TRIAGE CANCER®

Practical Guide to Parenting with Cancer

Developed in partnership with: Bright Spot Network

Practical Guide to Parenting with Cancer

The *Practical Guide to Parenting with Cancer* is designed to help families navigate the many practical, financial, and emotional challenges that can arise when balancing parenting responsibilities with a cancer diagnosis. Parenting while coping with cancer can feel overwhelming. In addition to managing treatment and side effects, many parents are also trying to maintain stability for their children, continue working, make financial decisions, coordinate caregiving and childcare, and plan for the future. This guide was created to help families better understand their rights, options, and available resources.

This guide is meant to serve as an introduction to some of the cancer rights topics that parents and caregivers often have questions about, including health and disability insurance, employment rights, caregiving, finances, 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 is a barrier to getting needs met and contributes to the financial burden of a cancer diagnosis. An understanding of your rights can help you get access to the care you need, improve your quality of life, reduce stress and anxiety, and can be the difference between losing your job, your health insurance, or even your home.

This guide also includes useful information about parenting during treatment, strategies for communicating with children about cancer, ideas for memory making and legacy projects, and practical ways to support children through the uncertainty and change of a parent's cancer diagnosis.

Every family's experience with cancer is different. There is no single path through these issues. However, having reliable information and understanding your rights and options can help families make informed decisions, tap into available resources, and feel more prepared for what lies ahead.

Note: 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.

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Triage Cancer® is a national nonprofit organization that provides free education on the legal and practical issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials, and resources, including a Legal & Financial Navigation Program. Learn more at TriageCancer.org.

Bright Spot Network is a national nonprofit supporting parents and guardians with cancer who are raising children ages 0–10 (including those diagnosed during pregnancy), providing tools to help families talk to kids about cancer, financial assistance, educational resources, and community support so no family faces a parent's cancer alone. Learn more at BrightSpotNetwork.org.

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If you are a parent who has been diagnosed with cancer, or if you are a caregiver for someone with cancer who is a parent, you may need to figure out how to continue working, take time off, return to work, or even retire. Understanding employment laws and your employer's policies can help you navigate these options and make the best decisions for you and your family.

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)
    - Note: Employees of the federal executive branch (e.g., United States Postal Service, federal agencies, etc.) are covered by Rehabilitation Act of 1973 (similar to ADA)

Requirements for Employees Covered by the ADA

- Must be "qualified" (i.e., you can perform essential functions of the job, with or without reasonable accommodations) **and**
- Must have a disability (i.e., a physical or mental impairment that substantially limits one or more major life activities)

Major life activities, according to the ADA, are "activities that an average person can perform with little or no difficulty." Activities include physical activities (breathing, hearing, seeing, talking, walking, other motor movements), mental activities (concentrating and learning) and social/professional activities (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, promotions, pay, benefits, job assignments, bonuses, training opportunities, and leaves of absence. You are protected against discrimination at work, if you:

- currently have a disability
- have a history of having a disability
- employer regards you as having a disability
- have a family, business, social, or other relationship with a person with a disability (e.g., you are a caregiver).

You also are entitled to reasonable accommodations if you currently have a disability or you have a history of a disability.

Your Rights at Work

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, return to work, or take time off, such as:

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

The reasonable accommodations that will work best for you will depend on the side effects that you are experiencing, your job responsibilities, and your workplace. Remember that when thinking about accommodations you may need, they must still be "reasonable." One accommodation might not address all of the challenges you are facing, so you can receive more than one accommodation.

Does an Employer Have to Provide a Reasonable Accommodation?

Yes, if you are eligible under the ADA or a state fair employment law. However, an employer does not have to accommodate you if the employer can show that the accommodation you are requesting would be an undue hardship or would pose a direct threat. An undue hardship is when providing the reasonable accommodation would cause the employer significant difficulty or expense. A direct threat is when there is a "significant risk of substantial harm to health or safety of self or others that cannot be eliminated or reduced by reasonable accommodation."

How Should You Ask for a Reasonable Accommodation?

The ADA does not require that you ask for a reasonable accommodation from a specific person, such as a supervisor, another superior, or a human resources (HR) representative. However, it is a good idea to check your employer's policies, often found in an employee handbook, to see whether your employer has a specific process to request reasonable accommodations.

When you make your request, you do not have to specifically mention the ADA or use the words "reasonable accommodation." Your request does not need to be in writing, but having a written record of your request, either by following up the conversation with an email or formal letter, confirming what was agreed upon, may be useful for future reference. Remember, your current supervisor may not always be your supervisor.

Once you make a request, you and your employer should engage in the "interactive process," which involves negotiating and agreeing on an effective reasonable accommodation.

Your need for an accommodation may change over time. For example, you may need a flexible work schedule while in treatment, but after treatment you may need more rest periods during the day. You and your employer should monitor accommodations to make sure they are still working for you. If not, restart the process.

Your Rights at Work

When Should You Ask for a Reasonable Accommodation?
Generally, you should ask for a reasonable accommodation when you realize that you need help to effectively complete your job responsibilities. If you delay the request and your job performance suffers, your employer may decide to let you go based on your poor job performance. But you may avoid this situation if you ask for a reasonable accommodation to help you effectively complete your job responsibilities.

Is Your Request for Reasonable Accommodations Confidential?
Generally, your employer cannot share information about your medical condition or why you have asked for, or received, a reasonable accommodation. But keep in mind that if you ask your supervisor for an accommodation, your supervisor may need to take your request to HR. And, in turn, HR might share information with company leaders, as appropriate. If you start with HR, because you do not want your supervisor to know about your medical condition, then HR can only share with your supervisor that you are getting an accommodation, not why. Coworkers may ask why you are receiving an accommodation, but your employer can only share that you are getting an accommodation, not share information about your medical condition.

Are Caregivers Eligible for Reasonable Accommodations?
Employers are not legally required to provide reasonable accommodations to employees who are 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.

State Fair Employment Laws
Most states have a state fair employment law. Many provide similar protections to the ADA, but some have a broader definition of disability, and some cover private employers with fewer than 15 employees. Visit TriageCancer.org/StateLaws to learn about the laws in your state.

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

You may be familiar with the FMLA when/if you took time off work for the birth or adoption of your child.

Example: Reasonable Accommodations

Jenny has been working during her chemotherapy treatment, but has been finding it hard to concentrate and remember things. She is concerned it is affecting her work. Jenny works for a sales company and her desk is in a cubicle on a floor of the building with an open floor plan with offices circling the cubicles. There are 2 desks per cubicle with low partitions between the cubicles. What reasonable accommodations could help Jenny continue to do her job effectively?

Jenny may be able to continue her job effectively with the following reasonable accommodations:

- Move to an office with closed door
- Move to a desk in the corner of the floor plan with less surrounding noise
- Have only one desk in the cubicle, instead of two
- Create higher partitions (e.g., wall or bookcase)
- Wear noise-cancelling headphones
- Allow headphones if not normally allowed
- Allow access to an office regardless of seniority
- Telecommute (work from home)
- Shift work hours to 7am to 3pm, when the office is quieter and has fewer distractions

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 the 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?

Caregiving can include helping with activities of daily living, such as:

- providing basic medical, hygienic, nutritional, or safety needs
- providing transportation to and from medical appointments
- providing psychological comfort
- assisting with housework or paperwork
- organizing prescription medication or grocery shopping
- assisting in chores

Your rights at work

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 mention a cancer diagnosis but does need to contain enough information so the employer can determine if you are eligible for FMLA leave. See the following section on disclosure.

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 or disability insurance benefits 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.

The FMLA and the ADA also can work together to give you time off work. For example, if you have used up your 12 weeks of FMLA leave during a 12-month period, you may be eligible for additional time off as a reasonable accommodation under the ADA. Court cases have suggested that additional time off as a reasonable accommodation will be considered reasonable only if the additional leave is for a definite period of time. How long is considered reasonable will depend on your job responsibilities and your workplace. The ADA only applies to private employers with 15 or more employees, as well as state or local governments. If you work for a smaller employer, you may be covered by a state fair employment law.

Your rights at work

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.

Disclosure, Privacy, and Medical Certification Forms

Choosing to disclose your cancer diagnosis in the workplace is a personal decision and should be made only after thoughtful consideration. Some individuals feel very comfortable that sharing their diagnosis in the workplace and in other arenas is right for them. Others have concerns about sharing their diagnosis for a variety of reasons. There is no "one size fits all" answer to disclosure.

- **Online**: Social media platforms and online tools can be a source of information and support. However, it is important to remember that disclosing a cancer diagnosis online makes the information public, and many employers search social media platforms and the internet in order to research job applicants and employees.
- **With family, friends, and others**: Once you decide with whom to share your diagnosis, you should consider telling family and friends your preferences about what you are choosing to disclose, so that they don't share your information with others against your wishes. An example of when these disclosure decisions can arise is when a family member or a friend wants to host an online fundraiser on your behalf. While crowdfunding may be a useful tool to cope with the financial burden of a cancer diagnosis, there are some possible ramifications to consider before starting a campaign, including privacy and keeping access to government benefits.
- **At work**: Whether you already have a job or are looking for a job, you need to make some decisions about what, if anything, you will share at work. Making educated, proactive decisions about disclosure is one way to regain some of the control you may have felt you lost when you were diagnosed.
- **At school**: You may choose to talk to your child's school about your diagnosis. Letting your child's teacher know the language you are or are not using can help them reinforce or maintain what is happening at home. If you have concerns about your child, teachers and other school professionals can alert you if they notice behavioral changes. They can also connect you to professional support, if needed.

Legal Protections
You have privacy rights related to your medical information, and these laws protect your rights in different ways:

- **Health Insurance Portability and Accountability Act (HIPAA)**: a federal law that requires your health care providers to get your permission before giving your personal health information to third parties.

Your rights at work

- **ADA:** The ADA has specific rules about an employer's access to your medical information. Before making a job offer, potential employers may not ask any questions about your medical condition or general health. After a job offer has been made, employers are allowed to ask you questions about your health history or to complete a medical exam, but only if they would be required of anyone entering a similar job. Employers are not allowed to rescind a job offer based on the results of a medical exam, unless the results show that you cannot perform the essential functions of that job, with or without a reasonable accommodation. Once you are working for an employer, you can be asked only to complete a medical exam or questions about your health history when it is "job-related and consistent with business necessity" or if there is a "direct threat" (e.g., requiring an eye exam for a school bus driver).

Your employer is entitled to medical certification from a health care provider to show why you need a reasonable accommodation. But your employer doesn't necessarily need to know about your cancer diagnosis if you don't want to share that information. Your employer only needs as much information as necessary to show that you are eligible for a reasonable accommodation. For example, if you are experiencing neuropathy as a side effect, the health care provider could focus on discussing the neuropathy on the medical certification form and not include information about your cancer diagnosis.

- **FMLA:** Your employer is entitled to medical certification from a health care provider to show you are eligible for FMLA leave. Again, your employer doesn't necessarily need to know about your cancer diagnosis if you don't want to share that information.

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 your cancer diagnosis confidential, you may not want to have your 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.

Note: 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 other than what is included on the certification form.

For more information, visit:

TriageCancer.org/Employment

TriageCancer.org/Caregiving

Disability Insurance

If you have been diagnosed with cancer and are undergoing treatment, you may find that you are no longer able to work and earn a living the way that you did before your diagnosis. Disability insurance may provide you with income if you are unable to work because of your medical condition. Disability insurance benefits are offered by the federal government, some state governments, and through private insurance companies.

Federal Disability Insurance

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are federal programs that provide financial assistance to individuals with disabilities. Both are administered by the Social Security Administration (SSA).

If you qualify for disability benefits from the SSA, you must have a disability within the SSA's definition of disability:

- You cannot do your job; **and** you cannot adjust to a new job; **and** your disability has lasted, or is expected to last, for at least one year or will result in death.

SSA uses this process to see if you qualify for disability benefits:

- Step 1: Are you working and is your earnings average more than the Substantial Gainful Activity (SGA) threshold this year? If yes, you will not be considered disabled for SSDI. If no, proceed to step 2.
- Step 2: Is your medical condition severe? If yes, proceed to step 3. If no, you will not be considered disabled.
- Step 3: Is your medical condition found in the list of disabling conditions/impairments? If yes, then you are considered disabled. If no, then the SSA will look at the severity of your condition. If the SSA decides the condition is severe enough, you are considered disabled. If the SSA does not decide the condition is severe enough, proceed to step 4.
- Step 4: Can you do the work you did previously? If yes, you will not be considered disabled. If no, proceed to step 5.
- Step 5: Can you do any other type of work? If yes, you will not be considered disabled. If no, you will be considered disabled.

SSI
You may qualify for SSI benefits if you have a low income level (income limit can vary) **and** are 65 and older, **or** blind, **or** "disabled." The monthly payment for SSI is capped. Most states provide a supplemental payment in addition to that amount. You will receive payments beginning the first full month after becoming disabled. Some states automatically provide Medicaid to individuals who are eligible for SSI. You may be able to receive both SSDI and SSI benefits at the same time.

SSDI

You may qualify for SSDI benefits if you are "insured," meaning that you have worked long enough and have paid Social Security retirement taxes to earn work credits. SSDI work credits are based on your total yearly wages or self-employment income. You can earn a total of four credits each year. You can register for a "My SSA" account online to track your credits at ssa.gov/myaccount. Your SSDI monthly benefit is proportional to your salary history, but it is capped at a certain amount each month. You will receive health insurance through Medicare after you have received SSDI benefits for two years.

How Do You Decide Whether to File for Disability Benefits or Retire?

If you are considering filing for Social Security disability benefits but are also close to your Social Security early retirement age or full retirement age, you should consider checking your Social Security statement to compare the amount of your monthly payments if you were to receive SSDI, retire early, or wait until you reach your full retirement age. This information can be found on your annual Social Security statement, which you can view in your "My SSA" account online.

Can You Receive Back Payments or Retroactive Payments?

The approval process for SSDI and SSI can take several months. To make up for the time it takes to approve an SSI or SSDI application, SSA makes back payments, which cover the time between the application date and the approval date. SSA also understands that individuals may not apply until after their disability began, so it also provides retroactive payments for SSDI. Retroactive payments cover up to 12 months from the date of application back to the disability onset date, after a five-month waiting period.

Do You Have to Pay Taxes on Social Security Disability Benefits?

SSI payments are not taxed. You may be responsible for paying income taxes on SSDI benefits, depending on your total household income level.

Can You Receive SSDI and Private Long-Term Disability Insurance?

If you have a private long-term disability insurance policy (LTD) that you either bought directly from an insurance company or that you have access to through an employer, that LTD policy may require you to apply for SSDI. Usually, the LTD policy will begin paying benefits before the SSA decides whether you are eligible for SSDI. If you are denied SSDI benefits, the LTD company may offer to help you with the appeals process, including hiring an attorney for you.

If you qualify for SSDI, you may be eligible for back payments or retroactive payments. If an LTD policy has been paying benefits to you for the same months that SSDI makes back payments or retroactive payments, then the LTD policy will likely require you to repay them for those months. So, it is important for you to wait to see if you need to pay back to your LTD policy before spending the back payments or retroactive payments from SSDI.

It is possible to receive benefits from both SSDI and a private LTD policy. However, the amount received from the private policy will be prorated. For example, if your LTD policy pays 80% of your salary and the amount that you receive from SSDI is only 60% of your salary, then moving forward, SSDI will pay 60% of your salary and the LTD policy will pay 20%.

Can You Apply for Social Security Disability Benefits and Unemployment Benefits?

Generally, you cannot be eligible for both Social Security disability benefits and unemployment benefits. Every state's unemployment program requires individuals to certify that they are able to work and actively looking for work, while the SSA requires individuals to be unable to work because of a medical condition. But there are limited exceptions where you may be able to receive both:

- If you are seeking work but the type of work is limited due to your disability and will pay you less than the annual SGA threshold, you may be able to collect unemployment and SSDI.
- If you are collecting unemployment and then become disabled, you may be able to continue collecting unemployment while you apply for SSDI.
- If you receive SSDI, start working through the Ticket to Work program for at least six months and are then laid off, you may be entitled to collect unemployment benefits while receiving SSDI.

Are There Programs to Help Your Family?

When you start receiving SSDI benefits, certain members of your family may also qualify for benefits based on your work record. Family members include:

- Your spouse, if they are age 62 or older.
- Your spouse at any age, if they are caring for a child of yours, who is younger than age 16, or who has a disability.
- Your unmarried child, including an adopted child, or, in some cases, a stepchild or grandchild. The child must be younger than age 18 (or younger than 19 if still in high school).
- Your unmarried child, age 18 or older, if they have a disability that began before age 22.

Each family member may be eligible for a monthly benefit of up to 50% of the worker's benefit amount. However, there is a limit to the amount of total benefits (i.e., retirement, disability, spousal, children's, and survivor benefits) that a family can receive based on one worker's record.

Are There Programs to Help You Return to Work?

Some individuals who receive SSDI or SSI have concerns about trying to return to work but being unable to work at the same capacity they could prior to a cancer diagnosis. They also may be concerned how that will affect their disability and health insurance benefits. SSA has programs to help you try to return to work while protecting your access to disability benefits and the health insurance programs that are tied to those benefits. These programs are called "work incentives," and they vary depending on whether you are receiving SSI or SSDI. The programs include a trial return to work period, vocational rehabilitation, and the Ticket to Work Program.

What Happens When You Reach Retirement Age?

For most SSDI beneficiaries born after 1960, full retirement age is 67. Once you turn 67, benefits will switch from SSDI to Social Security retirement benefits. In most cases, the amount will remain the same.

Do You Have to Report Changes to SSA?

If you are receiving SSDI or SSI, you are responsible for reporting any changes in your situation to SSA as soon as possible and no later than 10 days after the end of the month in which the change occurred. The types of changes that should be reported to SSA include any changes in work status, household size, address, immigration status, income, marital status, or health status. Failing to report changes in a timely manner could result in underpayment, overpayment (which must be paid back plus a penalty), or payments withheld by the SSA for up to 12 months.

Disability Insurance

What Happens if Your SSDI or SSI Application Is Denied?
Many applications are initially denied. You can appeal the denial, but make sure to follow the instructions for appealing and any deadlines. Work with your health care team to gather information for your appeal. There are four levels to the appeal process:

- **Request for reconsideration**: A Social Security agent who did not take part in the first decision will do a complete review of your claim.
- **Administrative law judge hearing**: This is conducted by an administrative law judge and is usually held within 75 miles of your home.
- **Review by Appeals Council**: The Appeals Council may deny a request if it believes the administrative law judge hearing decision was correct.
- **Federal district court review**: If you disagree with the Appeals Council's decision, or if the Appeals Council decides not to review your case, you may file a lawsuit in federal district court.

State Disability Insurance

California, Hawaii, New Jersey, New York, Rhode Island, and Puerto Rico, offer short-term disability programs that last from six to 12 months. You may be able to receive both SSDI and state disability, but check your state rules.

For information about state disability insurance programs:

- California: (800) 480-3287 or www.edd.ca.gov
- Hawaii: (808) 586-9188 or www.labor.hawaii.gov/dcd/home/about-tdi
- New Jersey: (609) 292-7060 or www.nj.gov/labor
- New York: (800) 353-3092 or www.wcb.ny.gov
- Puerto Rico: (787) 754-5353 or www.trabajo.pr.gov
- Rhode Island: (401) 462-8420 or www.dlt.ri.gov/tdi

Private Disability Insurance

You can purchase short-term and/or long-term disability insurance directly from a private insurance company. Private disability insurance also may be offered by your employer as an employee benefit.

For more information, visit:

TriageCancer.org/DisabilityInsurance

Paid Leave for Caregivers

Caregivers may also have access to paid leave options, depending on where they live and their employer's policies.

Employer Policies
Some employers offer paid sick leave, vacation time, general leave, or specific caregiver leave benefits that can be used to take time off while still receiving pay. It's important to review your employee handbook or speak with your employer to understand what benefits are available. Some of these types of leave are required under state or local law. For information about the laws where you live, visit TriageCancer.org/StateResources and TriageCancer.org/StateLaws.

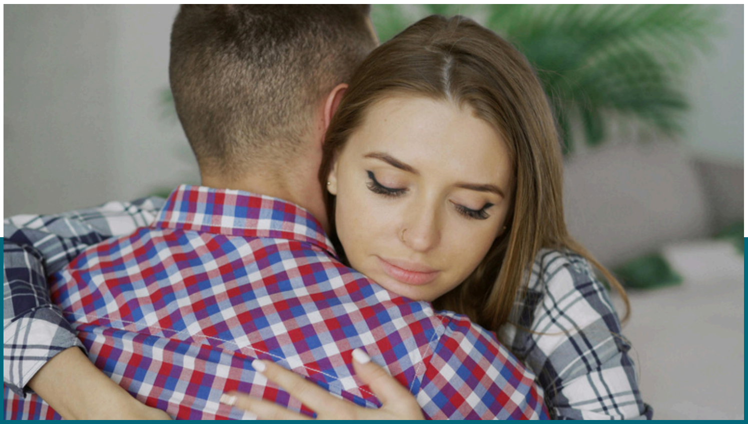
Caregivers should also know that even if paid leave is not available, they may still have job-protected leave through laws like the Family and Medical Leave Act (FMLA), which can be used alongside paid leave benefits when applicable. Understanding the different options and how they work together can help caregivers plan for time off while minimizing financial strain.

Kin Care Laws
Kin care laws are state laws requiring that if an employer provides accrued paid leave, the employer 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 the employee 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
General paid leave laws are state laws that require employers to provide paid leave to their employees to be used for any reason. States with general paid leave laws include Maine and Nevada.

Paid Family Leave Laws
Some states have Paid Family Leave programs that provide partial wage replacement for workers who need time off to care for a family member. Each state's program is different, but they typically cover a portion of the employee's salary for a set number of weeks and may be funded through employee payroll deductions. As of 2026, these states have paid family leave programs: California, Colorado, Connecticut, Delaware, Maine, Maryland (2028), Massachusetts, Minnesota, New Jersey, New York, Oregon, Rhode Island, Virginia (2028), Washington, and Washington, DC.

To learn more about paid leave laws, visit TriageCancer.org/StateResources and TriageCancer.org/StateLaws.



For more information, visit:

TriageCancer.org/Caregiving

Health Insurance Basics

Health insurance can be confusing. To understand your options and find coverage that is 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 percentage 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.

Terms Used to Understand Health Insurance Costs

Here are terms related to the cost of health insurance that you should understand.

- **Monthly premium**: 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 but never filing a claim.
- **Out-of-pocket**:
    - **Annual deductible**: 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 or $5,000. Some plans have a $0 deductible.
    - **Co-payment**: a fixed dollar amount you pay when you get medical care. For example, when you visit the doctor, you might have a $20 co-payment; if you go to see a specialist, you might have a $40 co-payment. You usually pay co-payments 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.
    - **Out-of-pocket maximum:** a fixed dollar amount that is the most that you will have to pay for your covered 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).

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.

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.
- **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.

Example: Prescription Drug Costs

Noah's Plan:
Deductible = $1,000 / Co-payment = $50 / Co-insurance = 70/30 plan / Out-of-pocket max = $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% of $9,000 = $2,700

But his out-of-pocket max 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

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: ask to cover a nonformulary drug.
- Tier exception: ask to treat a drug as if it were in a lower tier, reducing your out-of-pocket costs.
- Brand exception: ask 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:

(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.

Example: Picking an Insurance 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.

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 buy private health insurance coverage for individuals and families: through 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. 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 may be 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:
    - **Bronze plans** have a 60/40 cost-share, meaning that the insurance company pays for 60% of your covered 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 to December 15 for plans that begin the following 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, or moving 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. Also, if you have already met your out-of-pocket maximum or deductible for the year, it may be less expensive to pay the 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.

Table 1. Qualifying Events for COBRA Coverage

COBRA Qualifying Event	**Max 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**

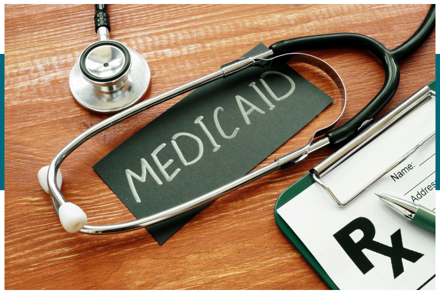
**There are two times when you may be able to extend COBRA coverage. There are also a few times when COBRA coverage may end early, such as when an employer stops offering health insurance coverage to all employees or when an employer goes out of business.*

Health Insurance Options

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, some states have a Medicaid Health Insurance Premium Payment Program that 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 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, DC, have expanded Medicaid 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, DC) 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.

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

- Between 100% and 138% FPL: You have access (for silver plans only).
- 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 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.

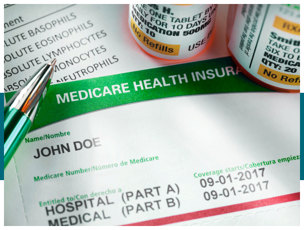
Health Insurance Options

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 about 70 million Americans enrolled in Medicare. Medicare coverage is broken down into four parts:

- **Part A: Hospital Insurance**. Includes hospital care, skilled nursing facilities, hospice care, and limited nursing home 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 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.
- **Part D**: **Prescription Drug Coverage.** Plans have options depending on where you live, with different premiums and formularies offered by private insurance companies.

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 co-pay, 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 is 80/20, which means that once you have paid your deductible, Medicare will cover 80% of your Part B health care costs and you will be responsible for 20%. With Part B, 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, 2023, but he waited until December 1, 2025, 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 premium cost for Part C is at least the same as Part B or more, but varies 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 people with higher income levels. After paying the annual deductible, you pay 25% of the cost of your covered drugs until you reach a certain amount in total out-of-pocket drug costs. In 2026, that amount is $2,100. At that point, you enter "catastrophic coverage," and you are no longer required to pay anything towards the cost of your covered drugs. If you are having trouble paying for your prescriptions under Part D, you can enroll in the Medicare Prescription Payment Plan. If you do not sign up for a Part D plan when you are first eligible, there are other enrollment periods you may use to sign up, depending on your situation. But you may pay a late enrollment penalty for life.

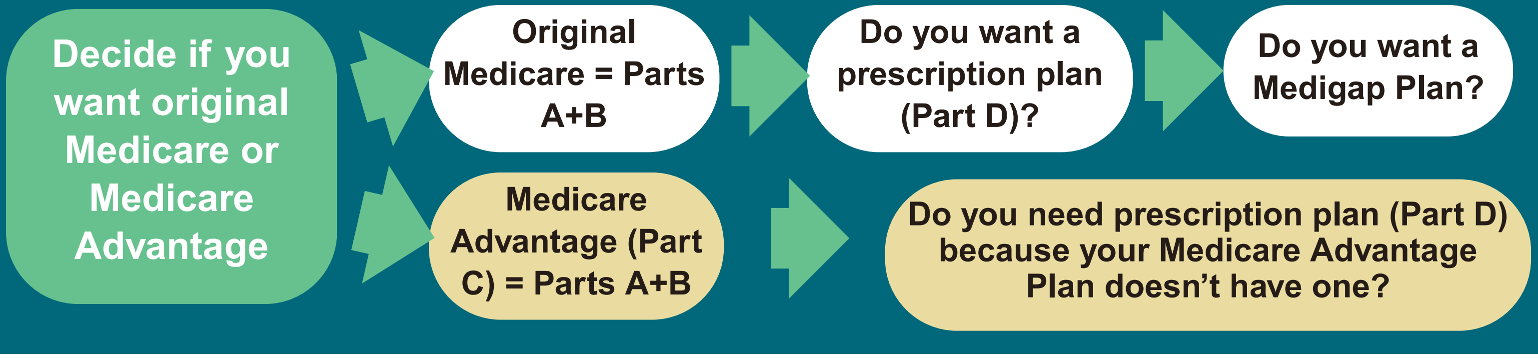
Medigap Plans

A Medigap plan is a supplemental insurance plan that will help pay for your deductibles, co-payments, and cost-share amounts. Plans are labeled A through N, and each plan with the same letter must offer the same basic benefits in most states. The premiums and deductibles vary for 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.

Health Insurance Options

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 do not sign up for Medicare when you are first eligible, during your initial enrollment period, there are other enrollment periods you may use to sign up, depending on your situation. However, you may pay a late enrollment penalty for life.



Decide if you want original Medicare or Medicare Advantage

Original Medicare = Parts A+B

Do you want a prescription plan (Part D)?

Do you want a Medigap Plan?

Medicare Advantage (Part C) = Parts A+B

Do you need prescription plan (Part D) because your Medicare Advantage Plan doesn't have one?

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, have a disability, 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 more information, visit: TriageCancer.org/HealthInsurance, TriageCancer.org/Medicare, or TriageCancer.org/Medicaid

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, many of us 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. 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 decide 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 more information, visit:

TriageCancer.org/HealthInsurance

TriageCancer.org/Appeals

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.** Avoid looking only at a plan's monthly cost when choosing a health insurance plan. You should also look at the out-of-pockets 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 appointments together helps you avoid extra co-payments for office visits. 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 get prior approval (also called pre-authorization, prior authorization, or pre-certification) before you get 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.
- **Leverage out-of-pocket maximums.** If you've reached your maximum for the year, consider getting any other health care you need, 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 (Explanation of Benefits), 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 received your insurance EOB to make sure 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. 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. programs to help offset the cost of your medical bills.

Parenting with Cancer

There are practical issues related to parenting with cancer, including how to communicate with children about cancer, managing routines, and supporting children through the uncertainty and change of a parent's cancer diagnosis.

Parenting with Cancer

A cancer diagnosis impacts the entire family, even the family's youngest members. Children of all ages can pick-up on changes to routine, a parent's stress, and hushed conversations. If you are raising children while navigating a cancer diagnosis, it is important to consider talking with them about what is happening, provide them opportunities to ask questions, and check-in with them about how they are feeling.

Supporting Children

These are some ideas of how parents can support children of different age groups:

Babies and Toddlers

- Maintain routines as much as possible.
- Keep caregivers consistent.
- Offer physical closeness and soothing voices.
- Expect clinginess or sleep changes during separations.

Preschoolers

- Focus on the present (this minute, after lunch, tonight, tomorrow).
- Keep sentences simple and short.
- Use children's books about cancer and feelings to help give them words to what they are experiencing.
- Use play, including the use of medical toys like play stethoscopes, syringes, or swabs, to explain procedures.
- Use repetition. Preschoolers often ask the same question over and over again. Answer the questions calmly each time.
- Expect separation anxiety and regressions during times of stress (ex: sleep training, toilet training).

Bright Reads

Bright Spot Network offers Bright Reads, a free program that sends two children's books directly to your family, along with discussion guides and additional resources to help parents navigate conversations with their kids about a cancer diagnosis.

School-Aged Children

- Use children's books about cancer to explain cancer, treatment, and emotions.
- Expand discussions about cancer and treatment as children show an interest. Some children will benefit from exploring facts and science about cancer.
- Encourage expression through talking, drawing, writing, or movement.
- Inform school staff so additional support is available to children.
- Consider a peer support group, camp, or connection with other kids their age who have a parent with cancer.
- Pay attention to signals that might show kids need more support: significant changes in appetite or sleep, challenges at school, disinterest in activities they typically enjoy, or constant worrying.

Teens

- Some teens may want to be more involved in discussions about treatment, changes, prognosis decisions that impact them.
- Recognize their need for peer connection, school continuity, and space for independence.
- Keep checking-in. Distress may show as irritability, withdrawal, or overachievement.

Guidelines and Suggestions for Talking with Children

Children benefit from honest and clear communication. Talking to your children about cancer helps them to understand what is happening, prepare for changes, and feel a sense of trust.

Be honest.

You do not need to tell kids everything, but what you tell them should be the truth. Honesty builds trust. When children don't have information, they can fill the silence with their imagination, which may be even scarier than what is really happening.

Use simple, concrete language.

Define words your children may overhear. Read children's books about cancer that explain the disease and treatment in kid-friendly words and pictures. Speak in short sentences. You can expand what you are telling your children as they understand more and have more questions. For example:

- "I have an illness called cancer."
- "I am going to a special doctor called an oncologist who will help me."
- "I am getting a medicine called chemotherapy."
- "The chemotherapy may make me feel sick and tired, or lose my hair."

Prepare children for changes.

Worries can be eased by knowing what to expect. Inform children of upcoming surgeries, schedule changes, new caregivers, or anything that will impact their lives.

Focus on the here and now and what affects them.

Children want to know who will pick them up from school, who will take them to activities, or who will tuck them in at night. Young children tend to do best when you talk about today, tomorrow, and the next few days. They may have a hard time thinking beyond a week.

Parenting with Cancer

Invite worries.
By helping our children speak about their fear, they may feel more empowered: “Some kids worry about what will happen if the cancer gets worse. Do you ever think about that?”

Show emotions.
Modeling emotions teaches children that all feelings are okay and manageable. It is okay to cry, laugh, or get angry. Name your feelings: “I am feeling disappointed that I will miss your soccer game because of treatment.”

All Children Need to Hear These Messages Often:
- “Cancer is not your fault. Nothing you did, said, or thought caused me to get cancer.”
- “Cancer is not contagious. You cannot catch it from me.“
- “It is not your job to fix this. I have doctors and adults helping me.”
- “Even when I’m not around, I am still your parent. My love for you is always here, even if I’m away at treatment or resting in my room.”
- “You will always be cared for. Adults are making plans to ensure you are safe and able to do the activities you want to do.”
- “You can ask questions anytime. Please come to me or another adult you trust.“
- “I will check-in with you, especially if there are updates that impact you.”

Parenting with Metastatic Cancer
Parenting with metastatic cancer is different from parenting through a short-term illness. Treatment may be ongoing. Scans may bring changes. Energy and abilities may shift over time.

Children notice these changes. They may not always have the words, but children sense shifts in mood, routine, and availability. Open, honest communication helps reduce fear and confusion, and builds trust and comfort. Children may wonder:
- “Is the medicine working?”
- “Will things get worse?”
- “Are you going to die?”

You do not need to share every medical detail. You need to help them understand what is going on around them. Clear updates build security, even when a medical situation is uncertain.

As much as possible, help your children to stick to their routines. Normalcy supports resilience. Give children permission to experience joy: “It makes me happy to see you having fun.” Encourage children to engage in healthy routines, which can include school, friendships, favorite activities, play, and creativity.

Support Groups

Bright Spot Network

Bright Spot Network offers a virtual support group for parents navigating a stage IV diagnosis. This is a drop in group to talk to others who get the stress and practical concerns of parents with an advanced diagnosis. For more information, visit: BrightSpotNetwork.org/Support-Groups.

Parenting with Cancer

Living With Ongoing Treatment and Uncertainty
Metastatic cancer often involves cycles of treatment and reassessment. Children may be confused about the seriousness of your illness if you look or act healthy. Here are some suggestions for how to address ongoing changes and updates:

Scan & Treatment Updates
- Acknowledge anxiety: “I have a scan this week. I may feel nervous.”
- Update children with changes:
    - “The cancer has spread to another part of my body.”
    - “The cancer has grown. We’re changing treatment.”
    - “The new medicine will help to keep the cancer from spreading more.”
- Affirming the on-going nature of your illness:
    - “This type of cancer usually does not go away completely.”
    - “The cancer is something I am likely to live with for a long time.”
    - “The treatment I’m on helps control it.”
- Short updates are important because they help prevent children from imagining worse outcomes.

Changes in Ability
- Name limitations directly:
    - “I can’t run like I used to because the cancer affects my bones.”
    - “I need more rest because of treatment.”
    - “I cannot go for long rides because my body hurts.”
- Reinforce connection and what you CAN do:
    - “I cannot run, but I’d love to watch you play soccer through the window.”
    - “I need to lie down–let’s cuddle up and read or watch a movie.”
    - “I can’t go on a roadtrip, but let’s have a campout in the living room.”

Practical Planning
Children feel safer when adults are planning. You do not need to share every detail. Simply reassure them that plans exist.This may include:
- Identifying backup caregivers
- Legal and guardianship planning
- Organizing important documents

Redefining Hope
- Acknowledge that hope can mean different things–more time, good days, comfort, meaningful experiences.
- Hope does not have to mean cure.

Bright Box

Bright Spot Network offers Bright Box, a free art kit designed to help parents and children stay connected during a parent’s cancer treatment. Creative activities can offer a gentle, low-pressure way for families to spend time together, connect, and for children to begin to process their feelings.

Memory Making and Legacy Projects

Parents with advanced cancer may want to create special memories or leave meaningful items for their children to have as touchstones after their death. These events and projects are a two-way street, as they help parents process feelings and leave a lasting legacy, and provide children with enduring connections to their parents. While it can be tempting to focus your energy on big trips or special events, remember that ordinary moments matter most to your children. Spending meaningful time together, even in bed, provides them with special memories of connection.

Ideas for Legacy Projects:

- Writing letters to your children or recording stories
- Sharing family traditions or cooking favorite meals
- Creating photo albums
- Visiting a favorite place (or somewhere new together)

Talking About Death and Dying

Talking about death and dying with your children can bring up a lot of emotions. This may not be a conversation you want to start, but avoiding the topic doesn't protect children from their fears. Clear, age-appropriate language and honesty helps to comfort and reduce children's confusion.

Follow their Lead

- Many children are not ready to talk about death and dying until their parent is visibly changing (ex: not getting out of bed, not eating, sleeping most of the time, using oxygen to breathe).
- When having difficult conversations with children it can help to talk while doing another activity. This might be throwing a ball, coloring, going for a walk, or driving in the car. Providing engagement and space for silence helps children to process the information and ask questions.
- Children may need time to play or go outside after difficult conversations–this is their way to manage big emotions. Remind children it is okay to laugh, be with friends, do favorite activities, and have fun even.

Use Direct Language

- Avoid euphemisms like passing away or going to sleep–this can be confusing for children or even increase their worries. Instead say: “At some point, the cancer will cause my body to stop working. That is called dying.”
- Explain that when someone dies: the body stops working; they do not breathe, eat, or feel pain; they cannot come back.
- Prepare children for increased sleeping, less talking, the presence of medical equipment, and changes in breathing
- It can be beneficial to explore beliefs you and your children have about what happens after death. Spiritual, religious and cultural practices, including specific rituals, can be discussed.

Give your Children a Choice

- Children may be uncomfortable or scared to be around the parent who is dying, which is very normal. Respect their choices and level of comfort.
- Explore their reasons for avoiding the parent and allow them to express concerns and feelings. Their reluctance may be due to misinformation, the need to set limits, or a desire to have someone with them. You may be able to provide what they need to feel secure.
- Consider alternative ways for children to connect with the parent who is dying if they do not want to physically be in the same space. They might want to send notes, drawings, stuffed animals, or record videos to play for the parent.

Reassure About Care

- Children often worry immediately about themselves and who will care for them.
- Be specific about the plan:
  - “If I die, you will live with ___.”
  - “They will take you to school and help with homework.”
  - “They will make sure you stay involved in your favorite activities and friends.”
- Some older children may want to be included in making decisions about who will take care of them, especially if the person who is dying is their only parent.

After Death

- Recognize that grief looks different for every person, including children.
- Remind your children over and over it is okay to feel however they need to feel. They can even be happy.
- Understand that grief unfolds over time. Expect waves of sadness, anger, or regression. Answer questions again as children grow.
- Maintain routines, engagement in favorite activities and connection to loved ones.
- Continue bonds with the parent who died. Share memories, display photos, and continue traditions they enjoyed.

Parenting with metastatic cancer requires holding love and uncertainty at the same time. There is no perfect script. What children remember most is honesty, warmth, and connection. Even in advanced illness, your presence, however it looks, matters deeply.

Practical Concerns

There are a number of practical things that families may need to naviagte when a parent is dealing with a cancer diagnosis, including keeping routines, staying organized, getting help from family and firends, and more.

Maintaining Routine

As much as possible, keep familiar routines around meals, school, bedtime, and activities. Consistent structure helps children feel secure during uncertain times. Knowing what the day will look like—and who will be there—helps children feel more prepared.

Visual reminders can help children understand what to expect. Consider using:

- A visual weekly schedule with colors or symbols for younger children that include treatment days, tired/sick days, special events, new caregivers, and any other change you want to help your child prepare for.
- A family calendar in a central place in the home for pre-teens and teens
- You can create simple visual calendars at home with paper and markers, erasable boards, or purchase pre-designed calendars.

Parenting with Cancer

Build a Support Circle

It can be helpful to identify trusted adults who can help with childcare, transportation, meals, or supervision during appointments. This might include family members, friends, neighbors, other parents from school, activities, or other members of your community. Delegate simpler tasks to people you don't know as well, such as neighbors or coworkers. You may find that people want to help but are unsure how. Offering specific ways they can support you makes it easier for them to step in. Some useful tools to help you organize your support circle to get the help your family needs:

- Caring Bridge: CaringBridge.org
- Lotsa Helping Hands: LotsaHelpingHands.com
- Meal Train: Mealtrain.com
- Cancer Support Community's MyLifeLine®: MyLifeline.org

Create a Childcare Plan

Having a simple written plan can make it easier for others to step in when help is needed. Consider keeping a document (print or online) that includes:

- School and activity schedules
- Emergency contacts, allergies, and medications
- Bedtime routines
- Comfort items or favorite activities

Try to keep the circle of caregivers small and consistent, so children can feel secure with who is taking care of them. When possible, introduce new caregivers before they are needed. Let children know ahead of time who will pick them up, stay with them, or help with bedtime. Predictability can ease anxiety and help children adjust to changes.

Finding Childcare Support

If you don't live near family and friends, finding childcare support can be an added stress. If you need help finding care, start by speaking with a social worker or patient navigator at your cancer care facility or a counselor at your child's school. They may know about local programs that provide financial help, or referrals to trusted childcare providers. Additional childcare resources:

- Depending on your income and location, you may qualify for government programs to help cover childcare costs or connect families with subsidized childcare providers.
- United Way / 211 (dial 211 or visit 211.org) to locate childcare, financial aid, and family support services in your area.
- Daycare expenses: FriendsofMan.org
- Help for women for home care, child care, and transportation: CancerCare.org/financial/information

People want to help you. Let them.

Keep a go-to list of 5-10 tasks you can text or share with people who ask, "How can I help?" Ideas include taking the dog for a walk, mowing your lawn, packing school lunches, picking up groceries, playing games with your kids in the backyard--anything that helps you to save your energy for time with your family. For more suggestions about asking for help, check out this guide from Bright Spot Network: https://bit.ly/bsn_peoplewillhelpyou

Bright Spot Network

People want to help you. Here are ways to let them.

Want our best advice? Let them.

Around the House

Entertainment

Outside the House

Care for your pets

Food

Care for your kids

Care for YOU

Care for your caregiver

REMEMBER: It's okay to ask for help.

It may feel hard to know what sort of help to ask for.

The right answer is: Anything you can think of.

BSN

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. Support may also be available from organizations, such as:

- Caregiver Action Network: caregiveraction.org
- Family Caregiver Alliance: caregiver.org
- Arch National Respite Network and Resource Center: archrespite.org
- Embracing Carers: embracingcarers.com

Getting Organized

A cancer diagnosis brings a wave of paperwork, appointments, medications, and decisions that can feel impossible to manage on top of parenting and daily life. Many people find that the organizational strategies that worked before a diagnosis are no longer as effective, especially when physical fatigue, stress, or cognitive side effects from treatment are part of the picture. The good news is that getting organized does not have to mean doing everything at once.

Start by identifying the biggest sources of clutter in your life, whether that is mail, medical bills, or a calendar that is hard to keep up with, and tackle one area at a time. Pick whatever system makes sense for you: a binder, a file box, a folder on your computer, or a scanning app on your phone. The right system is the one you will actually use.

When you have people in your life who want to help, centralizing information makes it easier for them to do so. A shared calendar means a family member can see when your next appointment is without having to ask. A group text thread means you only have to send one update instead of many.

Two practical tools worth setting up early are a command center and a go bag. A command center is simply one place, physical or digital, where important information lives: a whiteboard, a clipboard, or a digital display can all work. It becomes the hub for schedules, medication reminders, and anything the household needs to know. A go bag is a bag or tote you keep ready with everything you need for appointments: copies of your insurance card, a notepad for questions, your phone charger, and any comfort items that help you feel prepared.

A few digital versions of the same idea are worth setting up too. Take a photo of the front and back of your insurance card so it is always on your phone. Email yourself a list of your current medications, including dosages and any vitamins or supplements you take, so you can pull it up instantly when a provider asks.

When you are heading out the door to a medical appointment, especially on a day when energy is limited, not having to think about what to grab can make a real difference.

For more tips on getting organized, including tools for managing medical bills, finances, and daily life, watch Triage Cancer's free webinar, *Getting Organized:* TriageCancer.org/Webinar-GettingOrganized.

Planning Ahead

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. 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. But, there are a number of documents that could make up an estate plan.

Wills

A will is a legal document that provides instructions for what an individual would like to have happen to their property upon death. 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:
  - your will be in writing;
  - you be of "sound mind;" "Sound mind" generally means you have an understanding of what you are doing.
  - you sign the will; and
  - it be witnessed by an "uninterested party"(i.e., 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 costs 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.

Guardianship

If you have minor children, one of the most important estate planning steps you can take, is to choose a guardian who would care for your children if you were no longer able to. This is not an easy thing to think about, but having a plan in place gives you peace of mind and protects your children. When choosing a guardian, consider who your child already feels comfortable with, where that person lives, what their parenting style is like, and whether they are in a stable financial situation. You may also want to name a secondary guardian in case your first choice is unavailable. Once you have made your decision, include your choice in your will and consider writing a letter to the guardian describing how you would like your child to be raised, including your wishes around schooling, faith, and family connections. You can also write a separate letter to whoever will manage your child's finances, outlining your wishes for how that money should be used as your child grows up.

In addition, if there comes a time during your life when you are temporarily unable to make medical decisions for your child, you can designate another adult to do so. Talk with an attorney about the rules in your state, or ask whether your state has a Health Care Consent for Minor Children form you can use. For more information and a worksheet to help you compare potential guardian choices, visit TriageCancer.org/Checklist-MinorChildren.

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

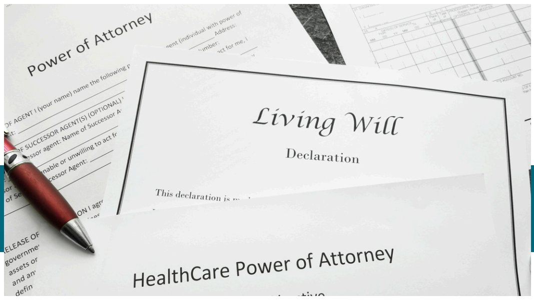
There may be a time when you become unable to make financial decisions for yourself and you may need help. A Power of Attorney for Financial Affairs is a legal document where you can authorize a trusted adult to make financial decisions for you. Those decisions could be as simple as depositing or withdrawing 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 a 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., 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. But, 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.

Life Insurance

Life insurance is insurance that individuals can buy to provide a specific amount of money to a person (or persons) of their choosing, in the event of their death. A main purpose of life insurance is that individuals can ensure that their loved ones are taken care of financially when they pass away. It can be difficult to purchase life insurance after an individual has been diagnosed with a serious medical condition, but not impossible. Life insurance companies are permitted to refuse to sell policies to people with pre-existing medical conditions. Because life insurance consumers do not have the same protections that are available in the health insurance arena, it is left up to each insurance company to decide if, or when, they will insure someone who has been diagnosed with a serious medical condition.

There are many companies in the United States that offer some level of coverage to individuals diagnosed with a serious medical condition. The only way to know which companies sell those policies is to contact the insurance companies that offer policies in your state and ask them. You can find which companies sell life insurance policies in your state, by contacting your state's insurance agency here: TriageCancer.org/StateResources. Some state insurance agencies list the life insurance companies on their website.

Sometimes, there are other options available for getting a life insurance policy, such as getting a group policy through an employer, a professional association, or an alumni association, where they may not ask medical questions and do not impose pre-existing condition exclusions.

For more information, visit:
TriageCancer.org/EstatePlanning

Conclusion

This *Practical Guide to Parenting with Cancer* is intended to help individuals and families better understand some of the most common legal, financial, and practical issues that can arise after a cancer diagnosis. While this guide covers important topics such as health and disability insurance, employment, caregiving, estate planning, finances, parenting during treatment, communicating with children, and memory making and legacy planning, it only scratches the surface of the many challenges that individuals diagnosed with cancer and their caregivers may face. Other important topics, such as education and consumer rights, can also significantly impact families navigating cancer. Triage Cancer and Bright Spot Network provide free education, resources, and support on all of these topics and more. Knowledge can reduce stress and anxiety, support informed decision-making, and help families feel more empowered and connected.

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.

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