, Medicare pays 75% of the cost of your brand-name and generic drugs, and you pay 25% until you reach a certain amount in total out-of-pocket drug costs. At that point, you enter "catastrophic coverage," and Medicare pays 95% of your drug costs. Beginning in 2024, Medicare will pay 100% once you enter catastrophic coverage. And, in 2025, there will be a \$2,000 cap on out-of-pocket costs under Medicare Part D. If you do not sign up for a Part D plan when first eligible, you will pay a late enrollment penalty for life.

Medigap Plans

A Medigap plan is a supplemental insurance plan that will help pay for your deductibles, co-payments, and cost-share amounts. Plans are labeled as A through N, and each plan with the same letter must offer the same basic benefits in most states. The premiums and deductibles vary with each plan. If you chose Original Medicare (Parts A and B), there is a 20% cost-share amount for Part B, so a Medigap plan can help pay for that expense. If you have Medicare Part C, you are not eligible to buy a Medigap plan.



How to Enroll

You can sign up for Medicare during a seven-month initial enrollment period, which begins three months before the month you turn 65, includes the month you turn 65 and ends three months after the month you turn 65. If you didn't sign up during your initial enrollment period, there is a general enrollment period from January 1 to March 30, but your coverage will not begin until the first day of the month following when you sign up. If you need to sign up for Part D, you can do between April 1 and June 30, but your coverage will not begin until July 1 and you may face late enrollment penalties.

Medicare Savings Programs

You may qualify for one of the four Medicare Savings Programs. Each program has different income and resource limits and provides different levels of help.

- **Qualified Medicare Beneficiary Program:** This program has the lowest income limits but covers the most out-of-pocket costs. It helps pay for Part A premiums, Part B premiums, deductibles, co-insurance, and co-payments.
- **Specified Low-Income Medicare Beneficiary Program:** This program only helps pay for Part B programs but has slightly higher individual and married couple income limits than the Qualified Medicare Beneficiary program. It helps pay for Part B premiums.
- **Qualifying Individual Program:** To qualify for this program, you must apply every year. Applications are approved on a first-come, first-serve basis, but individuals who received benefits in the previous year are prioritized. If you qualify for Medicaid, you cannot qualify for this program. This program has higher monthly income limits than the Specified Low-Income Medicare Beneficiary and Qualified Medicare Beneficiary programs. The Qualifying Individual Program helps pay for Part B premiums.
- **Qualified Disabled and Working Individuals Program:** This program accepts applicants who are working, disabled and under 65; have lost their premium-free Part A after returning to work; are not getting medical assistance from their state; and

meet the income and resource limits for their state. This program has higher income limits than other programs, but lower resource limits. It helps pay for Part A premiums.

The **Extra Help Program** helps individuals with limited income and resources pay Medicare's prescription drug program costs, such as premiums, deductibles, and co-insurance. Extra Help also is referred to as, the low-income subsidy. If you qualify for the Specified Low-Income Medicare Beneficiary or Qualifying Individual programs, you automatically qualify for Extra Help. In addition, you may be able to receive Medicare and Medicaid, depending on your income and resources.

For additional resources, visit: [TriageCancer.org/HealthInsurance](https://www.TriageCancer.org/HealthInsurance)

- Quick Guides & Checklists
- Animated videos
- Chart of state laws
- State resources
- Webinars
- [CancerFinances.org](https://www.CancerFinances.org)

Being a Prepared Caregiver

As a caregiver, there may be certain things that you will do while supporting that individual. For example, you may need to communicate with their health care team if they are in the hospital, or with the health insurance company if you are helping them file an appeal. You may also need to help them manage their medical bills, negotiate payment plans with providers, or submit their application for disability benefits. In these circumstances, those providers, companies, and agencies might want proof that they are allowed to communicate with you, and that you are acting on behalf of the person you are supporting.

You may also want to help the person you are caring for plan ahead by making sure that they have their wishes about their medical care and finances in writing, in case they are unable to make those decisions for themselves in the future. This can include everything from their preferences about who visits them in the hospital to writing a will.

The following sections include information that may be helpful to the person you are caring for, as well as yourself. The estate planning section also covers certain documents you may need to complete to act on behalf of the person you are supporting.

Accessing Medical Records

It is important to have a complete copy of your medical records. Having a copy will help you ensure the information in your records is correct, coordinate your medical care between your different providers, share information with your family and caregivers, and appeal denials of health insurance coverage.

When Can I Request My Medical Records?

HIPAA is a federal law that gives you the right to receive, inspect, and review copies of your medical records and billing records from health plans and health care providers that are covered by HIPAA. You can request a copy of your medical records from your health care provider and/or health plan at any time, for any reason. A health care provider may not withhold access to your medical records even if you have an outstanding medical bill. Under HIPAA, providers must provide a patient with a copy of their medical records within 30 days of their request, or 60 days if records are kept off-site. If the provider cannot either respond or provide the records within this time frame, they can use one 30-day extension.

How Much Does it Cost to Request a Copy of My Medical Records?

HIPAA allows providers to charge reasonable, cost-based fees related to providing you with a copy of your medical records (including the cost of supplies, labor, and postage). You may not be charged if someone else searches for your medical records. Per page fees are not allowed if records are stored electronically. Note: some state laws also allow for fees, and the amounts vary by state.

What Do I Do if I Want to Correct Something in My Records?

If you think there is information in your medical or billing record that is incorrect, you can ask your health care provider or health plan to make a change to your record. Your health care provider or health plan must respond to your request and make the change or addition. If they refuse, you have the right to submit a statement of disagreement that the provider or plan must add to your record.



Who Do I Contact if Denied Access to My Medical Records?

If a health care provider or health plan denies you access to your medical records, contact the U.S. Department of Health & Human Services' (HHS) Office for Civil Rights at 800-368-1019.

Understanding Appeals

At some point during cancer treatment, you may experience a denial of coverage from an insurance company, whether for an imaging scan, prescription drug, treatment, procedure, or genetic test. And most of us may take “no” for an answer. But those who don’t accept the denial and file an appeal may actually win and get coverage for the care prescribed by their health care team.

There are different rules for filing appeals depending on the type of health insurance coverage that you have (**Table 4**). Medicare, Medicaid, military, and veterans plans all have specific rules. If you have a private individual health insurance policy or a health insurance policy through work, you generally have two opportunities to appeal a denial of coverage via an internal appeal and an external appeal.

Internal Appeal

When an insurance company has denied coverage for care, you can file an “internal appeal” within your insurance company.

TABLE 4. Rules for Filing Appeal for Insurance Coverage Denial

Type of Appeal	Reason for Appealing	When Patient Should Submit Appeal	Timeline for Decision from Insurer
Pre-Authorization Appeal	Denial before services rendered. Denial prevented patient from receiving care.	Within 180 days	Within 30 days of initial appeal
Post-Treatment Appeal	Denial for payment of care received, meaning patient is 100% responsible for any charges.	Within 180 days	Within 60 days of appeal
Urgent Care (or Expedited) Appeal	Delay in treatment would seriously jeopardize life and overall health, affect patient ability to regain maximum function, or subject patient to severe and intolerable pain.	Within 180 days, but if urgent care, patient can ask for external review at same time as internal review	Within 72 hours of receiving appeal

Each insurance company has its own internal appeals process, so contact your insurance company for details or look for instructions on how to file an appeal on your denial letter. There are time frames related to filing an internal appeal. If your insurance company denies your internal appeal, you can request an external appeal.

External Appeal

Under the Affordable Care Act, all states must have an external appeals process; this is sometimes referred to as an External Medical Review or Independent Medical Review. State insurance agencies or the HHS administer external appeals through independent review organizations that determine if the insurance company should pay for your medical care. Decisions are binding on the insurance company.

If urgent, reviews can be expedited, filed at the same time as an internal appeal and decided within 72 hours. The HHS process is free, but states can't charge more than \$25 for an external appeal.

Appeals Before Care Versus After Care

You can file appeals both before and after you receive medical care. The processes for filing an appeal before care and after care are slightly different. An

example of when you might get a denial of coverage before you even receive care is when your insurance company requires a pre-authorization before getting care. If your insurance company denies pre-authorization, you can appeal that decision.

For additional resources, visit:
[TriageCancer.org/Navigating-Cancer-Health-Care](https://www.triagecancer.org/navigating-cancer-health-care)

- Quick Guides & Checklists
- Animated videos
- Chart of state laws
- State resources
- Webinars
- CancerFinances.org

Managing Medical Bills

Cancer treatment is expensive. But here are key tips on how to manage your medical bills to help you avoid unnecessary expenses.

Ways to Avoid Higher Medical Bills Before Care

While it is impossible to completely avoid out-of-pocket medical costs related to a cancer diagnosis, you can take steps to avoid higher-than-necessary medical bills.

- **Have the right insurance.** You may tend to look only at a plan's monthly cost when choosing a health insurance policy. However, you should also look at the out-of-pocket costs that you have to pay when you get medical care, such as co-payments, deductibles, and out-of-pocket maximums. You also need to make sure the plan covers your providers, hospitals, and prescription drugs. Reviewing your health insurance coverage is something you should do each year to make sure you have the best coverage for your current needs.
- **Discuss costs with your health care team before treatment.** Your health care team may have suggestions for reducing costs; for example, grouping health care appointments together helps you avoid extra co-payments for office visits. Furthermore, you might be able to negotiate your medical bill before you receive care. Ask for upfront pricing for all nonemergency tests and procedures and ask if there are any discounts available.
- **Get any necessary pre-authorization.** Many health insurance companies require you to obtain prior approval (also called pre-authorization, prior authorization, or pre-certification) before you receive medical care. If you don't get the pre-authorization, your health insurance company may deny your claim. Make sure your health care team contacts your health insurance company before treatments, testing, surgery, or hospitalization to check if you need a pre-authorization. If your health care team does not request a pre-authorization for you, you are responsible for getting approval from your insurance company. Also, even if you receive approval, it does not guarantee that your insurance will cover your care.
- **Go to in-network providers when possible.** To be a part of a plan's network, doctors and facilities contract with the plan and agree to accept a specific rate for their services under the plan. These doctors and facilities are considered "in network." Doctors and facilities that do not have a contracted relationship with an insurer are considered "out of network." Some PPO plans have limited coverage for out-of-network providers (e.g., 50%). Most HMO and EPO plans pay 0% for out-of-network providers.
- **Keep track of your out-of-pocket payments.** While your insurance company usually keeps track of what you have paid for out-of-pocket medical care and may even list that on each explanation of benefits (EOB) that you receive, it can be helpful to keep track on your own to ensure those amounts match. Mistakes happen, and you don't want to pay more than you are required to under your plan. Also, when you visit a provider, you may be asked to pay a co-payment when you check in. If you have an insurance plan that includes your co-payments in your out-of-pocket maximum, your provider may not know that you have already reached your out-of-pocket maximum and, therefore, aren't responsible for paying any more co-payments for the rest of your plan year.
- **Leverage out-of-pocket maximums.** If you've reached your maximum for the year, consider addressing any other health care needs you have, rather than waiting until the new plan year, where you will have to meet your deductible and out-of-pocket maximum again.

Communication About Medical Bills

The amount of paperwork generated each time you receive medical care can be overwhelming. Each time you get medical care, you can expect to receive some, or all, of the following items listed below in the mail, by email, or posted in your online insurance account or online electronic medical record offered by your provider.

From the **health insurance company**, you may get:

- A letter indicating it has received a claim from the health care provider.
- A letter saying it is processing the claim.
- An EOB, which details the claim received, how much the provider charged for the particular service (e.g., an X-ray), what the health insurance company is going to pay the provider and what the patient may owe the provider (often called the "patient responsibility"). Generally, EOBs are identified by the statement "THIS IS NOT A BILL" somewhere on the page.

From the **health care provider**, you may get:

- The bill with an amount that the patient is responsible for paying.

You should wait to send in a payment to your provider until you receive your insurance EOB to ensure that the bill and the EOB match and that they are correct. If you're concerned about missing the due date on the bill while waiting for your EOB, contact your provider and let them know that you are waiting for your EOB.

Reviewing Your Medical Bills

Once you've received a medical bill, it's important to review it to make sure it's accurate. Don't be afraid to ask your providers to explain codes or descriptions of services you received. Small errors, such as a wrong number or code, can make a big difference in your bill. Ask for an itemized list of charges, request a copy of your medical records and pharmacy ledgers, and check that everything matches up. If you need help managing your medical bills, consider asking family and friends for help. They can open mail, match EOBs to bills, and put payment due dates on your calendar.

Getting Organized

There are many tools available to keep track of your medical bills, EOBs, medical records, and other paperwork related to your medical care. But the key is to use the tool that makes it easier for you to stay organized, whether that is a box with file folders or a three-ring binder. You also should keep track of any communications that you have with your provider and health insurance company. One reason it is important to stay organized is that tracking all of your expenses related to your medical and dental care (including meals, lodging, and travel expenses related to medical care) could save you money. These expenses may be tax deductible, or possibly paid for through a Health Savings Account (HSA) or Flexible Spending Account (FSA).

Paying Your Medical Bills

If you receive a medical bill that you are unable to pay, it is important not to ignore it. Consider contacting your provider to ask for more time

or see whether your provider would be willing to negotiate a payment plan or accept a lower lump-sum payment.

It is important not to wait too long to contact your provider about an unpaid medical bill. Contacting your provider before unpaid bills get sent to collection agencies can help protect your credit score.

Be careful when you're considering paying medical bills with credit cards; they usually have high interest rates, and you could end up spending more than necessary. You should also be careful when considering taking out a home loan to pay off medical debt. Using your home as collateral transfers the debt from being unsecured to secured, which means that the lender could take your home if you are unable to make payments.

You may be able to qualify for financial assistance programs to help offset the cost of your medical bills.

For additional resources, visit:
[TriageCancer.org/HealthInsurance](https://www.TriageCancer.org/HealthInsurance)
[TriageCancer.org/Financial](https://www.TriageCancer.org/Financial)

- Quick Guides & Checklists
- Animated videos
- Chart of state laws
- State resources
- Webinars
- [CancerFinances.org](https://www.CancerFinances.org)

Estate Planning & Medical Decision-Making

Estate planning is a process that involves thinking about your wishes related to your health and finances, and then documenting those wishes to ensure that they will be carried out.

Most people think that you only need to plan your estate if you have a lot of money or property. But really, estate planning can be useful for every adult over the age of 18. Although it can be difficult to think about your mortality, creating an estate plan allows you to express your deeply held values and personal preferences. Thinking about these decisions and preparing in advance can provide you with the peace of mind that your loved ones will know your wishes.

There may come a point when the person you are caring for is unable to express their wishes about their finances or their medical care. In those cases, estate planning documents such as a financial power of attorney and an advance health care directive are useful tools for them to express their wishes as well as name an agent to make decisions on their behalf.



If you are the health care or financial agent for the person you are caring for, it is important to make sure you understand, and can execute, their wishes. Keep in mind that estate planning rules are different in each state.

Although estate planning plays a crucial role in financial and health care decisions, many people do not even have the most basic document, a will. There are a variety of documents that could make up an estate plan. As you learn more about estate planning in your role as a caregiver for someone else, you might benefit from starting to think about estate planning for yourself, too.

Wills

A will is a legal document that provides instructions for what an individual would like to have happen to their property upon death. A will is also a place where parents can name a guardian for any minor children or adult children with developmental disabilities. Each state has different rules about how to create a valid will, so it is critical to check the rules in your state. There are different types of wills:

- **Written:** Most states require that: 1) your will be in writing; 2) you be of “sound mind;” 3) you sign the will; and 4) it be witnessed by an “uninterested

party.” Some states may require two witnesses, that the witnesses are present when you sign the will, or that the will be notarized. “Sound mind” generally means that you have an understanding of what you are doing. An “uninterested party” generally means someone who is not getting anything in the will.

- **Statutory:** Some states (California, Maine, Michigan, New Mexico, and Wisconsin) have a statutory will form, which can be filled in with the details of your estate plan and your wishes. Will forms are free and you don’t have to hire an attorney. But, they can’t be customized, so they are better for simpler estates.
- **Oral:** Generally, oral wills are only allowed in very limited and unusual circumstances (e.g., statements made on one’s deathbed).

There are several do-it-yourself will options, if you have a relatively simple estate, or cannot afford an attorney. There are online services, books, and computer software that can cost anywhere between \$35-\$200. You may also want to consider hiring an estate planning attorney, especially if you have a complicated estate. When an attorney helps you create a will, you will typically be charged a flat fee or an hourly rate.

How much it will cost depends on factors such as the size of your estate or how complicated your wishes are. There are legal aid organizations that provide free or low-cost legal services for people with low- and moderate-income levels.

When you write a will, you should also consider who you want to be the executor of your will. This is the person who will make sure that your property is distributed according to your will.

You can change or revoke (cancel) your will at any time, as long as you are of sound mind. A codicil is a legal document that you can use to make changes to your will, and can be used for minor changes (e.g., adding a particular gift or updating the legal name of one of your beneficiaries after they get married). Codicils must be executed in the same way that wills are in your state. For example, if a state requires that a will be signed by two witnesses, the codicil must also be signed by two witnesses. If you need to make more substantial changes (e.g., completely removing a beneficiary or adding a new child as a beneficiary) you may want to consider revoking (cancelling) your current will and writing a new one. Generally, if you create a new will, you should destroy any older versions to avoid any confusion or doubt.

Trusts

A trust is a document that allows you to hold assets for one or more beneficiaries. A beneficiary is a person who receives the benefit of the assets in the trust. You can choose a “trustee” to oversee the assets in the trust, or you can act as your own trustee during your lifetime. Property that can be placed in a trust includes real estate, cars, bank accounts, stocks, art, and jewelry. When you place property into a trust, legal ownership is transferred from you to the trust itself. Then the trustee has a legal responsibility to manage the property in the trust the way that you specified in the trust document. The most common types of trusts are:

- **Living trust:** created while you are alive and is revocable until your death. Typically, you act as your own trustee, and while you are alive, you can make any changes for any reason.

- **Testamentary trust:** used to provide for individuals who need help managing their assets. Testamentary trusts can be especially useful to parents who have young children and want to provide for future education, healthcare, or general support. They may also be helpful in meeting ongoing expenses for dependent adults with special needs while safeguarding their government benefits (e.g., Medicaid).
- **Irrevocable trust:** cannot be changed or revoked once created, but may provide some tax benefits and protection from legal action or creditors.
- **Special needs trust:** can be used to meet the needs of an individual with a disability. The advantage of these trusts is that the assets in the trust are not considered “countable assets” for purposes of qualification for certain governmental benefits (e.g., Supplemental Security Income (SSI) or Medicaid).

If you are considering creating a trust, you should consult an estate planning attorney who is experienced in your state’s trust and tax laws to ensure that your trust is set up properly.

Powers of Attorney for Financial Affairs

There may be a time when you become unable to make financial decisions for yourself and you may need help. A Power of Attorney for Financial Affairs is a legal document where you can authorize a trusted adult to make financial decisions for you. Those decisions could be as simple as depositing or withdrawing funds from a bank account, or handling other personal matters, such as receiving mail or making travel arrangements. A durable Power of Attorney for Financial Affairs takes effect when you sign it and stays in effect even if you become incapacitated in the future, but it ends when you pass away. That is when your will takes over. A springing Power of Attorney for Financial Affairs “springs” into effect only if you become incapacitated.



Advance Health Care Directive

There may come a time when you can no longer express your wishes about your medical care. An advance health care directive is a legal document in which you can share your preferences and provide written instructions about your medical care, if you become unable to communicate. You can make decisions about whether or not you want to stop medical treatment at a future time when treatment may not be useful (e.g., stopping chemotherapy once it stops working). However, they can also be used to ensure the start or continuation of treatment at a future time when you may not be able to verbalize your consent (e.g., starting artificial hydration). You can also appoint a trusted adult to make medical decisions for you in the event you are unable to communicate.

When making decisions about end-of-life care, there are other resources that might be useful. The POLST (Physician Orders for Life Sustaining Treatment) Paradigm, encourages patients to talk with their health care providers about the kind of care they want. After talking, they document those decisions in a POLST Form, which can be used by emergency health care providers if patients are unable to speak for themselves. Depending on the state that you live in, a POLST Form might be called by another name.

HIPAA Forms

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that protects the privacy of your health insurance. HIPAA does allow your protected health information to be shared with your personal representative who has authority to make health care decisions for you (i.e., your health care agent or proxy). To guarantee your agent's access to information, a HIPAA authorization form must be signed and dated by you. Also, it must identify the information to be disclosed, the purpose of the disclosure, the recipients of the information, and an expiration date. This means that any advance health care directives should be clear about the scope of your agent's authority to receive protected health care information.

There are some other key reasons why it can be helpful to have a HIPAA authorization form. For example, if you have children over the age of 18, they may want you to be involved in their medical care, or have access to their medical information. Once your child turns 18, you no longer have the authority to make medical or financial decisions on their behalf. Your child could sign a HIPAA form to give you access to your medical information and communicate with your health care team. Also, if you are in a relationship with another person who is not your spouse, and that person would like you to have access to their medical information, they should have a HIPAA form.

Or, perhaps your best friend would like you to be able to communicate with their health care team. In that case, their HIPAA form should give you that ability.

As an agent you should make sure that you know where important documents (e.g., the advance health care directive or will), are kept as well as how to access accounts, safety deposit boxes, and storage units, if relevant.

Hospital Visitation Directives

Most hospitals are required by federal law to have written rules that give patients the right to choose their own visitors. However, in a crisis, or a moment when you are not able to communicate your decisions, it can be helpful to document your wishes about who you would like to visit you in a hospital. You can do that by creating a Hospital Visitation Directive. This document tells your health care providers to allow your chosen visitors to visit you. It can be a separate document or part of another document, like an advance health care directive. You can also use this document to exclude certain individuals if that is your choice. If you are caring for someone who is not related to you, it may be helpful for them to have a visitation directive that includes you.

Other Resources for Caregivers

Respite Care Options

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

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

Resources for Support

Caregiving can be stressful. These resources that can provide support:

- Embracing Carers: embracingcarers.com
- Stress Management Resources: TriageCancer.org/StressManagement
- StewArtworks Foundation: stewartworksfoundation.org
- MyLifeLine: MyLifeline.org
- Lotsa Helping Hands: lotsahelpinghands.com
- Meal Train: mealtrain.com
- Cancer Care: CancerCare.org

For additional resources, visit: TriageCancer.org/EstatePlanning

- Quick Guides & Checklists
- Animated videos
- Chart of state laws
- State resources
- Webinars
- CancerFinances.org

Conclusion

This practical guide addresses the most common issues that arise after a cancer diagnosis. However, it only scratches the surface of the legal and practical issues that individuals diagnosed with cancer and their caregivers may have to address. Life insurance, education rights, consumer rights, and family law are other common topics. Triage Cancer provides information and resources on all of these topics and more, for free. We believe that when individuals with cancer, their caregivers, and their health care professionals have a better understanding of how to obtain and use insurance coverage, appeal denials of coverage, take time off work, access workplace protections and accommodations, protect estates, and manage other financial issues associated with cancer care, quality of life and cancer survivorship outcomes improve.



Check out our animated videos at
TriageCancer.org/AnimatedVideos



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