

UW Medicine

Navigating Financial Challenges and Burdens

Christopher Su, MD MPH

Assistant Professor, University of Washington
Assistant Professor, Fred Hutchinson Cancer Center
Investigator, FHCC Hutchinson Institute for Cancer Outcomes Research

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THE NEW YORK TIMES, SUNDAY, NOVEMBER 16, 1997

Conquering Cancer, but Depleting Her Savings

By SANA SIWOLOP

OR Joan Winer Brown, the medical setbacks began in August 1984, when a stray bullet came barreling into her Bronx home, shattering an arm bone.

The next year, Ms. Brown's husband, Thomas, underwent a heart transplant. And two years later, he developed the lymphoma that would eventually kill him.

As for Ms. Brown, she developed cancer in one breast in 1986, and in the second breast in 1993.

ordess in 1998. Who has three children, was Ms. Brown, who has three children, was Ms. Brown, the children was the has fought her illness hard. She has made countess visits to doctors, had 11 years of chemotherapy and had both breasts removed. Now, at age 52, her doctors have stopped the chemotherapy and had she believes she is can-

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START
A periodic
look at
the crossroads
of personal
finance.

But she faces a new specter: rapidly vanishing savings. With a mountain of expenses and a modest salary, Ms. Brown, who now lives in New Rochelle, N.Y., thinks she may go broke in a year or less.

"I need prebankruptcy counseling," she said.
"As hard as I try, I still seem to be short

Ms. Brown's finances weren't as close to the edge in 1988, when she received a 140,000 life insurance payment after the death of her husband. But she used some of it for a down payment on her three-bedroom house and has dipped into the remainder for other reasons over the years. She is down to



A \$1,941 monthly mortgage payment is helping to deplete the savings of Joan Winer Brown, at home in New Rochelle, N.Y., with daughter Deborah and their dog, Skyler.

contracţ, a fixed-income instrument that i the plan's most conservative option.

And her illness still shadows her, financially speaking. She wants to increase her \$110,000 in life insurance, for instance, but that has been impossible because of her medical history.

OW should Ms. Brown grapple with her multiple money problems? The New York Times asked for advice from Percy E. Bolton and Patti Drivanos, planners who specialize, respectively, in financial-crisis counseling and in planning for cancer victims.

Both planners said they thought Ms. Brown's first priority is to cut spending sharply. "Her take-home pay has to take care of her life style; I don't see any other way for this to work," said Mr. Bolton, who works in Los Angeles.

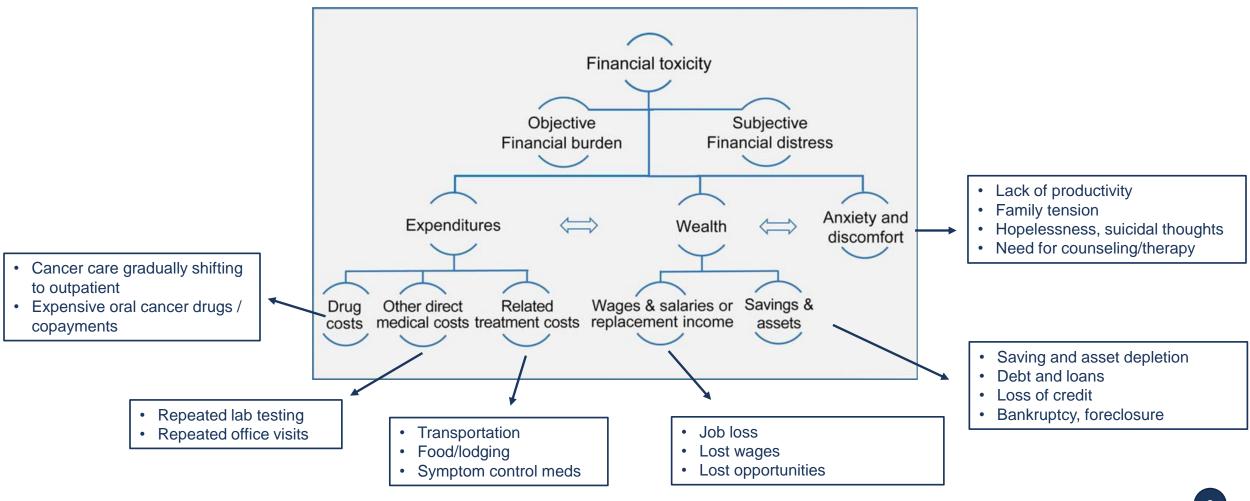
Their biggest recommendation was that Ms. Brown sell her house — which needs work — and move into something cheaper. "She can't afford to spend more than 40

"She can't arrord to spend more than 40 percent of her take-home pay" on housing. Mr. Bolton said. Currently, the mortgage, which carries only modest tax advantages given her low tax bracket, eats up virtually all her monthly pay.

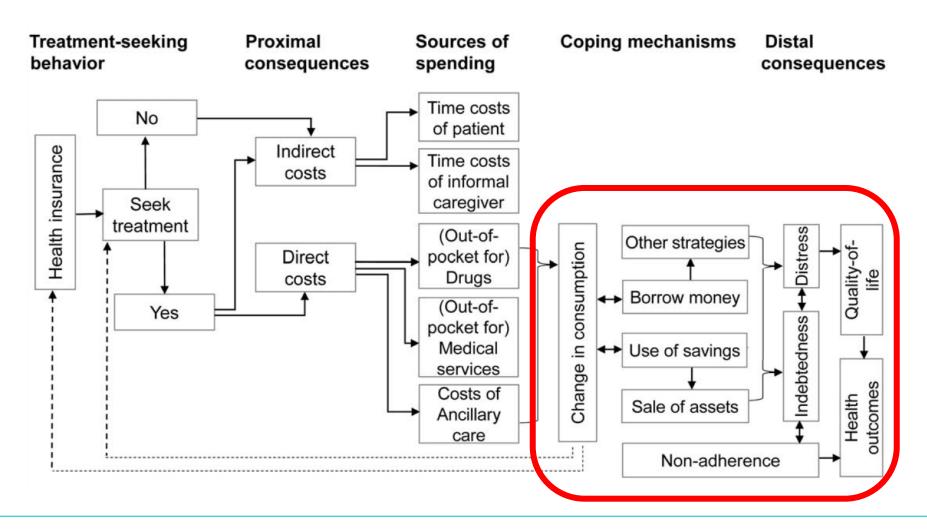
If Ms. Brown can retrieve the \$80,000 of equity that she has in her home, and addit to her \$31,000 in savings, she could have a nice income supplement, the planners said. It her money grew at a rate of just 5 percent, it would mean \$380 more before taxes each month. And if she were to rent an apartment for, say, \$1,000 a month, that would be \$941 less than she pays on her mortgage.

The planners also said Ms. Brown should be financially realistic in spending money on her children. "She's going through the surviving-parent syndrome, which makes "The unintended – but not necessarily unanticipated – objective financial burden on and subjective financial distress experienced by patients with cancer as a result of their treatment."

Financial toxicity is NOT only drug copayment



Consequences of financial toxicity



Impact of Medicare reforms on out-of-pocket cost in 2025

Figure 2 Changes to Medicare Part D for Brand-Name Drug Costs Share of brand-name drug costs paid by:
Part D Plans Drug manufacturers Medicare Inflation Reduction Act Current law: 2023 2024 2025 5% enrollee 0% enrollee 0% enrollee 20% 80% Catastrophic 80% Catastrophic 20% coverage OOP coverage 20% 15% ~\$3,100 ~\$3,250 spending 60% 25% 25% OOP threshold \$2,000 Coverage spending 70% 70% gap 25% cap 5% 10% 5% Initial coverage 65% Initial 75% 75% coverage Deductible 100% 100% Deductible 100%

NOTE: OOP is out-of-pocket. The out-of-pocket spending threshold will be \$7,400 in 2023 and is projected to be \$7,750 in 2024 and \$8,100 in 2025, including what beneficiaries pay directly out of pocket and the value of the manufacturer discount on brand-name drugs in the coverage gap phase. These amounts translate to out-of-pocket spending of approximately \$3,100, \$3,250, and \$3,400 (based on brand-name drug use only).

Helpful Resources

The first step is always to start with your designated **social worker** or **patient navigator** at your cancer center (if at all available) – they are the hub to all resources.

High Hospital Bills

"One thing that I think I'm — I've always been a great payer. I will put my bills before I eat. I will literally go hungry before I will [miss a bill].

The reason why is that if I can't pay my medical bills, then the hospital is not going to treat me."

I need help with...

Unaffordable Hospital Bills

- Washington State Law (RCW 70.170.060) mandates charity hospital care (free – in other words, no out-of-pocket costs) for patients and families making less than 300% of the federal poverty level, and discounts for those making up to less than 400%.
 - 2-person household: \$61,320 (300%), \$81,760 (400%)
 - 4-person household: \$81,760 (300%), \$124,800 (400%)
- However! There is an application process, and details about the charity care program may not be readily apparent even though this language is required by law to be printed on billing statements.
- Hospitals may require you to apply for maximal insurance coverage (for example, Medicaid or Medicare) before being eligible for charity care. Failure to complete application process for insurance may still lead to unresolved hospital bills.
- Discuss any remaining hospital bills directly with the billing department of the medical center.
 - Hospitals can send your outstanding bills to collection agencies, but many are willing to negotiate with you in good faith to set up a payment plan you can afford.
 - Nonprofit organizations like the Northwest Justice Project can help with negotiations or clarifying your rights.
- **DO NOT PLACE ANY MEDICAL BILLS ON CREDIT CARDS.**



Debt and Personal Finances

"Literally, I am living paycheck to paycheck right now. When I started my therapies, I put everything on a credit card, because I'm not going to ask my family for help on that. That was my disease. It was not their burden to carry. So, I'm still paying off credit cards from years of therapies."

I need help with...

Debt and Personal Finances

- Credit card companies may have hardship clauses. A cancer diagnosis may be used to negotiate for an interest pause or a lower interest rate.
- Federal student loans may be forgiven with a cancer diagnosis (filed under permanent disability).
- Financial counseling nonprofit agencies can help with credit card debt negotiations and personal finance restructuring.
 - Many different companies, but important to review nonprofit status – I am working with a non-profit on a financial counseling project for patients newly diagnosed with cancer.
- Common DO NOT's -
 - High-deductible insurance plans (with cancer diagnosis)
 - "Medical expense credit cards"
 - Taking out a personal loan with interest to pay off medical debt
 - Healthcare navigators that require payment
 - Free "medical screening" or "health counselors" at community fairs that require sign-up/disclosure of personal information



Other Resources

"The first 3 years we were dealing with [cancer], we never heated the house. We just had the kids wrap up in blankets, and luckily, we're in the Pacific Northwest, where it doesn't get super cold. There were weeks where it gets down below freezing and we would get one space heater and heat one room. We would all hang out in that room and play games, or watch TV, or whatever we could just to keep warm."

I need help with... Mortgage, Rent, Eviction, or Utilities

- Patients with cancer may quality for mortgage forbearance.
 This places a pause on mortgage payments or a smaller payment might be negotiated. This requires direct communication with the mortgage servicer. A financial counselor may help with the negotiation process if difficult.
- In Seattle, **King County Emergency Services and Solid Ground** can help with navigating impending evictions.
- Seek a second opinion from a nonprofit legal organization for impending evictions (Northwest Justice Project / CLEAR hotline).
- Aged, Blind, or Disabled (ABD) program provides Washington State residents over 65 or have a disabling medical condition with monthly \$450 (single) or \$570 (married) cash grants that can be applied towards rent.
- Housing and Essential Needs (HEN) program provides access to essential needs and limited rental assistance to low-income individuals unable to work in Washington.
- Seattle City Light offers a reduced utility program for families with hardship. Contact your local utility company for similar programs.





I need help with...

Transportation and Lodging

- **Discuss with your social worker** regarding local options for gas cards, transport funds, or donations.
- If you have Medicaid in King/Snohomish Counties, you can use HopeLink for free transportation to appointments.
- Consider a handicapped parking placard (WA State general definition: can't walk 200 feet without stopping) or discounted/free public transit passes.
- American Cancer Society Road to Recovery recruits volunteer drivers to drive patients with cancer to appointments.
- Many hospitals and cancer centers have discounted lodging options for patients traveling beyond a certain perimeter to seek care, but these can book up very early and still be relatively expensive.
- Many hotels within a perimeter from the cancer center have discounted rates for patients and families – call to inquire or ask your local social worker.
- Joe's House is an online guide that compiles lodging options across the US for patients with cancer.



I need help with... Employment and Disability

- Employment and disability are the least straightforward and requires coordination with various governmental offices – can be very slow for approval.
- Family and Medical Leave Act (FMLA) covers eligible employees under covered entities (public and typically large private employers) 12 weeks of unpaid leave a year, with covered health insurance benefits.
- Short (up to 6 months) and long-term disability insurance may continue to pay a portion of salary while disabled (short term disability insurance is often offered as an employment benefit). Even after cancer diagnosis, may still be eligible for coverage depending on treatment and stage of disease.
- Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) provide benefits if disability criteria are met, based on previous work history (SSDI, ends at 65 or return to work) or income level (SSI).
- Non-Grant Medical Assistance (NGMI) is a Washington State program that extends Medicaid benefits for those not meeting disability standards after SSDI and SSI determination.

It is never too early (or too late) to reassess your financial resources and truly understand your current insurance plan, in preparation for a "rainier" day.



Thank you!

I look forward to your questions, hearing about your experience, and learning from you.

Christopher Su, MD MPH chrissu@uw.edu



LEUKEMIA & LYMPHOMA
SOCIETY (LLS) IS AT THE
FOREFRONT OF THE FIGHT TO
CURE BLOOD CANCER.

We are the largest nonprofit dedicated to creating a world without blood cancers.

Since 1949, we've invested more than \$1.7 billion in groundbreaking research, pioneering many of today's most innovative approaches.

LLS is a global leader in the fight against





LLS MISSION

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.



RESEARCH

We are the largest nonprofit funder of blood cancer research, investing more than \$1.7 billion in the most pioneering science worldwide since 1949.





We are the leading source of free education and support for blood cancer patients and families. We provide personalized, one-on-one support, including assistance with identifying and enrolling in a clinical trial.

POLICY & ADVOCACY



With our nationwide grassroots network of more than 50,000 active online volunteers, we drive policy changes that accelerate the development of new cancer treatments and break down barriers to care.



LLS PATIENT RESOURCES

WWW.LLS.ORG



RESEARCHERS & HEALTHCARE PROFESSIONALS

HOW TO HELP

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SUPPORT RESOURCES

EDUCATION RESOURCES

ABOUT LLS

Leukemia

Contact an Information Specialist

COVID-19 Resources

Lymphoma

Financial Support

Myeloma

Online Chats

Peer-to-Peer Support

Support Groups

Myelodysplastic Syndromes

Videos

Myeloproliferative Neoplasms

Facts and Statistics

Caregiver Support

Children and Young Adults

Nutrition Consultations

Newly Diagnosed

LLS Patient Community

Managing Your Cancer

Podcast

Other Helpful Organizations

Treatment Clinical Trials

Suggested Reading

LLS Health Manager App

Informational Booklets

Webcasts

3D Model Library

Drug Listings

Blood Cancer Conferences

For personalized disease, treatment or support information, please contact one of our Information Specialists:

LLS SUPPORT







INFORMATION

RESIGNIFICATION SPECIALISTS (IRC)

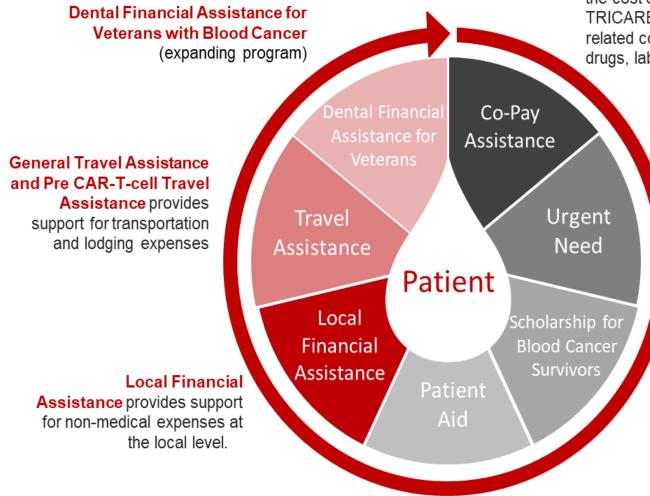
- Monday Friday, 9 AM to 9 PM ET
- Chat Live Online: Monday Friday, 10 AM to 7
 PM ET
- Email: All email messages are answered within one business day
- Leave a message 24/7 and we'll call back!

CLINICAL TRIAL SUPPORT CENTER

Work one-on-one with an LLS Clinical Trial Nurse Navigator who will personally assist you throughout the entire clinical-trial process. Clinical Trial Nurse Navigators are registered nurses with expertise in blood cancers.



FINANCIAL SUPPORT



Co-Pay Assistance provides supports toward the cost of Private, Medicare, Medicaid, and TRICARE insurance premiums, and treatmentrelated co-pays and co-insurance for prescription drugs, labs, scans, tests, etc.

Urgent Need provides assistance, to pediatric, adolescent, young adult and adult patients, in acute financial distress, for non-medical expenses.

Scholarship for Blood Cancer Survivors provides tuition support for virtual or in-person vocational, twoyear, or four-year post-secondary education.

Patient Aid provides a one-time stipend to help offset non-medical expenses



FINANCIAL SUPPORT: LLS PATIENT PROGRAMS

Patient Aid Program	 Offset non-medical expenses No income requirement, patients can be insured or uninsured, or undocumented (must reside in U.S) 	One-time, \$100
Susan Lang Pay-It- Forward Patient Travel Assistance	 Treatment-related transportation and lodging expenses, receive a Travel Credit Card Income requirement, patients can be insured or uninsured 	• 6 months, \$500
Susan Lang Pre CAR T-cell Therapy Travel Assistance	 Patients who are being evaluated to receive CAR T-cell therapy as either standard treatment or a clinical trial Treatment-related transportation and lodging expenses, receive a Travel Credit Card Income requirement, patients can be insured or uninsured 	• 6 months, \$2,500
Urgent Need Program	 Patients in acute financial distress, *HCP must complete* Offset non-medical expenses, received through a check Income requirement, patients can be insured or uninsured 	Yearly, \$500
Co-Pay Assistance Program	 Covers treatment related medical/pharmacy co-pays, premiums, co-insurance Income requirement, patients must be insured Can pay provider directly or reimburse 	Yearly, Funding based on Dx

FINANCIAL SUPPORT

Cancer Care Shouldn't Be a Financial Burden.

Introducing Our Medical Debt Case Management Program



The Medical Debt Case Management Program provides one-on-one, in-depth personalized support to empower patients to address their medical debt.

No patient should be worse off because they received cancer care



APPLY

By Phone: 1-833-507-8036

Monday to Friday: 8:30 a.m. to 5:00 p.m. EST

Online Enrollment Form



INFORMATIONA

LBOOKLETS LEUKEMIA & LYMPHOMA SOCIETY New Day

Ideas for coping with blood cancers



How stress affects you and ways to cope

CANCER AND YOUR FINANCES







LLS Community

A project of the Michael J. Garil

LLS Community is an ordine gathering place for patients. carenivers and healthcare professionals to share experiences and provide support. In addition, LLS provides information and resources to support patients







Help with Finances

The Leukemia & Lymphoma Society (LLS) offers financial assistance" to help individuals with blood cancer Visit www.LLS.org/finances or cell 877.557.2672 to find out about finencial. assistance for blood cancer patients.



The LLS Patient Aid Program provides a one-time \$100 stipend to offset expenses. Visit www.LL5.org/PatientAid

The Medical Debt Case Management Program helps patients address financial concerns, identify resources, assist with insurance plan evaluation, and navigate insurance benefits, denials of care. and out-of-pocket costs. Visit www.LLS.org/MedicalDebt or call The Urgant Need Program provides assistance for non-medical



expenses including housing, trainers patients receive a grant of \$500. Visit www.LLS.org/UrgentNeed The Co-Pay Assistance Program provides financial support toward the cost of insurance premiums and co-pays for prescription drugs. labs, scans, tests, etc. For a full list of covered expenses, visit



The Susan Long Pay-It-Forward Patient Travel Assistance Program expenses. Eligible patients receive a \$500 grant. Visit

Aunding for LLS's Co-Pay Assistance Program is provided by pharmoceutical companie Funding for other LLS financial assistance programs is provided by donations from individual donors, companies, and LLS compaigns.

LEUKEMIA 6 LYMPHOMA SOCIETY

FOOD ASSISTANCE

Millions of Americans are unable to access healthy foods because of finances, lack of

nearby grocery stores and/or transportation

The following resources and tips can help

you save money and access healthy foods.

Meal Planning and Grocery Shopping Meal planning is one way to save time and money

· Create a grocery list based on your meal plan

to prepare for your next grocery trip.

· Research for coupons and sales. At the grocery store

. Stick to your gracery list. . Do not shop while hungry.

or prepared meals.

Before you leave for the store

By planning out each week's breakfast, lunch, and dinner

you can use foods you already have in your home, use

trip to the store, and more easily stick to a grocery list,

leftovers, cut down food preparation time, make just one

which helps you keep to your budget. Here are some tips

. Take note of what food is left in the refrinerator frames and partry. Foods that expire soon should be used first.

- Buy foods in bulk that you eat often or have a longer shelf life

Visit www.foodsafety.gov to learn about safe food storage.

convenience items, such a pre-cut fruits and vegetables

they are often less expensive. Canned and frozen fruits

· Choose fruits and vegetables that are in season as

Make large portions and freeze leftovers to heat up for

- Buy generic (store brands) and avoid buying

and vegetables are also good options.



contact our Spanish-speaking Information Specialists who will connect you to the services you need.

800.955.4572 www.LLS.org





















Schedule a Free Nutrition Consultation

Call: 877.467.1936 - Visit: www.LLSnutrition.org/schedule



Our registered dietitians have expertise in oncology nutrition and provide free one-on-one phone consultations to patients and caregivers of all cancer types.

Consultations may include:

- Answers to questions about nutrition
- Strategies to manage side effects
- Recommendations to improve your autrition
- · Tips for meal planning and grocery shopping
- Information and advice for caregivers
- Questions to ask your healthcare team

Visit www.LLSnutrition.org for nutrition tips, resources, recipes and more

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and mysloma, and improve the quality of life of patients and their families. Find out more at week LLS are

LEUKEMIA 6 LYMPHOMA SOCIETY

Patti Robinson Kaufmann

First Connection® Program



PRODUCE GUIDE

Braccett, Green Beams, Radishes Brubert, Spinach

Summer Avocarios, Ref. Peppers, Berries, Cantaloupe Chemes, Corn, Cucumber Egoplant, Green Beans Okea, Peaches, Plums

COMMUNICATING WITH YOUR HEALTHCARE TEAM

Winter Squash

Winter Beets, Brussel Sprouts, Grapefruits, Kiwis Leeks, Lemons, Oranger Paranips, Pears, Potatoes, Purryskins, Rutabagan, Swi

Side-Effect Management: Memory and Concentration Problems in Adults



PEER-TO-PEER SUPPORT



SPEAK WITH A PEER VOLUNTEER

If you or a family member has been diagnosed with a blood cancer, you may find it helpful to speak with someone who has gone through a similar experience and learned how to manage the same disease you're trying to cope with each day.

BECOME A PEER VOLUNTEER

First Connection® peer volunteers are in a unique position to provide support and community resource information to others facing a similar cancer diagnosis. Patients and their family members are matched with peer volunteers based on diagnosis, age, gender and other factors that might create a mutual understanding and ease of communication.



GENERAL CANCER FINANCIAL SUPPORT &

Talk to a social Worker FIND RESOURCES Ask your healthcare team for a social worker who specializes in cancer support. Be specific about what you

Ask your healthcare team for a social worker who specializes in cancer support. Be **specific** about what you need—co-pay assistance, transportation, housing, etc.

Find Cancer-Specific Organizations

Look for nonprofits that support your specific diagnosis, as they can often direct you to diagnosis-specific resources. Examples:

- Leukemia & Lymphoma Society (LLS) Blood cancers
- PanCAN Pancreatic cancer
- Ovarian Cancer Research Foundation Ovarian cancer
- Susan G. Komen Breast cancer

Find Topic-Specific Organizations

Look for nonprofits that support your specific diagnosis, as they can often direct you to diagnosis-specific resources. Examples:

- CancerCare Financial assistance for patients in active treatment
- Patient Advocate Foundation Help with medical expenses & insurance challenges
- Triage Cancer Helps with general information related to legal and workforce challenges with a cancer diagnosis



- Medicaid & health coverage assistance
- Transportation aid
- Housing support
- Food assistance programs
- Utility payment assistance

Consider the value of offsetting your costs.

If you cannot find a program specific to your financial need, look at other resources that may offset more burdensome costs.

- Local programs offering grocery gift cards if you are not able to cover transportation costs.
- Nonprofits with utility bill assistance to offset the cost of medications/treatment.



INFORMATION

FINANCIAL



PLEASE VISIT OUR











Q&A