

Financial Handbook



For cancer patients and caregivers,
by cancer patients and caregivers.

Financial Handbook

A resource for cancer patients and caregivers, by cancer patients and caregivers.

Whether you are a caregiver or a patient yourself, you are facing the anxiety that comes with a cancer diagnosis. One concern you may have is how you will manage your finances throughout and beyond treatment. At Family Reach, we have been helping families manage the financial burden that accompanies cancer for the past twenty years. We know that you did not ask for this burden, and that you're likely feeling unprepared for what's next – and that's why we created this Financial Handbook. Inside, you can expect to learn about potential financial challenges, how to identify roadblocks and where and how to seek financial support. We will also share some tips and tricks from the patient and families who have received our help along the way. By reading this guide, you should feel prepared for what's ahead and empowered to advocate for your family's financial health.

“You are not in this alone. Lean on those who have traveled a similar path. Don't be afraid to ask questions and ask for help. People often want to help, but don't know what your needs are. Tell them.”

- Alice Beauregard, Family Council member, former Family Reach grant recipient

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I. Misconceptions About Cancer's Financial Burden and Available Assistance

"Being prepared to ask for help if you find yourself in need is the best thing you can do."



First and foremost, when it comes to cancer, **don't be ashamed or embarrassed to talk money. You are not alone.**

Many families are embarrassed to talk money when facing a cancer diagnosis – and we don't blame them. Personal finance is not discussed on a daily basis, so we don't expect you to feel ready to share these private details right away. But the reality is, financial hardship can hit your family and there are resources to help you. Being prepared to ask for help if you find yourself in need is the best thing you can do.

Some other misconceptions we want to address early on include:

- **"We are a middle class family with savings and have health insurance – we will be okay!"** Unfortunately, this is not always the case. Some families expect to get through cancer without any financial challenges, but then find that loss of income and daily costs not covered by insurance can drain their savings. We'll share what we've seen families struggle with so that you have an idea of what might affect you.
- **"Only low-income families qualify for financial assistance."** False! While there will always be some restrictions, resources are available to families from all socioeconomic backgrounds. The first step is to ask your social worker for help in identifying what might be best for you.
- **"If I don't pay my hospital bill right away, they will stop treating me or my loved one."** You will not be refused care if you do not pay a medical bill right away. Rather than draining all of your savings, make sure you talk to your hospital billing office about setting up a payment plan.
- **"When I find help, I can go back to them when I need them again."** Most organizations and foundations provide assistance on a one-time basis. Resources in this area are not unlimited. Any financial assistance you receive will not replace an income. Plan ahead and space out assistance.
- **"If another family qualified for help, I will qualify for help from the same program."** Organizations have very specific guidelines that they use to determine who is eligible for financial assistance. Though it can be helpful to speak to other families, don't assume that just because you or your loved one has the same diagnosis that you will qualify for the same programs.
- **"My immigration status will be compromised if I apply for financial assistance."** In many cases, this is untrue. Organizations and foundations that provide financial assistance are not affiliated with the government. Don't be afraid to ask an organization about their privacy policies.
- **"I have a private insurance plan, so I won't qualify for any type of assistance."** Some organizations, including Family Reach, will provide financial support to cover bills regardless of your insurance coverage status and plan.

II. Breaking Down the Cost of Cancer in Easy Terms



There are generally four ways to classify costs as it relates to serious illness. These costs are important to understand as you prepare for potential changes in your financial situation.

- **Direct Medical Costs:** Hospital or treatment center bills that cover visits, scans and surgeries, chemotherapy, radiation, doctor fees and medication or prescription drug costs. Any bill that comes from your insurer or your hospital or treatment center is a direct medical cost. Your insurance may cover some, but not all of these costs.
- **Out-of-Pocket Costs:** From your Direct Medical Costs come Out-of-Pocket Costs, which are your expenses for medical care that are not reimbursed by insurance. Out-of-pocket costs include deductibles, coinsurance, and copayments for covered services plus all costs for services that aren't covered.
- **Non-Medical Costs:** Includes but not limited to, transportation to and from treatment, over the counter medications, childcare, home care, medical devices and supplies, parking, treatment related hotel stays, therapy (physical & psychological), fertility treatments. A lot of added cost comes out of this bucket, so start tracking your spending right away.
- **Daily Living Expenses:** Basic life needs such as food, housing, utilities, transportation, childcare, parking. Prepare for an increase in these expenses and track them along with your non-medical costs.
- **Summary of Benefits & Coverage:** A short, plain-language overview of your insurance plan, including an outline of your coverage benefits, out-of-pocket expenses and exclusions. The Affordable Care Act standardized this document to ensure that within all commercial and employer-based health plans, you can easily compare and contrast various plans. This is not a substitute for the full-length document which defines your complete coverage benefits, provided to you by your insurer.
- **Deductible:** The amount you pay for covered healthcare services before your insurer begins to pay. Typically, you must reach your full deductible amount before your insurance will cover any of the costs associated with covered services (excluding preventive services).
- **Out-of-Pocket Maximum:** The most you'll have to pay for covered services in a policy period before your insurer will pay 100% of the cost toward covered services. Typically includes your deductible and additional patient responsibility elements like copayments and coinsurance. Premiums and un-covered services do not count towards your out-of-pocket maximum.

Thanks to our partners at the Patient Advocate Foundation for sharing their glossary with us. For more, visit www.patientadvocate.org/glossary.

III. Identifying Your Personal Roadblocks

“We weren’t expecting this whole other level of stress that comes along with a cancer diagnosis. Every trip to my daughter’s appointments, every tank of gas, every snack at the hospital cafeteria, every prescription, every bill that arrived in the mail felt completely overwhelming. Money became such a huge worry for us that I felt like we were never able to just focus on our daughter getting better.”

– Jennifer Watson, Family Council member, former Family Reach grant recipient



Loss of Income: Cancer treatment is a trying process and that can require an immense time commitment. Often a family member and caregiver is forced to take an extended leave of absence, or leave work entirely to maintain care of the patient and focus on their health and well-being. This interruption or loss of income, coupled with medical bills directly impacts the household. Costs increase as treatment is extended, if there are treatment complications, or if the cancer comes back.

Increase in Daily Living Expenses: You may experience additional childcare costs and travel costs, depending on your family size and where you live. When you have your treatment plan, take a look at how often you’ll have to be at the hospital and consider what additional costs you might incur from gas and parking. If you need to be at the hospital three times a week for a full day, who can step in to help with additional childcare needs and what will that cost? If you don’t live near your treatment center, it’s worthwhile to estimate how much you’ll be spending on gas, parking and tolls for your visits each week.

Direct Medical Costs Can Vary: Your medical bills will continue to fluctuate, depending on a number of factors. Your length of treatment, a relapse, a sudden surgery or a scan can make it hard to plan for a set end date. Treatments get delayed for a number of reasons, so the best thing you can do is plan as far ahead as possible.

Know Your Health Insurance Plan: It’s important to understand how your health insurance policy works to receive all of the benefits you and your family are paying for. Review your policy to understand what will be covered and if you need to take any additional steps to ensure maximum coverage. Ask your insurance company if they can assign you a case manager to help. Ask your social worker if he or she can help or lead you to a resource if you don’t have time to connect with someone from the insurance company.

Are Your Doctor and Hospital In Your Plan: Be sure to reach out to your insurance provider to determine if your doctors and treatment center are part of your care network. This is crucial when considering the cost of co-pay, deductibles and “out-of-network” costs.

Being aware of these potential challenges is the first step you can take to get ahead of your finances when facing cancer. The next step is to find help – and there are many people you can turn to.

IV. Where to Turn for Help: Know Your Team!

Where to find a social worker:

You were likely assigned a social worker when you were first admitted to your hospital or treatment center. If you have not yet met your social worker, ask your doctor, nurse or receptionist to send them your way.

Where to find a resource specialist:

Not all treatment centers have a Resource Specialist, but asking your social worker if you have one won't hurt. If you don't they can let you know where else you might be able to turn for help if they themselves cannot help you.

Where to find a Nurse

Navigator: Not all hospitals have nurse navigators, so check with your doctor or social worker. For more information, visit www.aononline.org.

Where to find a Patient

Navigator: Your hospital may have navigators available to you on site, so check with your social worker. If not, there are options at outside cancer organizations. A great place to start is the American Cancer Society or the Patient Advocate Foundation.

Remember, you are not alone. Although cancer can be a lonely and isolating experience, there are resources available to help you navigate the twists and turns you will face. Do not wait until you are in desperate financial hardship before seeking support. From your peers, to the hospital, to your employer, below is a list of resources that might be available to you.

- **Social Workers:** These specialized clinicians help families cope with every part of the cancer journey – from understanding the diagnosis and treatment plan, to navigating financial, social, and emotional issues, to assisting with the patient's transition back to school, work and regular activities after his or her care is complete. You can ask your social worker to connect you with available resources to help with financial challenges and help you navigate the unique resources available in your hospital or treatment center.
- **Oncology Resource Specialist:** The Oncology Resource Specialist can answer questions about transportation options for cancer patients and local lodging for patients and their families during treatment. They will also help navigating many of the resources we address in this guide, including government and organizational support.
- **Nurse Navigator:** A nurse navigator is a registered **nurse** who is dedicated to guiding you and your family through treatment, surgeries and beyond. If you do have a Nurse Navigator, this person will likely be by your side a majority of the time that you're on site at the hospital or treatment center. They will offer education and resources to facilitate informed decision making and access to quality health and psychosocial care throughout all phases of the cancer continuum.
- **Patient or Financial Navigators:** Patient Navigators (or Financial Navigators) guide patients through the complex healthcare system and typically focus on medical costs and insurance. They are trained to help you shop for insurance, and can assist with enrollment forms or plan options. Navigators are unbiased and work to help you find the best health plan for your needs.

Where to find Hospital

Financial Services: Ask your social worker if this resource is available to you.

Where to find a Peer:

Some hospitals offer peer-to-peer matching or support groups to ensure that you are connected with someone similar to you. At Family Reach, we can connect you with members of our Family Council. These former Family Reach grant recipients know better than anyone what it means to be in financial distress and will happily share their experience with you.

“Be strong enough to stand alone, smart enough to know when you need help, and brave enough to ask for it.”

– Shauna McLaughlin, Family Council member, former Family Reach grant recipient

- **Patient Billing / Hospital Financial Services:** Remember, your hospital will not refuse to treat you if you don't pay your bills right away. That said, your account should be kept in good standing. A payment plan can have many benefits including discounts on the total amount you owe. Many hospitals have billing departments that will meet with you and set up a plan that works well for your individual circumstances. Some even offer meetings with a Financial Counselor who will work closely with you on your insurance, cost obligations and identifying the right resources for you.
- **A Peer Caregiver or Patient Perspective:** With struggle comes experience. A patient or caregiver that has been down the same road as you can be a good resource. Do not hesitate to reach out to those around you in your treatment center or hospital. Just remember that they are not certified professionals, so take their advice as just that – advice – and use it to guide your next conversation with your social worker.
- **Family/Community:** This may sound obvious, but reach out to your local community! If family and friends want to help, ask them for gas cards, parking passes or food gift cards for restaurants near home or treatment center. Babysitting and carpools are also great ways for friends and families to help out that will offset costs. Websites such as MealTrain.com can help friends and family by creating a schedule of when they can prepare meals for your family. Like all support, we recommend being honest with your friends and family about needing to spread out your resources. Many people want to help when a diagnosis hits or treatment first starts, but the more you can spread out this support, the more impactful it will be.
- **Human Resources:** Your colleagues in your Human Resources department can help navigate employment and insurance related concerns. When you or your family member is diagnosed, meet with HR as soon as you can. You can ask about your Paid Time Off (PTO), if it's possible to set up a flexible schedule or reduce hours. Some employers even offer a shared PTO plan that allows other employees to donate their PTO (vacation and sick days) hours to you. Honesty is the best policy with your HR department, so come prepared to share all of the information they will need to advocate on your behalf.
- **Patient Assistance Programs:** Pharmaceutical companies sometimes offer discounted or free access to their products. If you know the name of your drug, you can search to see if they offer this type of assistance. These plans do have some restrictions, so your healthcare team can help you determine if you qualify.

V. Tips From Patients and Caregivers Who've Been There

“Never allow fear or embarrassment to prevent you from bringing up cost with your health care team.”



Over the past twenty years, we have seen families from all over the country and varying socioeconomic brackets reach out for help. These families have pulled together a list of their top tips that helped them stay afloat.

- **Advocate for Your Financial Health!** If you remember one thing from this handbook, let it be: never allow fear or embarrassment to prevent you from bringing up cost with your healthcare team. Often, doctors won't directly ask about financial concerns, so it can be up to you to start the conversation. Your social worker, patient navigator, and insurance company can also all provide guidance in this area.
- **Prepare and Plan**
 - **Upon diagnosis, start tracking your spending** (all of your direct and indirect medical costs).
 - **Set up a budget.** Visit www.familyreach.org/financial-edu for links to budget templates that our families have found useful.
 - **Contact and update your creditors,** and set up payment plans on all outstanding debt to continue a strong credit history.
 - **Meet with your hospital billing office** to learn about your options for setting up payment plans.
 - When you learn about opportunities for financial assistance, **spread out what you request** across the expected treatment course.
- **Fundraising*:** There are websites you can use to crowd fund through friends and family to help support your expenses. These sites allow you to easily set up a fundraiser, share your story and access the funds raised right away. Be cautious and take the time to educate yourself on all aspects of these platforms. They often have services fees, but many consider it well worth the fee as these fundraisers are easy, often successful and provide an option for families and friends that offer to help. The **majority** of donations you receive through these sites are considered “personal gifts” and typically are not taxed as income. There are always exceptions. If you're receiving government assistance like Medicaid, funds from these websites could be considered income, which may impact your Medicaid status. It is important that you consult with your tax adviser for additional information regarding this type of contribution and to keep close track of all donations made to you or your family.
- **Create a Payment Plan:** If you have a large hospital bill, co-pay or deductible, you can create a payment plan at most hospitals to pay a portion of your bills and keep your account in good standing. If you show good faith of payment you can then prioritize your crucial bills - housing, utilities, transportation, and food.

“If you have one month where you feel more financially sound than another, take advantage by saving what you can.”



- **When You Need Help:** You may find that there are times throughout treatment where your income or expenses are more impacted than others. Your employment status may change or non-medical costs (like heat) may increase during certain times of year. If you can, meet with a financial professional early on, as he/she can assist you in creating a plan to manage your expenses throughout the entire treatment process. Your social worker can also connect you with helpful outside resources.
- **Managing Your Leave from Work:** After you meet with HR, try your best to spread out the PTO you have been allotted to keep an income as long as possible. Leverage friends and family where possible to help manage your time. Enroll in intermittent FMLA - find ways to work on the days that you can, starting very early on. Where possible, many families will prioritize one parent's job to ensure security of their primary income and insurance source.
- **Put Money Away:** As often as you can, put a little money in savings. If you have one month where you feel more financially sound than another, take advantage by saving what you can. This will help offset the tougher financial months down the line.
- **Take Care of your Needs:** It's important to know when you should ask for help in coping with stresses that may arise outside of the financial space. Many families face psychosocial or physical challenges as a result of a cancer diagnosis. Talk with your healthcare team to learn more about support groups, individual counseling or peer-to-peer support. Cancer impacts the whole family, and resources are available not only for patients and caregivers, but for siblings and other loved ones, too.
- **Bankruptcy:** Not all families fighting cancer consider declaring bankruptcy, but if you find yourself at risk, be sure to talk to a financial professional to better understand that process and the consequences of doing so.
- **Health Insurance Appeals:** If your health insurance denies coverage for your cancer care, you can and should appeal. Read every bill or letter that comes from your health insurance company carefully. When you see a denial of coverage, call your insurance company or visit their website to determine how to appeal. If you have a financial navigator, they can help with this process.

VI. Knowing Your Rights As Citizen and Consumer



Family Medical Leave Act: www.dol.gov/whd/fmla

The FMLA gives certain employees the right to take up to 12 weeks of unpaid, job-protected leave per year. It also requires that the employee's group health benefits be maintained during the leave. FMLA applies to all public and private employers with 50 or more employees.

Typically an employer will require 30 days notice for FMLA but in the case of sudden illness 1-2 days notice. FMLA can also be taken all at once or broken up into smaller blocks of time. You will need "medical certification" or a doctor's note for your employer.

Talk to your Human Resources department about your FMLA rights as soon as you are able.

COBRA: www.dol.gov/ebsa/publications/cobraemployee.html

COBRA requires continuation coverage to be offered to covered employees, their spouses, their former spouses, and their dependent children when group health coverage would otherwise be lost due to certain specific events. In other words, if you find yourself having to leave your job to care for your child or yourself, you may be eligible to continue receiving your healthcare benefits.

If you decide to leave your job or reduce hours significantly, your health coverage may be terminated. Depending on the details of your health plan, COBRA will allow you to continue receiving coverage even after you leave.

When considering COBRA, you should talk to both your Human Resources team and your social worker or resource specialist at the hospital. HR will provide you with the paperwork and will explain what your COBRA rights are. Your social worker or resource specialist may know some state resources that can help cover the cost of COBRA.

Affordable Care Act / Patient Bill of Rights

In 2010 President Obama signed the Affordable Care Act into law accompanied by a "Patient's Bill of Rights." The Patient's Bill of Rights included the following protections and more:

- Ban on discriminating against patients with a pre-existing condition.
- Ban on insurance companies dropping coverage.
- Ban on insurance companies limiting coverage, choice of doctor, and restricting emergency room care.
- You are guaranteed the right to appeal.
- Young adults can receive coverage under a parent's plan up to age 26.
- Preventative care covered at no cost.

If you enrolled in an ACA plan before early 2017, many of the above protections will apply to you. Please note that the details of both the ACA and Patient's Bill of Rights are subject to change in 2017 and beyond under a new administration, so be sure to stay informed by checking with your social worker or resource specialist.



HIPAA: Protecting your Privacy

You give detailed personal and medical information to your healthcare providers during cancer treatment, so it's important to know that it will remain confidential. Your right to privacy in the field of healthcare is protected under the Health Insurance Portability and Accountability Act (HIPAA).

HIPAA regulates the way healthcare providers, like doctors, pharmacies, and insurance companies, are able to share your Protected Health Information, such as your medical condition as well as your name, address, and Social Security number. To make sure you know about the practices they follow, healthcare providers must give you a notification of privacy practices, explaining exactly how your medical information will be used. HIPAA also allows you the right to access your own medical records, and to request corrections of any errors you find.

Tax Deductions: Budget & Track Your Spending

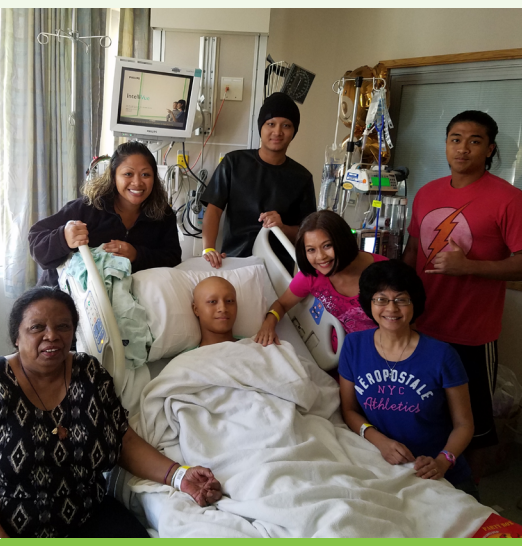
The IRS allows you to deduct qualified expenses you pay for medical and dental care for yourself, your spouse, and your dependents. There are rules that accompany these deductions and Family Reach recommends working with a certified accountant when tax season rolls around to ensure you aren't missing anything. As you get started, the best thing to do is be prepared. As your expenses add up, it is important to track them in detail so that you are prepared for potential deductions. Keep appropriate documentation of the expenses for IRS audit protection purposes and keep the records for at least 3 years.

How to track:

- **Create and maintain a budget.** A budget is a financial plan for tracking the flow of money into and out of your life.
- **There are many online resources to create a budget.** Some of these may also help you track medical expenses. One of our favorites can be found at <http://bit.ly/FRbudget>.
- **Computer software programs such as Quicken's Medical Bill Tracker** (which is marketed as Quicken Medical) are designed specifically for this.
- **Keep a calendar that tracks your mileage,** parking, appointments, number of days in-patient and retain any receipts related to costs on these days. All of these items fall under medical deductions.
- **If you have one, be sure to inform your tax advisor** or accountant that you are facing a cancer diagnosis so that they can help you prepare for your tax return.

VII. Government Resources

“There are many government resources available at both the state and federal level for families facing a cancer diagnosis.”



There are many government resources available at both the state and federal level for families facing a cancer diagnosis. It is important that you speak with your social worker or resource specialist who can help you navigate and quickly identify what you may or may not be eligible for. Programs vary from state to state, so the best thing you can do for your family is to know what programs are out there.

Social Security Administration (SSA) is a federal income program designed to help disabled people with little or no income pay for clothes, food and shelter. They pay monthly cash benefits through two programs:

- **Social Security Disability Insurance**
- **Supplemental Security Income**

For more information, call 800-772-1213 or visit www.ssa.gov or talk to your social worker.

Medicaid is run by your state's government so it is again very important to speak with an expert on your healthcare team. At a minimum, Medicaid will often help cover co-pays and deductibles that private insurance requires. A common misconception for many patients or families is a fear of making too much money to qualify for Medicaid. This is often not the case, and in many states patients are eligible for Medicaid based on diagnosis and despite their income level. You should consider applying, especially if you've lost income as a result of diagnosis.

Food Costs: There are government programs available to help with food costs. Your marital status, income level and health will impact whether or not you qualify for these programs. Some families may be eligible for more than one.

- **Supplemental Nutrition Assistance Program or SNAP** (formerly the Food Stamp Program). It allows people to shop for food in grocery stores using a special Electronic Benefits Transfer card, much like a bankcard.
- **Food Distribution Programs** (these programs distribute food directly to needy families):
 - **Commodity Supplemental Food Program (CSFP)**
 - **The Emergency Food Assistance Program (TEFAP)**
 - **National School Lunch Program**



- **WIC:** WIC provides supplemental foods, healthcare referrals and other support to low-income pregnant, breastfeeding, and postpartum women, and to infants and children up to age five who are found to be at nutritional risk. WIC offers a pre-screening tool online that takes about fifteen minutes to complete. To find out if you are eligible, visit <http://bit.ly/wicscreening>.

Utility Costs: The Low Income Home Energy Assistance Program (LIHEAP) is a federal program that assists eligible low-income families with heating and cooling energy costs. For more information about LIHEAP, you can call the National Energy Assistance Referral (NEAR) project. NEAR is a free service providing information on where you can apply for LIHEAP. You can speak to someone at NEAR Monday through Friday, from 7 a.m.- 5 p.m. (Mountain Time). You can call the toll-free phone number at: 1-866-674-6327 or send an e-mail to energy@ncat.org.

Your local utility company may also have a program for low-income families, so try contacting them directly, too.

VIII. Foundation & Organizational Resources

National and local foundations and nonprofits can be fantastic resources for support during cancer treatment, for financial assistance and a number of other challenges. Given the volume of organizations dedicated to cancer patients and their families, an easy first step is to work with your social worker or resource specialist to identify which of the many organizations could best support your unique family situation.

**Disclaimer: We are not financial advisors. All information was collected from the patients and families we serve and is vetted by social workers from our national partner hospitals. To learn more, please visit www.familyreach.org.*



X. Acknowledgments

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