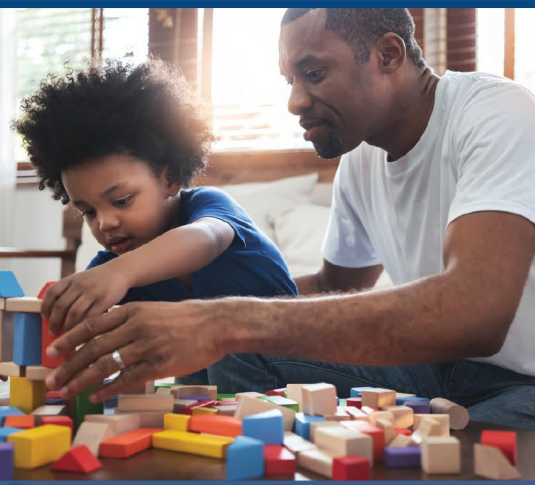


TRIAGE CANCER

A Practical Guide to Cancer Rights for Young Adults



A guide to the legal and practical issues that may affect young adults who are diagnosed with cancer, their caregivers, and the professionals who treat them.

TRIGE CANCER

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



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



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

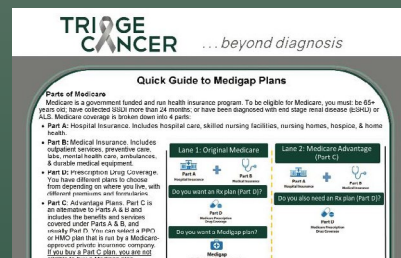
Educational Events



Animated Videos



Quick Guides & Checklists



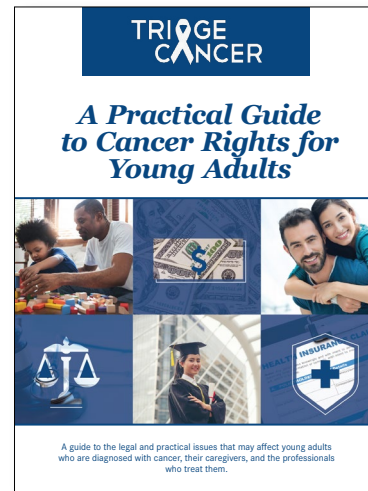
CancerFinances.org



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

Table of Contents

- 4** Your Rights at School
- 6** Your Rights at Work
- 13** Disability Insurance Options
- 16** Health Insurance Basics
- 19** Health Insurance Options
- 25** Accessing Medical Records
- 25** Understanding Appeals
- 27** Managing Medical Bills
- 29** Other Concerns for Young Adults
- 32** Planning Ahead



What is Cancer Rights Law?

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

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

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

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

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

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

A Practical Guide to Cancer Rights for Young Adults: Education, Employment, Insurance, & Finances

Your Rights at School

A cancer diagnosis may disrupt your education. You may need to take time off or wait to start school. You may also experience cancer-related complications and side effects that impact your education. It is important to know that there are laws that help protect students with a disability. There are two laws in particular that are important to know related to education rights for students attending a college, university, vocational, or graduate school: 1) Section 504 of the Rehabilitation Act of 1973; and 2) the Americans with Disabilities Act (ADA). These laws are in place to help protect students against discrimination, to provide access to reasonable accommodations, and ultimately, to ensure that students with disabilities have access to equal educational opportunities.

- **Section 504 of the Rehabilitation Act** applies to colleges, universities, vocational schools, or graduate schools, that receive federal funding. Section 504 not only applies to public schools but also applies to most private colleges and universities because they receive federal financial assistance by participating in federal student aid programs.
- **The ADA** is a federal law that prohibits discrimination in the workplace, transportation, communication, government, and public accommodations for people with disabilities. Specifically, Title II of the ADA prohibits state and local governments from discriminating against individuals with disabilities in all state and local government services, programs, and activities. This includes state-funded colleges, universities, and vocational schools.

Under the ADA and the Rehabilitation Act, eligible students are entitled to receive accommodations to overcome any challenges posed by their medical condition in a learning environment. In addition to education rights, Title I of the ADA also provides

protections in employment, so as you begin to look for jobs and pursue your career goals, the ADA can provide protection against discrimination and access to reasonable accommodations in the workplace.

Reasonable Accommodations

Reasonable accommodations are any changes that help a student overcome challenges associated with their medical condition while getting an education. For example, a student receiving cancer treatment may face side effects that could pose both medical and nonmedical complications related to education. Reasonable accommodations can include physical changes at school, a modified schedule, technology tools, and changes to rules or policies. For example, having someone take notes for you in class or additional time to complete an assignment could be reasonable accommodations.

Most schools have an office, department, or person who is responsible for ensuring that students with disabilities get the accommodations they need. Students are responsible for contacting the school, identifying the need for accommodations, and providing up-to-date documentation of their medical conditions. Self-advocacy is important to get access to needed services, support, and accommodations, so ask for an accommodation as soon as you realize that you need one.

Applying to Graduate School

In addition to the laws and protections above, eligible students may be able to access accommodations at different points during the graduate school application process. For example, students who are taking Education Testing Service (ETS) exams can request a variety of test accommodations. These tests include the GRE® General Test and the GRE® Subject Tests, as well as the TOEFL® Test (Test of English as a Foreign Language for non-native speakers). ETS offers services for students with disabilities and health-related needs.



Financial Help to Pay for School

School can be expensive! There may be financial assistance available to you, to help pay for your living expenses, medical expenses, and student loans. Think broadly and creatively about the type of financial assistance that might be available to you. For more information, visit: studentaid.gov.

There are many opportunities for students to apply for and earn scholarships for undergraduate, graduate, and professional schools. Some schools may offer merit-based or need-based scholarships when you are accepted into the school based on your prior experience, academic success, or financial need. There are also many scholarships available to students with medical challenges or health conditions. Your school's financial aid office may have a list of external scholarships for which you can apply, but many scholarship opportunities can be found online. You can also find financial assistance resources for school at CancerFinances.org.

Managing Student Loans

Student loan debt can be significant, and individuals diagnosed with cancer may face additional barriers to repayment. Here are some tips on how students can start to get a handle on their student loan debt:

- **Figure out how much you owe and who you owe it to:** Do you have federal loans? Do you have private loans? Or both?

- There are two types of federal loans – Direct Loans from the U.S. Department of Education and loans that are serviced by a private company. You can find the contact information for each loan servicer and who services your loan at studentaid.gov/h/manage-loans.

- If you have private loans, you will need to contact the loan carrier.

- **What is the interest rate on each loan that you have?**

- **Avoid defaulting on your loans:** to protect your credit, you should communicate with lenders before you stop making payments for any reason. There may be options to lower your monthly payments or reschedule your payments to make it easier for you to stay current on your payments.

- **Identify your options:** Speak with a loan counselor. Find out what your options are for payment plans, refinancing loans, consolidating loans, deferring loans, forbearing loans, or even forgiving or discharging loans. Make sure you are getting information from a reputable source (e.g., Federal Student Aid).

- **Deferment:** when an eligible individual can temporarily stop making payments or reduce their monthly payment for a certain amount of time.

- **Deferment for Cancer Treatment:** Under a new federal law, qualified borrowers may receive a deferment on their qualifying loans while they are receiving cancer treatment, and for the six months following the conclusion of treatment. Deferment may be available for Direct Loans, Federal Family Education Loans (FFEL), and Federal Perkins Loans:

- Made on or after September 28, 2018, or
- That entered repayment on or before September 28, 2018.

- **Forbearance:** similar to deferment; however, an individual may be responsible for paying the interest that has accrued on certain types of loans while in forbearance.

- **Loan Forgiveness & Cancellation:** Under certain circumstances, an individual may be eligible for loan forgiveness or cancellation, which means that you no longer need to repay part or all of your loan. For example, some loans may be eligible for forgiveness if the individual has a job in public service. These different types of repayment programs apply to Direct Loans, Federal Family Education Loan (FFEL) Program Loans, and Perkins loans.

- **Loan Disability Discharge:** If eligible, an individual may also be able to get their loan discharged as a result of their disability.

- **Total and Permanent Disability Discharge:**

Individuals who have a total and permanent disability can be discharged from repaying their student loans. To be eligible, individuals must demonstrate that they are totally and permanently disabled. There are three ways to do this:

- you are a veteran with a service-related disability;
- you are receiving Social Security Disability Insurance or Supplemental Security Income; or
- you are able to submit a medical certification form from a licensed medical doctor or doctor of osteopathy declaring that you are totally and permanently disabled. The doctor must provide certification that you are unable to engage in any substantial gainful activity. This must be supported by a medical reason, and that the total and permanent disability can be expected to last for a continuous period of not less than 60 months, has lasted for a continuous period of 60 months or more, or can be expected to result in death.

- Some private lenders also offer disability discharge options for individuals with disabilities. These lenders may have

different rules, so it is important to contact your lenders for more information.

Disclosure at School

If you are over 18 and want another person involved in your education, you may need to give permission to your school to discuss your records with another person, like your parents, a spouse, or a significant other. The Family Education Rights and Privacy Act (FERPA) protects the privacy of your education records. Generally, schools need your written permission to release information from your education record. If you want another person involved, talk to your school about their process for receiving your permission to release information to the people you choose.

See Triage Cancer’s Module on Education Rights at CancerFinances.org for more information about legal rights to get help in school, accommodations at school, rights during the graduate school application process, and more.

For additional resources, visit:
TriageCancer.org/Cancer-Finances-Education

■ Quick Guides & Checklists	■ State resources
■ Animated videos	■ Webinars
■ Chart of state laws	

Your Rights at Work

If you have been diagnosed with cancer, you may need to figure out how to continue working, take time off, return to work, or even start your career. Understanding employment laws may help you navigate these options and make decisions.

Americans with Disabilities Act

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

Employers Covered by Title I of the ADA

- Private employers with 15 or more employees.
- Employment agencies, labor organizations, and joint labor-management committees.
- State and local governments of any size.
- Employees of the federal legislative branch (e.g., employees of the Senate, House of Representatives, and agencies that support Congress).
 - Employees of the federal executive branch (e.g., United States Postal Service, federal agencies, etc.) are covered by 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 functions (breathing, hearing, seeing, talking, walking, other motor movements), mental functions (concentrating and learning) and social/professional functions (working or caring for oneself).

When Are You Protected by the ADA?

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

You are protected against discrimination at work if you currently have a disability, if you have a history of having a disability, if your employer regards you as having a disability, or if you 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.

What Are Reasonable Accommodations?

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

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





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 barrier).
- 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 7 a.m. to 3 p.m., when the office is quieter and has fewer distractions.

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 request additional accommodations, if needed.

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 employers’ policies, often found in the employee handbook, to see whether your employer has a specific process to request reasonable accommodations.

When you make your request, you do not have



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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 on the conversation with an email, formal letter, or contract 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 additional rest periods during the day. You and your employer should monitor accommodations to ensure they are still effective. If not, restart the process.

When Should You Ask for a Reasonable Accommodation?

Generally, you should ask for a reasonable accommodation when you realize that you need one 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 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.

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.

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 child, 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, child, 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.

Employers Covered by the FMLA

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

Employees Eligible for Leave Under the FMLA

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

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

What Activities Count as Caregiving?

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; and assisting in chores.

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

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

When Should You Ask for FMLA Leave?

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

How Do You Ask for FMLA Leave?

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

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 of many factors. Some individuals feel very confident 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 to research job applicants and employees. You may think only your friends and followers will see that information, but keep in mind that may not be the case.

- **With family, friends, and others:** Once you decide with whom to share your diagnosis, you need to tell 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. These disclosure decisions can arise when a family member or a friend wants to host an online fundraiser on your behalf, for example. 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.
- **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.

Legal Protections

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

- **Health Insurance Portability and Accountability Act (HIPAA):** HIPAA is a federal law that requires your health care providers to get your permission before giving your personal health information to third parties.
- **ADA:** The ADA has specific rules about an employer's access to your medical information. Prior to receiving an employment 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 a medical certification from a health care provider to show why you need a reasonable accommodation. However, 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. However, your employer doesn't necessarily need to know about your cancer diagnosis if you don't want to share that information.

- 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.

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.



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

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

Disability Insurance Options

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, or you are unable to start your career as you had planned. 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 and some state governments or through a private insurance company.

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 will use 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 deemed 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 deemed disabled.

Step 3. Is your medical condition found in the list of disabling conditions/impairments?

- If yes, then you are deemed disabled.
- If no, then the SSA will look at the severity of your condition. If the SSA deems the condition severe enough, you are deemed disabled. If the SSA does not deem the condition severe enough, proceed to step 4.

Step 4. Can you do the work you did previously?

- If yes, you will not be deemed disabled.
- If no, proceed to step 5.

Step 5. Can you do any other type of work?

- If yes, you will not be deemed disabled.
- If no, you will be deemed disabled.

SSI

If you have not worked and paid Social Security retirement taxes, you may want to start by seeing if you qualify for SSI. You may qualify for SSI benefits if you have a low-income level, low resource level (assets); **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 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.

■ **SSDI based on your own earnings history result in death.**

For adults under the age of 31, you are “insured” if you are:

- Under age 24 – you must have 6 credits earned in the 3-year period ending when your disability starts.
- Age 24 to 31 – generally, you must have worked half the time between age 21 and the time your disability starts.
 - Ex., if your disability starts at age 27, you need 12 credits in the past 6 years (between ages 21 and 27)
- Age 31 or older – generally, you need 20 credits in the last 10 years immediately before your disability starts.

■ **SSDI based on a parent’s earnings history.**

You may qualify for a “child” benefit, if you are an adult with a disability that began before age 22, and one parent:

- Is receiving Social Security retirement or disability benefits, or
- Is deceased and worked enough to qualify for Social Security retirement benefits

It is called a “child” benefit because it is paid on a parent’s Social Security earnings record. SSDI disabled adult “child” benefits continue as long as you have a disability, although your eligibility for this benefit may be affected if you get married.

Your SSDI monthly benefit is proportional to your salary history, but it is capped at a certain amount each year. You will receive health insurance through Medicare after you have received SSDI cash benefits for two years.

Can You Receive Back Payments, Retroactive Payments or Advance 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 federal and state 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 without a waiting period and 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 substantial gainful activity 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 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.

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.

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. The following states skip this level: Alabama, Arkansas, California (Los Angeles North/Los Angeles West only), Colorado, Louisiana, Missouri, New Hampshire, New York, and Pennsylvania.
- **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, and Rhode Island, plus the territory of Puerto Rico, offer state 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 edd.ca.gov
- Hawaii: (808) 586-9188 or labor.hawaii.gov/dcd/home/about-tdi
- New Jersey: (609) 292-7060 or nj.gov/labor
- New York: (800) 353-3092 or wcb.ny.gov
- Puerto Rico: (787) 754-5353 or trabajo.pr.gov
- Rhode Island: (401) 462-8420 or dlt.ri.gov/tdi

Private Disability Insurance

You can also purchase short-term and/or long-term disability insurance directly from a private insurance company. However, they can take into consideration any pre-existing conditions that you may have when you apply. Private disability insurance can also be offered by your employer as an employee.

For additional resources, visit:
TriageCancer.org/DisabilityInsurance

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

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 portion of the allowed amount, depending on your plan.

Common types of managed care plans are:

- **Health Maintenance Organizations (HMOs):** Your health care services start with your

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.



primary care physician, and you usually need a referral to see another health care provider, except in an emergency. For example, if you have a skin rash, you first go to your primary care physician. If needed, that physician will refer you to a dermatologist in your network. Generally, HMOs have smaller networks of providers, and providers outside of your network will not be covered by your HMO. While you may have less choice in providers, HMOs are often less expensive.

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

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

Health Insurance Cost Terms

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

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

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

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

Example: Prescription Drug Costs

Noah's Plan:

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

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

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

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

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

- **Co-payment:** A fixed dollar amount you pay when you get medical care. For example, when you visit the doctor's office, you might have a \$20 co-payment; if you go to see a specialist, you might have a \$40 co-payment. You usually pay your co-payment at the time you receive care.
- **Co-insurance (aka cost-share):** A percentage difference in what the insurance company pays for your medical expenses and what you pay for your medical expenses. For example, if you have an 80/20 plan, the insurance company pays 80% of your medical expenses and you are responsible for 20% of your medical expenses after paying your deductible.
- **Out-of-pocket maximum:** A fixed dollar amount that is the most you will have to pay for your medical expenses out-of-pocket during the year. Your out-of-pocket maximum will depend on your plan. It is a very important thing to find out! Generally, you reach your out-of-pocket maximum by paying your deductible, plus any co-payments that you make during the year, plus any co-insurance payments you make. So, it's everything that you pay, except your monthly premiums. Once you reach your out-of-pocket maximum, your insurance pays 100% of your medical expenses

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

Prescription Drug Terms

Here are some helpful terms to understand prescription drug coverage:

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

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

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

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

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

Picking a Health Insurance Plan

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

- What will the plan actually cost me?

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

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

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

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

Health Insurance Options

The health insurance options available to you depend on where you live, your age, your employment, your income level, and other factors.

- Although about half of Americans get health insurance through work, many entry-level jobs do not offer health insurance.
- Individuals under age 26 may be eligible to join, remain on, or rejoin a parent's group health insurance plan, even if you are married or no longer living with your parent.

Here are some of the main options for health insurance coverage for young adults.

Health Insurance Marketplaces

The Patient Protection and Affordable Care Act (ACA) created a new way to find and buy private health

insurance coverage for individuals and families: state health insurance marketplaces. Originally called “exchanges,” the term “marketplace” refers to a place where you can find health insurance options from private insurance companies. These marketplaces have been compared to an insurance shopping mall. The marketplaces for most states are operated by the federal government at HealthCare.gov. Some states run their own marketplaces.

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

- **Out-of-pocket maximum cap:** There is a cap on the out-of-pocket maximum for plans sold through the marketplace, which is often lower than some employer plans. Also, out-of-pocket maximums for all marketplace plans must include everything you spend for deductibles, co-payments, and co-insurance for in-network providers.
- **Standardized plans:** Plans sold through the marketplace are standardized by their level of cost-sharing:
 - **Bronze plans** have a 60/40 cost-share, meaning that the insurance company pays for 60% of your medical expenses and you are responsible for

40% of your medical expenses. Bronze plans generally have lower monthly premiums but higher out-of-pocket costs.

- **Silver plans** have a 70/30 cost-share.
- **Gold plans** have an 80/20 cost-share.
- **Platinum plans** have a 90/10 cost-share, with higher monthly premiums but lower out-of-pocket costs.

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

The marketplace open enrollment period (OEP) is usually from November 1 through 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:

Example: Picking a Plan

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

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

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

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

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

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

COBRA

COBRA is a federal law that allows eligible employees to keep their existing employer-sponsored health insurance

plan after experiencing a “qualifying event.” **Table 1** lists the qualifying events that may entitle you to continue coverage under COBRA and the maximum length of time you can keep your plan.

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

A main barrier to COBRA coverage is cost. Typically, you pay 100% of what your employer was paying for your coverage, plus a possible 2% administrative fee (for a total of 102%). But there may be some benefits to COBRA. For example, if you are in the middle of treatment, with COBRA coverage, you wouldn’t have to find a new insurance plan that has the same coverage for your doctors, hospitals, and prescription drugs. Also, if you have already met your out-of-pocket maximum or deductible for the year, it may be less expensive to pay the higher COBRA premiums and not have any out-of-pocket costs for the rest of the year. You should do the math to figure out which option would cost you less.

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

TABLE 1. Qualifying Events for COBRA Coverage

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

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

(e.g., COBRA), Medicaid may pay your monthly premium for the group plan.

Another Group Health Plan

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

Medicaid

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

Qualifying for Medicaid Coverage Based on Income Level

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

- Up to 138% of the FPL: You have access to Medicaid.

- Between 138% and 250% FPL: You have access to marketplace premium tax credits and cost-sharing subsidies (if you pick a silver health insurance plan).
- Between 250% and 400% FPL: You have access to marketplace premium tax credits.

- Above 400% FPL: You can buy a marketplace plan, but you do not qualify for financial assistance in most states. Some states provide additional assistance. For example, in California you can qualify for premium tax credits up to 600% FPL.

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

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

Note: Under the American Rescue Plan Act, if your household income is above 400% FPL, you may qualify for marketplace premium tax credits to lower your health insurance costs to 8.5% of your household income. This additional benefit is set to expire December 31, 2025.

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

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

FPL, federal poverty level.

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

Medicare

Medicare is a government health insurance program. To be eligible you must be 65 or older, or have been diagnosed with end-stage renal disease or amyotrophic lateral sclerosis. If you have collected SSDI for more than 24 months, you may be eligible for Medicare regardless of your age.

Medicare coverage is broken down into four parts:

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

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

Medicare Costs

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

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

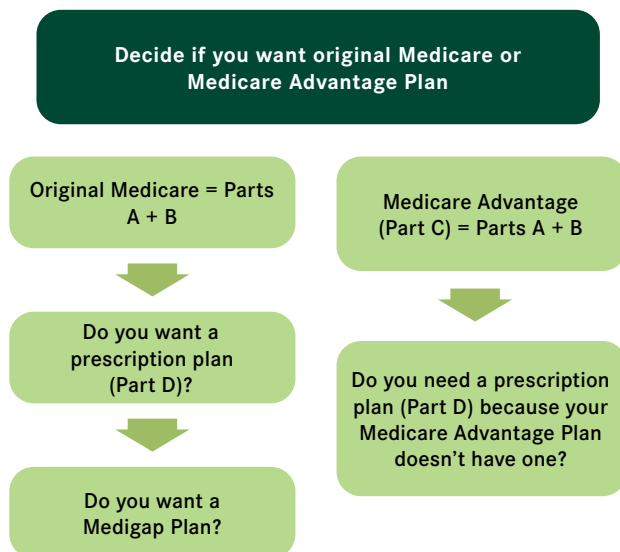
Benefits Available by FPL			
100% FPL	138% FPL	250% FPL	400% FPL
Cost-Sharing Subsidies (Silver Plans Only) → → → → → →			
Medicaid → →	Premium Tax Credits → → → → → →		

FPL, federal poverty level.

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

Medigap Plans

A Medigap plan is a supplemental insurance plan that will help pay for your deductibles, co-payments, and cost-share amounts. Plans are labeled as A through N, and each plan with the same letter must offer the same basic benefits in most states. The premiums and deductibles vary with each plan. If you chose Original Medicare (Parts A and B), there is a 20% cost-share amount for Part B, so a Medigap plan can help pay for that expense. If you have Medicare Part C, you are not eligible to buy a Medigap plan. If you qualify for Medicare because you are under age 65 and are receiving SSDI, you may not be eligible for a Medigap plan in your state.



Medicare Savings Programs

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

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

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

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

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

Accessing Medical Records

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

When Can I Request My Medical Records?

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

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

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



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

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

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

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

Understanding Appeals

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

There are different rules for filing appeals depending on the type of health insurance coverage that you have (**Table 4**).

TABLE 4. Rules for Filing Appeal for Insurance Coverage Denial

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

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 determine if the insurance

company should pay for your medical care. Decisions are binding on the insurance company.

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

Appeals Before Care Versus After Care

You can file appeals both before and after you receive medical care. The processes for filing an appeal before care and after care are slightly different. An example of when you might get a denial of coverage before you even receive care is when your insurance company requires a pre-authorization before getting care. If your insurance company denies pre-authorization, you can appeal that decision.

**For additional resources, visit:
TriageCancer.org/HealthInsurance**

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



Managing Medical Bills

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

Ways to Avoid Higher Medical Bills Before Care

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

- **Have the right insurance.** You may tend to look only at a plan's monthly cost when choosing a health insurance policy. However, you should also look at the out-of-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 health care appointments together helps you avoid extra co-payments for office visits. Furthermore, you might be able to negotiate your medical bill before you receive care. Ask for upfront pricing for all nonemergency tests and procedures and ask if there are any discounts available.

- **Get any necessary pre-authorization.** Many health insurance companies require you to obtain prior approval (also called pre-authorization, prior authorization, or pre-certification) before you receive medical care. If you don't get the pre-authorization, your health insurance company may deny your claim. Make sure your health care team contacts your health insurance company before treatments, testing, surgery, or hospitalization to check if you need a pre-authorization. If your health care team does not request a pre-authorization for you, you are responsible for getting approval from your insurance company. Also, even if you receive approval, it does not guarantee that your insurance will cover your care.

- **Go to in-network providers when possible.**

To be a part of a plan’s network, doctors and facilities contract with the plan and agree to accept a specific rate for their services under the plan. These doctors and facilities are considered “in network.” Doctors and facilities that do not have a contracted relationship with an insurer are considered “out of network.” Some PPO plans have limited coverage for out-of-network providers (e.g., 50%). Most HMO and EPO plans pay 0% for out-of-network providers.

- **Keep track of your out-of-pocket payments.**

While your insurance company usually keeps track of what you have paid for out-of-pocket medical care and may even list that on each explanation of benefits (EOB) that you receive, it can be helpful to keep track on your own to ensure those amounts match. Mistakes happen, and you don’t want to pay more than you are required to under your plan. Also, when you visit a provider, you may be asked to pay a co-payment when you check in. If you have an insurance plan that includes your co-payments in your out-of-pocket maximum, your provider may not know that you have already reached your out-of-pocket maximum and, therefore, aren’t responsible for paying any more co-payments for the rest of your plan year.

- **Leverage out-of-pocket maximums.** If you’ve reached your maximum for the year, consider addressing any other health care needs you have, rather than waiting until the new plan year, where you will have to meet your deductible and out-of-pocket maximum again.

Communication About Medical Bills

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

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

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

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

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

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

Reviewing Your Medical Bills

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

Getting Organized

There are many tools available to keep track of your medical bills, EOBs, medical records, and other paperwork related to your medical care. But the key is to use the tool that makes it easier for you to stay organized, whether that is a box with file

folders or a three-ring binder. You also should keep track of any communications that you have with your provider and health insurance company. One reason it is important to stay organized is that tracking all of your expenses related to your medical and dental care (including meals, lodging, and travel expenses) could save you money. These expenses may be tax deductible, or possibly paid for through a Health Savings Account (HSA) or Flexible Spending Account (FSA).

Paying Your Medical Bills

If you receive a medical bill that you are unable to pay, it is important not to ignore it. Consider contacting your provider to ask for more time or see whether your provider would be willing to negotiate a payment plan or accept a lower lump-sum payment.

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

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

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

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

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

Other Concerns for Young Adults

Dealing with a cancer diagnosis as a young adult means you may be dealing with many of the other concerns of young adulthood that your friends and peers are facing, in addition to your medical



concerns. You may be dealing with school and/or work, managing your own finances and insurance, family planning, and planning for the future for the first time. There are resources to help you navigate these issues. You are not alone.

Adulting 101: The financial burden of a cancer diagnosis, called financial toxicity, can impact your quality of life. In addition to understanding your rights and options related to school, work and insurance, it can be helpful to understand strategies to manage your finances, including understanding credit scores, budgeting, taxes, and paying bills.

Credit Scores

Part of your financial picture involves your credit score. A credit score is a three-digit number determined by looking at the main categories of your financial history: debts you owe, new credit, length of credit history, type of credit used, and payment history. Your score is used to determine your credit risk and affects your ability to rent an apartment or buy a home, a car, and car insurance. Some employers look at your credit score when deciding to hire you.

Another part of your financial picture is your credit report. You can get a free copy of your credit report each year, but you have to order a copy. One place to order your report is [annualcreditreport.com](https://www.annualcreditreport.com). It can be helpful to check your report for inaccurate information that may lower your credit score.

Budgeting

Creating a budget can help you manage your finances. Apps, credit counselors, and financial planners can be helpful to the budgeting process.

Step 1. Pick a method – software, app, spreadsheet, pen and paper, or putting cash in an envelope each month to pay your bills.

Step 2. Identify all income – wages, other earnings, child support and alimony, disability or insurance payments, etc.

Step 3. Identify all expenses, and be realistic – housing, transportation, food, living expenses, savings, paying off debt, entertainment, etc.

The more realistic your budget, the better chance you have of sticking with it.

Taxes

Everyone who earns enough taxable income is required to file an income tax return each year with the Internal Revenue Service (IRS), usually by April 15. Even if you are not required to file an income tax return, you may still want to do so. Some individuals qualify for a refund of more money than they actually paid in taxes during the year. If you are entitled to receive money back from the IRS, you will need to file a return in order for the IRS to send you the refund. Each state also has its own requirements for filing a state income tax return.

Paying Bills

If you are having trouble paying your bills, it can be helpful to contact your creditors before unpaid bills are sent to collections agencies. Some creditors have options available if you ask for them:

- More time to make a payment
- Change the date of your monthly payments
- Write off a portion of what you owe
- Negotiate a payment plan
- Accept a lower lump sum payment

These programs may be available from your landlord, credit card company, student loan company,

or other creditors. Some creditors will be flexible if they know you have faced a significant hardship like a cancer diagnosis.

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

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

Fertility Preservation

Cancer treatment, such as chemotherapy, radiation therapy, or surgery, may affect an individual's fertility or ability to have biological or genetically-related children. This is called iatrogenic infertility. Fertility preservation is the process of saving or protecting eggs, sperm, or reproductive tissue so that a person can use them to have children in the future. If you are interested in becoming a parent in the future, it is important to talk to your health care team before you start your cancer treatment. You should ask about the reproductive risks of your treatment, and about your options for preserving your fertility. Consider consulting a reproductive endocrinologist (women) or a reproductive urologist or andrologist (men). These are doctors who specialize in reproductive medicine and fertility.

Because the field of fertility preservation is relatively new and growing, many health insurance companies have argued that fertility preservation is not covered or is experimental. However, it is important that you understand your rights and your health insurance company's rules before you start any preservation treatments.



Currently, no federal law requires insurance companies to specifically cover fertility preservation, but some states have passed laws to require coverage, including California, Colorado, Connecticut, Delaware, Illinois, Maryland, New Hampshire, New Jersey, New York, Rhode Island, and Utah. For an up-to-date list of these laws and pending legislation, visit: allianceforfertilitypreservation.org/state-legislation.

If your health insurance company tells you that fertility preservation isn't covered by your plan, you have the right to appeal their decision. Each insurance company has their 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. Under the Affordable Care Act, all states are required to also have an external appeals process – this is also sometimes referred to as Independent Medical Review or External Medical Review. For information on your state's external medical review process contact your state's insurance agency: TriageCancer.org/StateResources. This process is underutilized, but when people appeal, they are more likely to have their treatment covered by an insurance company.

There is also an option to file an “expedited” or “urgent” external medical review, where a decision must be provided within 72 hours. This faster decision can be helpful for those making fertility preservation decisions before beginning cancer treatment.

When appealing denials of coverage, it is important to argue that fertility preservation for iatrogenic infertility is not “elective” or “experimental,” but rather, a “medical necessity” to prevent infertility. It can also be argued that fertility preservation is a “medically necessary” treatment for a side effect of cancer treatment. Your health care team may be able to help you submit an appeal to your insurance company.

Cancer Survivorship Care Plans

Because your need for care does not end with your last day of cancer treatment, a survivorship care plan can be a valuable tool. It gives you and your health care providers a guide to monitor and manage your ongoing care and can also help you navigate any additional follow-up care needs you may have.

An effective cancer survivorship care plan is a written document that includes a summary of your treatment, recommendations for your follow-up care, and other relevant information to help you anticipate

and address the long-term and late-term physical, psychosocial, practical, and financial effects of cancer treatment. Another goal of cancer survivorship care plans is to assist in the coordination and transition of your care from your oncology health care team to your primary care providers, as oncology treatment is completed. You should provide a copy of your care plan to your primary care providers. Talk to your cancer care team to learn more about getting a cancer survivorship care plan.

Medical Marijuana

Medical marijuana is a way to treat different types of side effects of cancer treatment, such as nausea, pain, and a weak appetite. Before deciding to use medical marijuana, it is very important to talk about that option with your health care team and to understand the legal and practical issues involved. Many states have legalized the use of medical marijuana, and some states have legalized marijuana for recreational use. However, even if you live in a state that has legalized medical marijuana or the recreational use of marijuana, it is still illegal to have or use marijuana under federal law. This conflict between federal law and many state laws may affect you:

- **At work:** generally, employers have a right to have a drug-free workplace policy. An employee can be fired if they test positive on a drug test, even if they have a prescription for the use of medical marijuana. There are a few states that require employers to accommodate the use of medical marijuana off-site and off-duty.



- **At home:** generally, your landlord may be able to have a zero-tolerance policy for marijuana.

It is also important that you talk to your health care team about how you would like to use marijuana to manage your side effects from cancer treatment. Be aware that this is a frequently changing area of the law. Know your rights if you decide to use marijuana.

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

- Quick Guides:
Quick Guide to Fertility Preservation
[TriageCancer.org/QuickGuide-Fertility](https://www.triagecancer.org/QuickGuide-Fertility)
Quick Guide to Medical Marijuana
[TriageCancer.org/QuickGuide-MedicalMarijuana](https://www.triagecancer.org/QuickGuide-MedicalMarijuana)
- Animated video:
Cancer Survivorship Care Plans
[TriageCancer.org/Video-SurvivorshipCarePlans](https://www.triagecancer.org/Video-SurvivorshipCarePlans)

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.

Estate planning includes medical and financial decision-making, your physical property, and even your digital property. In this day and age, when so much of an individual's life may take place in the electronic space, it can be useful for individuals to think about how they want to handle their digital assets and how to include them in their estate plan. Digital property like online bank accounts, electronic devices, files, music and photos on electronic devices, e-mail accounts, social media accounts, blogs, and

intellectual property are also considered part of an individual's estate.

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

Although estate planning plays a crucial role in financial and health care decisions, many people do not even have the most basic document, a will. There are a variety of documents that could make up an estate plan.

Wills

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

- **Written:** Most states require that: 1) your will be in writing; 2) you be of "sound mind;" 3) you sign the will; and 4) it be witnessed by an "uninterested party." Some states may require two witnesses, that the witnesses are present when you sign the will, or that the will be notarized. "Sound mind" generally means that you have an understanding of what you are doing. An "uninterested party" generally means someone who is not getting anything in the will.
- **Statutory:** Some states (California, Maine, Michigan, New Mexico, and Wisconsin) have a statutory will form, which can be filled in with the details of your estate plan and your wishes. Will forms are free and you don't have to hire an attorney. But, they can't be customized, so they are better for simpler estates.
- **Oral:** Generally, oral wills are only allowed in very limited and unusual circumstances (e.g., statements made on one's deathbed).

There are several do-it-yourself will options, if you have a relatively simple estate, or cannot afford an attorney. There are online services, books, and computer software that can cost anywhere between \$35-\$200. You may also want to consider hiring an estate planning attorney, especially if you have a complicated estate. When an attorney helps you create a will, you will typically be charged a flat fee or an hourly rate. How much it will cost depends on factors such as the size of your estate or how complicated your wishes are. There are legal aid organizations that provide free or low-cost legal services for people with low- and moderate-income levels.

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

Trusts

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

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

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

Powers of Attorney for Financial Affairs

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



Advance Health Care Directive

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

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

HIPAA Forms

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

There are some other key reasons why it can be helpful to have a HIPAA authorization form. For example, if you are over the age of 18, but you would like your parents to be involved in your medical care, or have access to your information, you could sign a HIPAA form to give them 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.

Hospital Visitation Directives

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

Once you have completed your estate planning documents, you should keep them in a safe, but accessible location. Make sure that your executor, trustee, agent, or a trusted loved one knows about the existence and location of the documents and has access to them

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 cancer, 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 now 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 cancer. There are many companies in the United States that offer some level of coverage to individuals diagnosed with cancer. 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](https://www.triagecancer.org/state-resources). 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 additional resources, visit:
[TriageCancer.org/EstatePlanning](https://www.triagecancer.org/estateplanning)**

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

Conclusion

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

Check out our animated videos at
TriageCancer.org/AnimatedVideos



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