

Caregiver Resources:

Navigating Financial, Legal, and Advance Health Care Planning Concerns

This guide will help you to:

- Understand financial, legal, and advance planning concerns.
- Identify how these concerns may be affecting your loved one and you as the caregiver.
- Develop individualized strategies to help navigate and better manage these issues.

> When you have exhausted all possibilities, remember this – you haven't.
>
> —Thomas Edison

As a caregiver, you may need to deal with financial and legal matters concerning your loved one.

Caregivers may find themselves in situations where they have to negotiate medical bills, maintain insurance coverage, and get financial assistance.

They may also need to make medical and legal decisions for their loved one. *Advance health care planning* is a process of discussion about future care. This type of planning, sometimes called a *living will* or *advance directives*, allows a patient to put someone in charge of making life or death decisions for them if they are unable to (for example, if they do not want to stay on life support if their disease condition is terminal.)

Understanding and navigating these areas can be overwhelming and stressful, especially if you are not used to being the one that handles your loved one's financial and legal issues. The good news is that help is on the way—many resources are available to you and your loved one.

This guide will cover common issues you may encounter as a caregiver and offer key information, insights, and strategies to assist you and your loved one. Being aware of your options for financial and legal assistance can help ensure that you and your loved one's wishes are protected. It can also help you improve your quality of care and be better prepared when changes occur.



How Do Caregivers Describe Financial, Legal, and Advance Health Care Planning Concerns?

What about you?

Check off any items that you and your loved one are experiencing. Write in any other financial and legal concerns that you may be going through.

There are many financial issues facing people diagnosed and receiving treatment for gynecologic cancer, as well as their caregivers and family members. Are you and your loved one experiencing any difficulty with the common concerns listed below?

Financial concerns

- ☐ Being underinsured or uninsured
- ☐ Not sure about eligibility for Medicare or Medicaid
- ☐ Needing help with medical debt
- ☐ Negotiating medical bills and organizing plans for payment
- ☐ Getting financial assistance with medications and treatments
- ☐ Keeping insurance coverage (COBRA, HIPAA, Affordable Care Act)

Legal and advance planning concerns

- ☐ Getting legal advice that is affordable and trustworthy
- ☐ Protecting the wishes of your loved one and yourself
- ☐ Setting up advance legal planning to designate guardianship for minor children, assign a financial power-of-attorney, and prepare a legal will
- ☐ Setting up advance health care directives to assign health care proxies (medical power-of-attorney) and draft a living will that documents your loved one's wishes about end-of-life care

YOUR THOUGHTS

In what ways have concerns over financial and legal issues affected you and your loved one?

What are some of the biggest barriers to managing these problems?

1) _____

2) _____

3) _____

4) _____

5) _____

Now, let's explore some strategies and ways to help you overcome these barriers.

Managing Financial Concerns

The costs associated with cancer and treatment can quickly add up. Whether needing relief from medical debt to finding financial help for treatment and medications, there are options available. Understanding these options and taking the necessary action helps ensure your and your loved one's needs are met.

Financial Assistance Programs

If you and/or your loved one are in financial need, or if you are *underinsured* or *uninsured*, financial assistance programs may be available to support your health care costs. Each program has different eligibility criteria. Knowing your loved one's financial situation can help determine the steps to take in order to acquire the assistance you need.

Note that registration for most government programs can take a long time. Try to make decisions while your loved one is feeling well.

Medicare. This federally-funded health insurance program helps cover health care costs for those ages 65 or older (certain people younger than 65 are eligible if they meet specific criteria). To be eligible, a person (or their spouse) must also have been employed for 10 years or more in Medicare-covered employment and be a citizen or permanent resident of the United States. In general, the different types of Medicare coverage include:

- **Part A:** (hospital insurance) helps cover inpatient care in a hospital or skilled nursing facility following a hospital stay, plus some home and hospice care.
- **Part B:** (medical insurance) helps cover doctor and other provider services. Hospital outpatient care, medical equipment, home health care, and some preventive services are also covered.
- **Part C:** (*Medicare Advantage*) provides additional coverage offered through private insurance companies, as well as Part A and Part B coverage. Most Part C plans also cover prescription drug, dental, vision, and hearing.
- **Part D:** (prescription coverage) helps lower the costs for generic and brand-name prescription medications. Most plans have a list of drugs that are covered, which must always meet Medicare's requirements. There is usually a monthly premium.

Definition:

Underinsured
Holding a health insurance plan, but it is not enough to cover all costs of care. May cause difficulty affording treatments, medications, supportive services, follow-up care, and out-of-pocket expenses.

Uninsured
Not holding any health care insurance plan. National and regional resources are available to obtain coverage. Financial assistance programs can help cover the cost of health care and medical debt.

Learn More

Medicare Advantage availability varies by state. Check with your state to find information and resources.

Visit: www.medicareadvantage.com

***Extra Help* program**. If you have limited income and assets, you may qualify for the *Extra Help* program from the Social Security Administration. To learn more about this program and eligibility requirements, visit: www.ssa.gov/benefits/medicare/prescriptionhelp

Medicare offers additional information about the *Extra Help* program for caregivers in the publication: Understanding the Extra Help with Your Medicare Prescription Drug Plan, Publication No. 05-10508.

Medicaid. Jointly funded by federal and state governments, the Medicaid health insurance program is available to certain low-income individuals and families. Each state sets its own guidelines and rules concerning eligibility and services. To qualify, you and/or your loved one must meet financial eligibility requirements, such as:

- Low-income parents and families that meet certain financial requirements
- Pregnant women with a certain income
- Child, parent or caregiver of a child
- Age 65 or older
- Blind or disabled individuals who receive cash assistance under the SSI program
- U.S. citizenship status
- Resident of the state in which you apply

In certain states with expanded Medicaid coverage, you can qualify based on income alone if your household income is below 133% of the federal poverty level. Learn more about your state's eligibility requirements at: www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you

Applying for *Extra Help*

After learning about eligibility for you and/or your loved one, apply online at: www.ssa.gov/extrahelp

To apply over the phone or to ask for an application, call Social Security at: 1-800-772-1213

(TTY 1-800-325-0778)

You can also apply at your local Social Security office.

Affordable Care Act (ACA). The ACA provides coverage for people who are low- and middle-income by offering premium tax credits for the purchase of private health insurance. The ACA also allows young adults to remain on their parents' insurance plans up to age 26 and requires most individuals to secure minimum essential coverage.

The Supplemental Nutrition Assistance Program (SNAP). This federal program is available to help eligible low-income households obtain food and groceries. Recipients are able to use an issued debit card to purchase a wide variety of items at qualifying locations. SNAP benefits can vary by state. To learn more about the program and eligibility requirements, visit: https://www.fns.usda.gov/snap/supplemental-nutrition-assistance-program.

Additional Financial Assistance for Medications and Treatments

Some pharmaceutical companies offer programs to help people who are in need obtain medications at a reduced cost. Each drug manufacturer's website may also offer assistance programs. Some of these programs help with copayments. Others may be free of charge to eligible patients and specific to helping with a particular diagnosis. Talk to your cancer care providers about whether there are programs for your particular medications. They can help you apply.

Negotiating the Bill

Insurance companies may limit the amount they are willing to pay for a given service or procedure and will negotiate medical bills directly with providers for an amount less than the *standard fee*, or the billed amount. Many consumers, however, aren't aware that they too can negotiate. Providers will often accept a lower amount of payment than the standard fee, but it is necessary for you to ask for the discount.

It is very important that you learn as much as possible about the cost of the health care services your loved one receives. You have the right to ask the cancer care provider or other health care providers about the cost of tests and/or hospital procedures *before* receiving care.

Setting Up Payment Plans

If extra time is needed to pay medical bills, many health care providers offer payment plans as a general policy. Call and ask to speak with a billing specialist. Share that your loved one is unable to pay their medical debt in one large payment and would like to work out a payment plan. Other tips to keep in mind:

- Make sure any plan agreed upon allows enough money to be kept for other bills and needs.
- Avoid using a credit card to pay for medical bills. Credit cards often carry higher interest rates and can quickly become unmanageable.



Making a Financial Plan



Helpful Tip:

Create a plan. You and your loved may want to think ahead about your financial and legal challenges and put together an action plan. This great resource can help you get started: https://us.aicpa.org/content/dam/aicpa/interestareas/cpeandevents/downloadabledocuments/20170811-financialplans.pdf

Planning ahead for your and your loved one's financial security is key to staying financially stable. A good plan should take into account:

- Out-of-pocket medical expenses; be aware of the range of costs and estimate higher if uncertain
- Travel costs
- Hospital stays
- Prescription drug costs; keep in mind these prices can vary widely
- Lost income due to disruption in work schedules
- Home health care costs
- Home services (cleaning, cooking, etc.)

Estimate how much you think each of these items will cost. If you are unsure, talk with your cancer care provider for guidance. Once you know your expenses, put together a plan for your loved one's (and your own) income and benefits. Consider savings and investments as well. Being fully aware of your expenses and income can help you adjust your budget, plan for the future, and be better prepared for whatever happens.

Tips for Financial Management



Helpful Tip:

It is crucial that someone knows how to access your loved one's sources of income and legal documentation in case they develop problems managing financial and legal issues. The stress of having gynecologic cancer and/or receiving treatment can sometimes make it difficult to handle additional complicated and stressful situations.

Many caregivers report that developing a system for routinely organizing financial information helps them gain a sense of control. It is recommended to:

Establish a filing system. Keep contact information for all doctors, insurance, medical center, and support services. Read all bills and explanations of benefits immediately and make sure to check for errors or inaccuracies.

Record insurance policy information. Remember to update this list if changes occur. Record all:

- Claims filed
- Reimbursements and explanations of benefits
- Non-reimbursed or outstanding medical costs or copayments

Record dates and names. Keep a detailed written record of all doctor's appointments, test results, conversations with insurance representatives and support services, medication changes, and any other important dates.



Obtain itemized copies. Ask your health insurance or assistance provider for itemized copies of bills for all care, tests, and treatments. Review these carefully.

Request an insurance case manager be assigned to you. This helps you contact the same person each time.

Record expenses related to your loved one's care. These might include:

- Meals, lodging, and travel expenses related to medical care
- Regular monthly bills—a friend/family member can help you track these and set up payment options

> It was just so overwhelming, I didn't know where to begin. Talking to the navigator was so helpful. She was able to help me break the process down. Baby steps.

If You Have Medical Debt

Many individuals experience medical debt due to too many uncovered expenses. There are several important sources of support when you have copayments or medical expenses that are uncovered, and you are unable to pay.

Health Care Providers. Talk with the cancer care provider's office to let the staff know you have this problem. Work with them to agree upon a reasonable payment plan. Ask if funds are available to assist your loved one or if a fund exists for uninsured patients.

Foundations. Look into foundations or organizations that help insured patients with out-of-pocket costs.

Insurance Providers.

- Read all insurance policy information carefully to see if some expenses that should have been covered were not and should be reimbursed.
- Contact your loved one's insurance representative (if applicable) to appeal a decision that does not seem financially fair to you.
- Contact the insurance provider to ask about your loved one's level of coverage, for all treatments, procedures, and ongoing care.

Learn More

To learn more about managing health insurance, disability and workplace issues, go to the guide **Caregiver Resources: Navigating Employment and Insurance Concerns in this series**



Keeping Employer Insurance Coverage

If your employer provides insurance to you and/or your loved one as part of a group plan, it is important to:

- **Know your options.** If you have an opportunity to renew or change plans, consider all options before deciding.
- **Know your network.** Check which doctors and facilities are in-network and out-of-network with your insurance provider. Many insurance companies have steep penalties for using an out-of-network provider.
- **Make informed choices.** For example, a preferred provider organization (PPO) may be less expensive than a health maintenance organization (HMO), but limits options for out-of-network care.

COBRA and HIPAA. These laws protect you and your loved one's ability to temporarily keep insurance coverage, or in some instances, to get coverage if it has been lost.

- **COBRA:** allows you and your loved one to keep your group health insurance benefits for up to 18 months in the event of reducing work hours, quitting working, or losing a job.
- **HIPAA:** The Health Insurance Portability & Accountability Act protects working people and their families from being denied health insurance due to a medical condition that occurred before they tried to buy health insurance ("pre-existing condition").

Learn more about COBRA: www.dol.gov/general/topic/health-plans/cobra

Learn more about the ACA and health care plans: www.dol.gov/general/topic/health-plans/consumerinfhealth

Managing Legal Concerns

As a caregiver, you may need legal assistance when handling your loved one's financial plans, health care decision-making, and wills and estate planning. Having legal assistance can help reduce stress and support peace-of-mind by knowing you have someone else managing these important matters.

Planning ahead may involve discussions about preferences and wishes for:

- Assigning a financial power-of-attorney
- Preparations for making a legal will and designating guardianship (legal custody or responsibility) for minor children
- Types of care and/or treatment for your loved one

Financial Power-of-Attorney

This is a legal document that permits someone to make decisions or conduct business for your loved one regarding financial matters. The process of selecting a financial power-of-attorney should include:

- Making a list of financial obligations
- Deciding how these obligations will be handled if your loved one is not able to
- Discussing decisions with your loved one
- Choosing someone that your loved one has a trusting relationship with to be their agent
- Selecting an additional agent in case the first is not able to carry out this role

Powers-of-attorney can be either *durable* or *nondurable*.

Durable power-of-attorney: often used when an individual is unable to make effective decisions due to a chronic or incapacitating illness. Generally, this type of power-of-attorney is activated only if a doctor determines that the individual is unable to handle their own affairs.

Nondurable power-of-attorney (sometimes referred to as a special power-of-attorney): used for specific and often temporary situations.



Helpful Tip:

Don't know where to find legal assistance? The Cancer Legal Resource Center (CLRC) can help.

Visit: cancerlegalresources.org or call 866-843-2572

The CLRC is a national program that provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, health care professionals, employers, and others coping with cancer.



Learn More

For more specific information about why it is important to prepare a legal will and what your loved one should do to make a will legally valid, visit: https://info.legalzoom.com/article/how-make-my-own-will-free-charge

Legal Will

A *legal will* specifies how you want your finances, property, and assets to be dealt with in case of death. If your loved one has minor children, a legal will allows for deciding who will care for the children and naming a legal guardian.

Often, we tend to postpone the act of creating and signing a will. It can be uncomfortable to talk or even think about the decisions that need to be made in case your loved one dies. If someone dies without a will, the state decides how to distribute an individual's property and assets.

There are several steps to making a valid and legal will. Many resources are available, but you should explore your options and talk to a trusted source before making any legal decisions for yourself and/or your loved one.



Learn More

Many legal problems reported by those with gynecologic cancer deal with employment issues. Specific topics and resources related to employment issues (including tips for helping you talk with employers) are discussed in the guide **Caregiver Resources: Navigating Employment and Insurance Concerns** of this series.

Advance Health Care Directives

Advance health care directives are legal documents written in "advance" of when they are needed. These documents specify the kind of medical care a person wants if they become too ill to express their wishes. Having these decisions legally documented avoids any confusion about end-of-life care. Even more important is that making these decisions ahead of time can allow your loved one to be in control during a time when keeping that sense of control is more difficult. Types of advance health care directives are:

Medical power-of-attorney, or health care proxy. This person describes who is authorized to make medical decisions on your loved one's behalf. The person should be a trusted individual, selected specifically by your loved one.

Living will. Different from the legal will, a *living will* documents your loved one's wishes about end-of-life care. It specifies your loved one's likes and/or dislikes about health care intended to maintain and prolong their life. Some of these issues include the use of tube feedings, a breathing machine (ventilator), dialysis, being resuscitated if heartbeats/breathing stop, and organ donation.

How to Talk with Others About Financial and Legal Concerns

Your loved one's cancer care provider is familiar with the financial burden that treatment places on families, even if you have insurance and extra income. Whether your loved one has health care insurance coverage or not, it is important to talk openly with the cancer care provider's office as soon as possible about health care costs. Maintaining this type of communication is essential.

When scheduling an appointment, let them know that you have questions. Write down the answers so you can easily refer to your notes again. The cancer care provider's office may recommend:

- Ways to help reduce or manage the costs related to treatment and care
- Referrals to a social worker and support services
- Research studies that may provide monetary or medication compensation for your loved one's participation

Not sure what to ask? Find helpful questions to ask about financial concerns at Cancer.net: www.cancer.net/all-about-cancer/managing-cost-cancer-care

Your family, friends, and community are also excellent resources for both you and your loved one. They may be able to help you understand financial and legal issues, provide meals, coordinate transportation, and even plan a fundraiser. Sometimes, family and friends offer financial help to ease the burden with a loan or donation.

Share this guide with others so they can better understand how they can help you manage your financial and legal matters.

"What can I do to help?"
There are many online tools that make it easy for your family members and friends to lend a hand.

Fundraiser ("crowd-funding") websites
Others can send donations to help with medical bills, for example, plus offer words of encouragement and virtual "hugs." Visit: www.GoFundMe.com

My Cancer Circle
This free, private, and secure online community support website helps others support caregivers and people facing cancer. You can create an account at: mycancercircle.lotsahelpinghands.com



QUICK REFERENCE

Below is a recap of the general strategies that can help you as a caregiver manage your and your loved one's financial and legal concerns. Check those that you would like to try with your loved one. You can use this page as a quick reference.

- [ ] Determine if you and/or your loved one qualify for Medicare, Medicaid, and other financial assistance programs. (Page 18:5)
- [ ] Ask about reduced medication costs. (Page 18:7)
- [ ] Set up payment plans with your health care provider to avoid paying all medical costs upfront. (Page 18:7)
- [ ] Help your loved one create a financial plan to budget expenses and determine the level of financial assistance needed. (Page 18:8)
- [ ] Develop a system to routinely track and manage your finances. (Page 18:8)
- [ ] Address medical debt by communicating with your loved one's cancer care provider and exploring other sources for financial help. (Page 18:9)
- [ ] Know your options and rights for keeping employer-sponsored health care plans, including COBRA and HIPAA laws. (Page 18:10)
- [ ] Stay prepared by setting up a financial power-of-attorney to handle your loved one's financial matters and guardianship of children. (Page 18:11)
- [ ] Help your loved one prepare a legal will to record their wishes regarding finances, assets, and other non-health related matters. (Page 18:12)
- [ ] Help your loved one set up Advance Health Care Directives to record their wishes for future care. (Page 18:12)
- [ ] Ask the cancer care provider for guidance/advice on handling medical expenses, including connecting with a social worker. (Page 18:13)
- [ ] Involve family and friends who wish to help. (Page 18:13)

Resources & Links

- Medicare Advantage plan: www.medicareadvantage.com
- Medicare Extra Help program: www.ssa.gov/benefits/medicare/prescriptionhelp
- Medicaid: www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you
- COBRA: www.dol.gov/general/topic/health-plans/cobra
- ACA and health care plans: www.dol.gov/general/topic/health-plans/consumerinfhealth
- SNAP: https://www.fns.usda.gov/snap/supplemental-nutrition-assistance-program
- Legal will: https://info.legalzoom.com/article/how-make-my-own-will-free-charge
- Health care costs: www.cancer.net/all-about-cancer/managing-cost-cancer-care
- Crowdfunding sites: www.gofundme.com
- My Cancer Circle: www.mycancercircle.lotsahelpinghands.com
- Cancer Legal Resource Center: cancerlegalresources.org

YOUR GOALS & STRATEGIES

What strategies make the most sense to you? How can you and your family use those strategies in your own life?

Create a Plan:
Think about specific goals you want to accomplish. Just tackle one or two goals at a time.

My goal is to _____(what do you hope will happen) **by** _____(timeframe) **so that** _____(why it's important).

What specific strategies will you use to reach your goal? Think about the very next steps you can take to get started.