

ENGLISH

Your Financial Guidebook for Pediatric Cancer



This guidebook is offered by Family Reach and The LiFT Network to help parents and caregivers of children with cancer manage the financial side of the diagnosis.

About Family Reach

Family Reach is a national 501(c)(3) nonprofit organization dedicated to removing the financial barriers standing between a cancer patient and their treatment. Loss of income, out-of-pocket expenses, and socioeconomic factors create disparities in the financial burdens families face. Family Reach delivers financial education, financial coaching, resource navigation, and emergency relief funds to patients and caregivers facing a cancer diagnosis so no family has to choose between their health and their home.

The LiFT Network powered by Family Reach

Uniting members in the fight against the financial burden of cancer, The LiFT Network is a pioneering collective of cancer nonprofits from all corners of the nation. Together, the members distribute Family Reach's Financial Treatment Program to cancer patients and their families.

This guidebook is part of the Financial Treatment Program. Please visit [**www.familyreach.org**](http://www.familyreach.org) to learn more.

Thank you to our partner and guidebook sponsor



we know.

Overwhelmed, confused, sad, angry –
whatever you're feeling right now,
it's valid.

We understand that you might not
have the energy for more information
right now.

All we ask is that you take this guidebook home.
When you're ready, it will help you manage your
money to prepare for what's ahead.

It doesn't have to be today, tomorrow, or even this
week. You don't have to get through it all at once.
You don't have to carry any blame or shame. None
of this is your fault.

Just know that this guidebook is here to help.

Sincerely,
Family Reach

Table of Contents

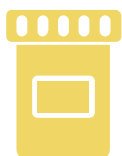
3	A Clinical and Financial Journey
5	Checklist of Expenses
11	Step 1: Determine Your Child's Treatment Costs
12	Step 2: Consider Prescription Costs
13	Step 3: Calculate Insurance Coverage and Options
16	Step 4: Account for Additional Financial Costs and Your Assets
20	Step 5: Learn the Laws That Can Help You
23	Mark Your Calendar
25	Notes
29	Conclusion
30	Financial Resources
35	Thank You, Contributors and Reviewers + References

Resource Key

Throughout the guidebook, you will see these colors and icons. They indicate a specific type of financial resource to help you pinpoint the most useful information for your biggest needs and concerns.



Medical/Treatment Costs



Prescription Costs



Guaranteed Out-of-Pocket Costs

A Clinical and Financial Journey

Before we get into the details, let's start with some context.

People often refer to cancer as a journey. It starts with learning about your child's diagnosis and continues as you learn more about their health, meet their care team, and begin treatment.

Far from a straightforward path, your child's cancer journey may take unexpected turns and hit roadblocks, such as negative side effects to treatment, surgical complications, dietary issues, or anxiety. While supportive therapies will help reduce your child's physical and emotional reactions to treatment,¹ caregivers don't always realize that some of these roadblocks can be financial barriers.

In reality, the financial side effects of cancer can impact your family's quality of life as well as your child's ability to access treatment.² The American Society for Clinical Oncology advises clinical teams to inform caregivers about the cost of treatment³, although the financial side of cancer is often overlooked or not considered until families are in the thick of financial distress.

"Journey" may feel right for your family, or you might find other words that resonate more. The important thing to remember is that financial burdens can play a significant role in your family's experience with cancer. Not because you did anything wrong, but because it's the reality for any family facing cancer. No two cancer experiences are the same, but feeling the financial side effects is not something only your family will experience.



Nearly 1 in 3

families are unable to meet their own basic needs while a child is in treatment.⁴

Using this guidebook

- » Please know that if you're worried about being able to afford your child's care, you're not alone and you don't have to feel ashamed. This guidebook will advise you on how to alleviate the financial pressure so you can focus on what you do best: Showering your child with love and being their rock when things get tough.
- » This Financial Guidebook includes the costs you should consider, savings options, and financial resources to help you manage your money while your child goes through treatment.
- » Don't worry about completing the action items all at once, especially because you may need to reach out to different people for information, start ongoing conversations, or revisit sections at a later date. Go through the guidebook at your own pace, taking breathers whenever you need them.
- » You don't have to go through the guidebook alone. Your trusted loved ones, Family Reach Resource Navigators, child's social worker, Child Life Specialist, hospital billing department, and the rest of your care team are also there to help.
- » Don't wait until you have financial problems to read through this guidebook or talk about cancer costs with your child's care team. Armed with knowledge and resources, you can preserve your family's financial health before it gets in the way of your child's healing.



Mars

This Guidebook helps parents like me prepare for what they're about to take on financially and highlights many of the challenges that we don't immediately think about when entering uncharted territory.

Checklist of Expenses

You can use the checklist on the next page to help you keep track of your costs. There are some examples on this page for you to reference when filling out your own.

Don't worry about filling in all the blanks at once, and feel free to ignore the ones that don't apply to you. You also don't need to know exact numbers - estimates are absolutely fine for helping you get a big-picture view of expected costs.

If your child has health insurance and their services, prescriptions, and providers are considered in-network, the most you will pay each year is the sum of your monthly premiums and out-of-pocket maximum. For example:

	Month	# of months	Yearly total
Monthly premiums	\$400	12	\$4,800
Out-of-pocket maximum	Varies*	Varies**	\$8,200**
The most you will pay for covered medical services in a year			\$13,000

* When you pay your out-of-pocket maximum will depend on your health insurance coverage and when you have medical services. Your deductible, coinsurance, and copayments generally count toward your out-of-pocket maximum for the year. After you reach your out-of-pocket maximum your insurance company pays 100% for covered services.

** \$8,200 is the out-of-pocket maximum for an individual plan in 2020 under the Affordable Care Act.

You can find more information about what you can expect to pay at www.healthcare.gov.

You will also have treatment-related costs that are not considered medical expenses, but can add up over time. Planning ahead can help you find ways to pay for these costs. For example:

	Unit cost	# of units	Yearly total
Parking at hospital	\$25 per visit	20 visits	\$500

Helpful tip: If your monthly expenses and/or your child's treatment plan or insurance coverage change, you can go to www.familyreach.org/downloads to print out as many fresh versions of the Checklist of Expenses as you would like.

Tear the next two pages out!

Checklist of Expenses

If you have health insurance, use this table to estimate the most you will pay each year for your medical expenses.

	Month	# of months	Yearly total
Monthly premiums			
Out-of-pocket maximum			
Medical costs not covered by insurance			
Out-of-network care and services			
Medications			
Quality of life expenses			
The most you will pay for medical services in a year			

Use this table to estimate your child's treatment-related costs that are not considered medical expenses. The blank rows are there for any costs related to your treatment that aren't already listed.

	Unit cost	# of units	Yearly total
Parking at hospital			
Meals at hospital			
Scarves, hats, wigs, etc.			
Nutritional supplements			
Wheelchair/access modifications			
Counseling			

Knowing the total costs that you usually pay to maintain your home and lifestyle will help you plan for the added costs of cancer treatment. Use this table to estimate those typical costs.

	Month	# of months	Yearly total
Mortgage or rent			
Electric			
Gas for heat/cooking			
Water and sewer			
Internet			
Cell phone			
Groceries			
Meals Out/Takeout			
Credit card			
Car Insurance			
Gas for car			
Childcare or eldercare			
Subscriptions			
Other loans			
Entertainment/Recreation			
Streaming services (Netflix, etc.)			
Personal care items			
Gifts			

Here's a blank table for any costs that aren't already listed.

	Month	# of months	Yearly total



Step 1: Determine Your Child's Treatment Costs

Once you have an idea of the services your child will have during treatment, you can estimate the medical part of your cancer costs and identify potential areas for savings.

The American Cancer Society estimates that patients can pay anywhere from \$5,654 to \$10,114 in out-of-pocket medical costs for cancer treatment each year.⁵ More often than not, families have to seek financial resources to cover such a high amount. Before you can find those resources, though, you need to know your child's specific treatment plan.

Your total costs will depend on many factors, including:

- The type, frequency, and duration of treatment your child will receive
- The type and frequency of medical imaging your child may need
- The type of anesthesia used in your child's treatments
- The medications your child will need during treatment
- The number of doctors involved in your child's care
- Your child's insurance coverage
- Your child's eligibility for patient assistance programs

Take action

- » Talk with your child's clinical team to understand the type and number of services needed in the coming months.
- » Estimate how much your family will be responsible for paying. Consider factors such as what the copay might be for each oncologist visit and your annual deductible before insurance kicks in.
- » Call your insurance company to understand if your child's providers and services are in-network. If they are out-of-network, ask what percentage the insurance will cover.
- » Ask your child's oncologist if there are alternative treatment options that will still be effective but have lower out-of-pocket costs.
- » Ask the billing department at your child's care center for more guidance on your bills and financial assistance programs.
- » Please note: We will go into more detail about insurance starting on page 13.
- » Enter the information you can on your Checklist of Expenses.



Step 2: Consider Prescription Costs

Prescriptions are part of your child's treatment costs, but it helps to separate them into more specific action items.

If your child's cancer treatment includes prescription medicines, it may be difficult to manage the copay costs associated with the medications. There are many resources dedicated to helping caregivers with prescription costs.

Take action

- » Contact the National Childhood Cancer Society (www.thenccs.org) to ask about getting a discount prescription drug card.
- » Ask your child's doctor for a list of medications they plan to prescribe. Share the list with your insurance company to determine which ones are covered.
- » Speak to your child's oncologist, navigator, or the drug manufacturer directly to find out which medication can be covered by a Patient Assistance Program (PAP). You can also work with an organization like NeedyMeds, Vivor, or GoodRX to find PAPs for your child's medication.
Note: When using a PAP, such as a copay card, funds provided by the drug manufacturer may not be applied toward your insurance deductible. For instance, if your plan has a "Copay Accumulator," you may not be able to use a copay card to cover out-of-pocket prescription costs. It will be helpful to clarify this with your insurance company when looking into PAPs.
- » Talk with your pharmacist about generic versions of your child's prescribed medication.
- » Ask your child's oncologist about alternative medications that may be just as effective, but will cost you less at the pharmacy.



Step 3: Calculate Insurance Coverage and Options

With costs for medication and services in mind, you can determine which of those expenses your family will need to pay. Health insurance is a major part of this calculation.

If your child **does not** have health insurance...

You're technically responsible for paying your child's treatment costs. However, depending on your income, state-specific requirements, work status, and the time of year, your child may be eligible for alternative options, such as:

- Federal insurance programs like Medicaid or the Children's Health Insurance Program (CHIP)
- Health insurance through the Health Insurance Marketplace/Health Insurance Exchange (made available through the Affordable Care Act)
- Free or reduced-cost care through your hospital

Take action

- » Speak with a member of your hospital's billing department or financial office to find out which assistance programs apply to your child.
- » Visit www.healthcare.gov or contact your state's Medicaid office to determine eligibility for Medicaid or CHIP.

What is Medicaid/CHIP?

These "federal-state" insurance programs are available for some low-income children and families. There are federal guidelines to access Medicaid and CHIP, but eligibility will still vary depending on which state you live in.

How can you apply?

1. Visit the Health Insurance Marketplace at healthcare.gov/medicaid-chip or call 1.800.318.2596 and select your state.
2. Speak to your child's social worker or hospital billing specialist for more information.



If your child **has** health insurance...

You aren't responsible for all of your child's treatment costs, but you can expect to pay some of them. Some insurance plans use networks of doctors, hospitals, and pharmacies. Your share of the cost for your child's treatment could be less if you use providers in your network.

Medical costs you may be responsible for include:

- **Monthly premium:** The amount you must pay for your child to stay covered by an insurance plan.
- **Deductible:** The amount you must pay before your child's insurance company will start paying medical bills. Generally, your monthly premium and any copayments you are responsible for will not count towards the deductible.
- **Copayment:** The amount you pay for every health service, procedure, or prescription, typically due at the time of service. Copayments will vary.
- **Coinsurance:** The percentage of the total cost of a service, procedure, or prescription that you pay. It may be difficult to get information on the total cost before your child receives the service, procedure, or prescription. Ask your child's healthcare professional or insurance company to estimate this cost for you.
- **Out-of-pocket maximum:** The limit on what you must pay each year before your child's insurance company starts to pay 100% for covered services.
- **Uncovered medical services, procedures, and prescriptions:** You will need to pay 100% of services that are not covered by your child's insurance company.
- **"Off-label" treatment or medication:** Your child's doctor may prescribe a treatment outside of its FDA-approved indication. This is called 'off-label'. You might be responsible for the cost of any 'off-label' treatments or medications as they may not be covered by your child's insurance company. You may be able to work with your child's doctor to find an alternative treatment option at a lower cost that could be just as effective.

Find out if your child's insurance plan uses a specific network:

1. Call your child's doctor, hospital, or pharmacy to obtain the provider's tax ID number.
2. Contact your insurance company or check their website to see if your child's plan considers these providers "in-network."

Be sure to have your child's insurance card and the tax ID numbers handy!



Take action: Billing

- » Contact the billing office at your hospital and doctors' offices to ask them about an interest-free payment plan for your medical expenses. It is less expensive to pay back the hospital or doctor directly than to pay your medical bills with a loan or credit card that charges interest.
- » Review every bill and letter that comes from your child's health insurance company carefully - including the fine print. If your child is denied coverage for a service or medication for cancer, you can and should appeal. If that happens, you can call your child's insurance company or visit their website to find out about their appeal process.

Take action: Insurance coverage

- » Work with your child's insurance company and healthcare professional to estimate your family's cost for each service and medication that your child will receive. Depending on the insurance, you can request a Case Manager to help you work through insurance-related issues.
- » Review your child's health insurance policy to find out if your child's providers - including hospital or clinic, oncologist, surgeon, and anyone else involved in your child's care - are considered "in-network." Be sure to ask the insurance company if "out-of-network" expenses will count towards the deductible and out-of-pocket maximum.
- » Consider alternative coverage, if necessary. There may be other insurance options, such as Medicaid, CHIP, or coverage through the Health Insurance Marketplace/Health Insurance Exchange (made available through the Affordable Care Act), that would lower your family's overall cost of care. Note that you can only enroll in new health insurance coverage during an "Open Enrollment Period," which occurs towards the end of each calendar year, or a "Special Enrollment Period," if you qualify. Go to [healthcare.gov](https://www.healthcare.gov) or call 1.800.318.2596 to learn about your options.
- » Consider setting up a Flexible Spending Account (FSA) through your employer's health plan. This money can help you pay for copayments, deductibles, some prescriptions, and other medical costs. An FSA can also reduce your taxes.
- » Update the numbers on your Checklist of Expenses based on your child's coverage.



Step 4: Account for Additional Financial Costs and Your Assets

The medical costs are the obvious expenses, but your out-of-pocket costs, unfortunately, won't end there. Be sure to account for these additional costs and your assets.

Non-medical costs

You may encounter some unexpected costs that are linked to your child's treatment, but not considered a true medical expense that insurance can cover. These can include:

- Travel expenses to and from the hospital, such as gas and parking or ride-sharing and public transportation
- Temporary housing near the treatment center, such as a hotel
- Over-the-counter medicines and supplies, such as syringes, gloves, thermometers, masks, monitors, cleaning supplies, or special skincare products
- Clinical trial expenses, such as airfare or temporary lodging
- Food when you and other caregivers attend treatment with your child
- Wigs, beanies, or headscarves
- Books, toys, electronics, and other entertainment for long appointments
- Childcare for your other children when you're at the hospital
- Eldercare when you're at the hospital
- Tutoring if your child cannot attend school during treatment

Note: When accounting for these costs, remember that medical centers in major cities tend to have higher costs for temporary housing and meals.

Benjamin

"It's very difficult to concentrate on the financial issues when your child has cancer - but know that you are not alone and there are true hearts out there waiting to help!"



Everyday living costs

As a caregiver, you may have to stop working to be by your child's side during treatment. Even with flexible working arrangements, taking care of a child during cancer treatment can be mentally and physically exhausting and you may need to take more time off than you originally planned.

This, unfortunately, doesn't mean the bills will stop coming. You will still need to cover your family's typical monthly costs of living in addition to your child's medical bills. This can include:

- Rent or mortgage
- Utilities (electricity, natural gas, cable, Wi-Fi, etc.)
- Car payments
- Public Transportation
- Groceries
- Childcare for siblings, eldercare, or pet care
- Debt (credit card balances, car loans, student loans, equity lines of credit, etc.)

Quality of life costs

There are many costs to consider when living with cancer, and it's still important to enjoy the luxuries of life, make memories, and take your mind off of treatment. These entertainment and recreation expenses are an important part of healing. Depending on what makes you and your child happy, this can include:

- Art/craft supplies, video games, or books
- Meals out with friends and family
- Streaming services, such as Netflix or Spotify
- Shopping
- Traveling
- Sports game or concert tickets

Financial assets

Do you have financial assets that can help you pay for treatment? These may include:

- **Income:** Take into consideration that you may experience reduced income during treatment if you have to take time off work. If you have a partner or another caregiver, they may also have to take unpaid time off work.
- **Bank accounts:** Money in checking, savings, money market, and other accounts is generally easy to access for immediate needs.
- **Health savings account:** Some employers offer this type of savings account, which lets you set aside money on a pre-tax basis to pay for qualified medical expenses. If you have one, now's the time to use it.
- **Flexible Spending Account:** This special account allows you to set aside money to pay for certain out-of-pocket medical costs. You won't have to pay taxes on this account.⁶
- **Fundraising:** For some families, crowdfunding can be a really effective way to rally support from their networks that will help mitigate their financial burdens. There are various platforms to host your fundraiser, such as Gofundme, so be sure to research your options. It's also important to consider the potential unintended consequences of holding a fundraiser, such as eligibility changes for Medicaid and other income-based programs, platform fees, tax implications, or the emotional impact of making medical information public. Triage Cancer has a Quick Guide to Crowdfunding (bit.ly/TriageCrowdfunding), which is a great resource for starting your research.

Take action

- » Talk to your child's clinical team about potential side effects of treatment that may prevent you from working so you can care for your child. This will help you estimate your income during treatment.
- » Speak to your employer's Human Resources department to understand what options you might have. For example, some companies will allow "donated sick leave."
- » Visit www.ssa.gov or call 800.772.1213 to identify government programs that can help you pay for your typical living expenses, such as the cost of food, utilities, and housing. Social Security Disability Insurance and Supplemental Security Income are examples of these programs. Depending on your child's condition and your household income, your child may also be eligible to receive these benefits.
- » Talk to a Certified Financial Planner™ professional for expert advice on managing your finances during cancer treatment. You can request free financial coaching services from Family Reach by visiting www.familyreach.org/ftp or calling 973.394.141.
- » Keep track of expenses that may be tax-deductible, such as durable medical equipment, wigs, and transportation to name a few.
- » Record these additional costs on your Checklist of Expenses.



Step 5: Learn the Laws That Can Help You

Laws are complicated by nature, so we understand that they're quite likely the last thing you want to read about at this moment. But we promise you won't regret learning about these ones.

There are federal and state laws that can protect your assets, employment, and your child's right to access care during cancer treatment. Here are the ones to know:

Insurance Coverage

The Affordable Care Act (ACA) Patient's Bill of Rights

This law offers protections for patients that apply to almost all health insurance plans. Here are the relevant specifics:

- Bans insurers from setting lifetime limits on your health insurance coverage
- Restricts the use of annual limits on health insurance coverage
- Prevents insurance companies from requiring you to get prior approval before seeking emergency care at a hospital outside your plan's network
- Allows children to stay on their parent's health insurance policy up to age 26
- Helps children with pre-existing conditions gain and retain coverage

More information: www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/aca-new-patients-bill-of-rights.html

Consolidated Omnibus Budget Reconciliation Act (COBRA)

This federal law requires employers with 20 or more employees to offer continuation coverage to its employees as well as their spouses, former spouses, and dependent children when group health coverage would otherwise be lost due to certain specific events. Essentially, if you or another caregiver is one of 20+ employees, the insurance you receive through that employer should cover your child during treatment.

More information: www.dol.gov/general/topic/health-plans/cobra

Education

The Individuals with Disabilities Education Act (IDEA)

This nationwide law makes free public education available to eligible children with disabilities, including early intervention, special education, and other related services. It also authorizes grants to state educational agencies, institutions of higher education, and other nonprofit organizations to support this access to education.

More information: www.sites.ed.gov/idea/about-idea/#ADA

Section 504 of “The Rehabilitation Act”

A federal law designed to protect the rights of individuals with disabilities, Section 504 requires school districts to provide a free appropriate public education to all qualified students with disabilities. It ensures your child’s educational needs will be met as adequately as those of students who aren’t going through cancer treatment.

More information: www2.ed.gov/about/offices/list/ocr/504faq.html

Student Loan Deferment Act

If your child is in active treatment for cancer and has federal loans, they may be able to defer their monthly payments until six months after their treatment ends.

More information: www.studentaid.gov/manage-loans/lower-payments/get-temporary-relief/deferment

Employment

Family and Medical Leave Act (FMLA)

Caregivers are eligible for a leave of absence to care for a spouse, child, or parent who has a serious health condition (cancer included), regardless of if they live with you.

This law means that you as a caregiver might be able to take a leave of absence for up to 12 workweeks in a 12-month period when your child is going through treatment. Plus, you can continue group health insurance coverage through your employer under the same terms and conditions that applied before you took the leave.

Note: This law varies by state, so be sure to check the FMLA website to confirm your eligibility.

More information: www.dol.gov/whd/fmla/

Genetic Information Nondiscrimination Act (GINA)

GINA prohibits insurance companies or health plan administrators from requesting your genetic information. It also stops employers from using genetic information when making decisions about terms of employment, including hiring, firing, and promotions. In other words, insurance companies can't say no to you or your children just because you had cancer. And your boss can't let you go because of it, either.

More information: www.eeoc.gov/laws/statutes/gina.cfm

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA guarantees your access to health insurance in certain circumstances, as well as your ability to carry it over to another job. What's more, it prohibits discrimination based on a cancer diagnosis in certain situations and protects your child's medical privacy, meaning all the information surrounding their diagnosis and treatment.

More information: www.dol.gov/agencies/ebsa/laws-and-regulations/laws/hipaa

Mandated paid leave

There are no federal laws in the United States that require employers to provide paid sick leave for their employees. However, it's worth noting because there are state-specific laws for paid sick leave that may apply in your area.

More information: www.ncsl.org/research/labor-and-employment/paid-sick-leave.aspx

Take action

- » Contact the Human Resources Department at your (and, if married, your spouse's) place of employment to learn about how these laws may benefit you during your child's treatment.
- » Visit the Cancer Legal Resources Center's website (www.thedrlc.org/cancer) or call 866.THE.CLRC (866.843.2572) for more information.
- » Visit www.triagecancer.org/statelaws for a list of state-specific laws that may help support you during your child's treatment.



Mark Your Calendar

Keep in mind that some of your expenses will fluctuate throughout the year. We know you have a lot of other things on your mind, so you can reference this list for quick reminders.

Monthly

- How many doctor's appointments does your child have scheduled this month?
- How many rounds of treatment?
- How many times will you need to refill your child's prescriptions?
- Do you plan to work this month? If you have a partner or caregiver, are they working?
- How much leave (sick time, PTO) do you have left?
- How are your other children coping? Do you need to arrange childcare for them when you're at the hospital? Should you take them to a support group, event, or other resource dedicated to helping siblings of cancer patients?
- Do you have any schooling costs, such as homebound or private tutoring?
- Do you qualify for a special enrollment period? This could mean selecting a better insurance plan for your child's needs.
- Review each medical bill and explanation of benefits (EOB) from your insurance company carefully. If a service is denied by your insurance company, you can and should appeal. Call your insurance company or visit their website to determine how to appeal. A financial navigator at the hospital may help you with this process.
- Review your list of care sites and providers, including your anesthesiologist, psychologist, dietician, and anyone else involved in your care, to make sure they are still in your network.
- Make sure the financial assistance programs you're using have the same funding status. You can use this tool from PAN Foundation to sign up for alerts: [fundfinder.panfoundation.org](https://www.panfoundation.org/fundfinder)
- Lean on the financial resources listed in this guidebook to reduce expenses you may be struggling to afford.

Spring

- How will tax season affect your finances?
- Are you a homeowner? Your home may require seasonal maintenance.
- Are you renting a house or apartment? If so, do you need to renew your lease or rental insurance?

Summer

- Do you have other children at home? This might mean additional costs for childcare, camp, food, etc.
- Gas prices may increase during this time of year.
- Your electric bill may increase from air conditioning usage.
- Are you a homeowner? Your home may require seasonal maintenance.
- Are you renting a house or apartment? If so, do you need to renew your lease or rental insurance?

Fall

- Do you have children at home? If so, you may have to consider back-to-school costs.
- Are you a homeowner? Your home may require seasonal maintenance.
- Are you renting a house or apartment? If so, do you need to renew your lease or rental insurance?

Winter

- Your utility bills may increase from heating usage.
- Yearly deductibles will reset in January, meaning increased out-of-pocket costs until your insurance kicks in again.
- Are you a homeowner? Your home may require seasonal maintenance.
- Are you renting a house or apartment? If so, do you need to renew your lease or rental insurance?

Notes

Here's some extra room in case you want to jot down notes, questions, or numbers.

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Conclusion

we know.

You didn't budget for cancer.

No one does.

Hopefully, you feel more prepared to handle the financial impact of your child's diagnosis after making your way through this guidebook. If anything, we hope you walk away with this:

- Cancer will affect you financially. Start preparing sooner rather than later.
- There are lots of resources that can help you save on cancer costs.
- Don't hesitate to bring up your financial concerns with your care team.
- Financial distress is a common side effect. You didn't do anything wrong.

This doesn't have to be the end of your relationship with Family Reach. We can also provide support through free services like financial coaching and resource navigation. We're here to help.

Sincerely,
Family Reach

Financial Resources

You're not alone. The financial burden of cancer can affect virtually any family - no matter the diagnosis, income, insurance, or savings. Don't hesitate to lean on the resources that can lighten the burden.

Care Team

Your child's clinical team can help you manage the financial burdens of a cancer diagnosis and treatment. They may even be able to connect you with resources not listed here. For easy reference, feel free to record their contact information here:

Hospital: _____

Doctors: _____

Social Worker: _____

School Liaison: _____

Child Life Specialist: _____

Other: _____

Financial Assistance

There are nonprofit programs that provide financial relief for various costs associated with your treatment. This is not a comprehensive list, but it will help you get started.

Medical costs

Includes copayments, medications, coinsurance, deductibles, and medical expenses not covered by your insurance company.

CancerCare: www.cancercarecopay.org or 866.55.COPAY

HealthWell Foundation: www.healthwellfoundation.org or 800.675.8416

PAN Foundation: www.panfoundation.org or 866.316.7263

Patient Advocate Foundation: www.copays.org or 866.512.3861

Triage Cancer Quick Guide to Managing Medical Bills: www.triagecancer.org/quickguide-medicalbills

Non-medical costs

Includes transportation, lodging, and other expenses associated with travel to a treatment center.

Cancer Support Community's Airbnb Program: www.cancersupportcommunity.org or 888.793.9355

Family Reach's Zipcar and Hilton Rewards Program: www.familyreach.org or 973.394.1411

Joe's House: www.joeshouse.org

NCCS Transportation Assistance Fund: www.thenccs.org/financial-assistance

Ronald McDonald House Charities: www.rmhc.org

Everyday living expenses

Includes rent, mortgage, utilities, childcare, and other expenses that you typically pay to live in your home or maintain your quality of life.

Alex's Lemonade Stand Foundation: www.alexlemonade.org

Andrew McDonough B+ Foundation: www.bepositive.org

CancerCare: www.cancercare.org or 800.813.4673

Family Reach: www.familyreach.org or 973.394.1411

Hope Portal: www.anddit.com/hope-portal

Low Income Heat and Energy Assistance Program (LIHEAP): www.acf.hhs.gov/ocs/programs/liheap/about

NCCS Emergency Assistance Fund: www.thenccs.org/financial-assistance

Supplemental Nutrition Assistance Program (SNAP): www.fns.usda.gov/snap/supplemental-nutrition-assistance-program

Financial Coaching

Financial coaching is a service that Family Reach developed as part of the Financial Treatment Program to help families overcome financial challenges during treatment. It works by connecting you with a free Certified Financial Planner™ professional who can help you manage your finances and answer any questions you have.

Think of them like an oncologist for your financial health. Here are some of the topics they can help you with:

- Best ways to reduce or negotiate debts (student loans, credit card, medical, and more)

- How to organize and prioritize bills with a personalized payment plan
- Cost-saving options that are specific to your situation

Family Reach's Financial Coaching: *Financial Planning for Cancer*. Apply for the Financial Treatment Program at www.familyreach.org/ftp, ask your social worker to apply on your behalf, or call our team at 973.394.1411.

Income and Employment

Americans with Disabilities Act: www.ada.gov/2010_regs.htm

Cancer and Careers: www.cancerandcareers.org or 646.929.8032

Fair Debt Collection Practices Act: www.consumer.ftc.gov/articles/debt-collection-faqs

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

Government Benefits: www.benefits.gov

Local Benefits: Contact your County Welfare Department or Human Services Office

State-Specific Paid Leave: www.ncsl.org/research/labor-and-employment/paid-sick-leave.aspx

Supplemental Security Income (SSI): www.ssa.gov/ssi

Temporary Assistance for Needy Families (TANF): www.benefits.gov/benefit/613

Triage Cancer: www.triagecancer.org or 424.258.4628

Triage Cancer Quick Guide to Crowdfunding: bit.ly/TriageCrowdfunding

Verywell Health Tax Deductions Guide: www.verywellhealth.com/tax-deductions-for-cancer-patients-2248827

Insurance

Your Insurance

Member ID #: _____

Group #: _____

ACA Patient's Bill of Rights: www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/aca-new-patients-bill-of-rights.html

Children's Health Insurance Program (CHIP): www.healthcare.gov/medicaid-chip/childrens-health-insurance-program

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

Family Reach Financial Navigators: For help assessing your insurance options to lower your share of medical costs treatment, visit www.familyreach.org or call 973.394.1411

GINA: www.eeoc.gov/laws/statutes/gina.cfm

HIPAA: www.dol.gov/agencies/ebsa/laws-and-regulations/laws/hipaa

Marketplace: www.healthcare.gov

Pan Foundation Copay Accumulator Programs Guide: panfoundation.org/files/Info-to-Know_Copay-Accumulators_Web.pdf

Special Enrollment Period: www.healthcare.gov/glossary/qualifying-life-event/

Medication

GoodRX: www.goodrx.com

Medicine Assistance Tool by PhRMA: www.medicineassistancetool.org

National Childhood Cancer Society: www.thenccs.org or 800.532.6459

NeedyMeds: www.needymeds.org or 800.503.6897

Vivor: www.vivor.com/patients

Schooling and Education

While some of these resources might not provide direct or immediate financial assistance, they will help you when developing a long-term game plan, especially as school is so important for bringing a sense of normalcy into your child's life during and after treatment.

The Individuals with Disabilities Act (IDEA): www.sites.ed.gov/idea/about-idea/#ADA

National Children's Cancer Society: www.thenccs.org

Saint Jude's School Support: www.together.stjude.org/en-us/for-families/school

Section 504 of "The Rehabilitation Act": www2.ed.gov/about/offices/list/ocr/504faq.html

Student Loan Deferment Act: www.studentaid.gov/manage-loans/lower-payments/get-temporary-relief/deferment

Transition to College: www.thenccs.org/wp-content/uploads/2017/03/transition-to-college.pdf

Summer Camps and Scholarships

Camp Kesem: www.campkesem.org

Other camps: www.cancer.net/navigating-cancer-care/children/camps-and-retreats-families-and-children-affected-cancer

College scholarships resources: www.chop.edu/health-resources/scholarship-opportunities-survivorship-and-oncology-patients

Wish Granting Organizations

Kids Wish Network: www.kidswishnetwork.org

Make-a-Wish: www.wish.org

Sunshine Foundation: www.sunshinefoundation.org

Recursos en Español

This guidebook is also available in Spanish. You can access it on Family Reach's website or ask your social worker for a printed copy.

CancerCare: www.cancercare.org/espanol

Cancer and Careers: www.cancerandcareers.org/es

GoodRX: www.goodrx.com/es

Beneficios del Gobierno: www.benefits.gov/es/

HealthWell Foundation: www.healthwellfoundation.org/es/en-espanol

Medicine Assistance Tool de PhRMA: www.medicineassistancetool.org/es

Nueva Vida: www.nueva-vida.org or [202.223.9100](tel:202.223.9100)

Social Security Association: www.ssa.gov/espanol or [800.772.1213](tel:800.772.1213)

Triage Cancer: www.triagecancer.org/espanol

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 - More about Coils to Locs: www.coilstolocs.com
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References

1. Cancer Treatment & Survivorship Facts & Figures 2016-2017. American Cancer Society Atlanta: American Cancer Society. 2016.
2. Zafar SY, McNeil RB, Thomas CM, Lathan CS, Ayanian JZ, Provenziale D. Population-based assessment of cancer survivors' financial burden and quality of life: a prospective cohort study. J Oncol Pract. 2015;11(2):145-150.
3. Meropol NJ, Schrag D, Smith TJ, et al. American Society of Clinical Oncology guidance statement: the cost of cancer care. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2009;27(23):3868-3874.
4. Gordon LG, Merollini KMD, Lowe A, Chan RJ. A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay. Patient. 2016:1-15.
5. The Cost of Cancer Care. Addressing Patient Cost. Cancer Action Network American Cancer Society <https://www.acscan.org/sites/default/files/Costs%20of%20Cancer%20-%20Final%20Webpdf> accessed July 30, 2017. April, 2017.
6. Health Care Options, Using a Flexible Spending Account FSA. HealthCare.gov. Accessed June 2019. <https://www.healthcare.gov/have-job-based-coverage/flexible-spending-accounts/>



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