Helping Patients Navigate the Cost of Cancer Care

A Quick Guide for Community Health Workers

COMMUNITY HEALTH WORKER
CHW
Oncology-focused Training Program



Community Health Workers, or CHWs, play an important role in helping people affected by cancer navigate the financial challenges of their diagnosis and treatment. What makes you effective is not just what you know, but the trust you have built and your ability to help people feel seen, heard, and supported.

This Quick Guide will help you:

1. Identify when cost is a barrier to care and start the conversation without judgment
2. Connect the person you are supporting and caregivers to financial assistance resources through CSC and partner organizations.

WHAT IS FINANCIAL TOXICITY?

Financial toxicity is the term healthcare providers use to describe the financial hardship and emotional stress that can result from the costs of cancer treatment. It includes not just medical bills, but also lost income, travel costs, medicines, and the stress of trying to pay for care. It is not just about money. Financial stress can affect a person's health, treatment decisions, and quality of life.

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER
GILDA'S CLUB

Studies show that up to **50% of cancer patients face financial hardship related to their diagnosis.** High costs can lead patients to skip doses, delay care, miss appointments, and experience anxiety and depression. When financial stress goes unaddressed, it becomes a barrier to getting well.

As a CHW, recognizing and addressing financial toxicity is part of your role in supporting people affected by cancer.



SIGNS SOMEONE MAY NEED FINANCIAL HELP

Most people affected by cancer will not bring financial concerns up on their own. Watch for these warning signs:

- Asking to "stretch out" a prescription or skipping doses
- Canceling appointments due to "transportation issues"
- Withdrawing from social support or activities
- Mentioning difficulty paying bills, rent, or buying food
- Expressing anxiety about insurance, bills, or employment
- Stopping treatment without a medical reason

You can support people affected by cancer by asking directly: *"I want to make sure nothing is getting in the way of your care, including cost. Is that something on your mind?"*

AREAS TO EXPLORE WITH THE PERSON YOU ARE SUPPORTING:

- Insurance status and any recent changes
- Income or employment changes
- Transportation access to appointments
- Food insecurity
- Housing instability
- Caregiving responsibilities
- Language barriers to accessing services
- Immigration-related fears (if relevant and appropriate to ask)





QUESTIONS CHWS CAN ASK TO OPEN THE CONVERSATION:

Have you skipped or delayed any care because of cost?
Are there medicines or treatments you have not picked up because they were too expensive?
Has treatment affected your work, income, or ability to keep up with bills?
Do you need help understanding your insurance or bills?
Are you having trouble with transportation, food, child care, or other costs related to treatment?
Have you had to reduce your hours or stop working because of your diagnosis or treatment?
Has worrying about costs made it harder to focus on your treatment or recovery?
Is there anyone helping you manage the financial side of this, or are you navigating it on your own?

You don't need to be a financial expert.
Your role is to know when to ask, how to listen, and where to refer.

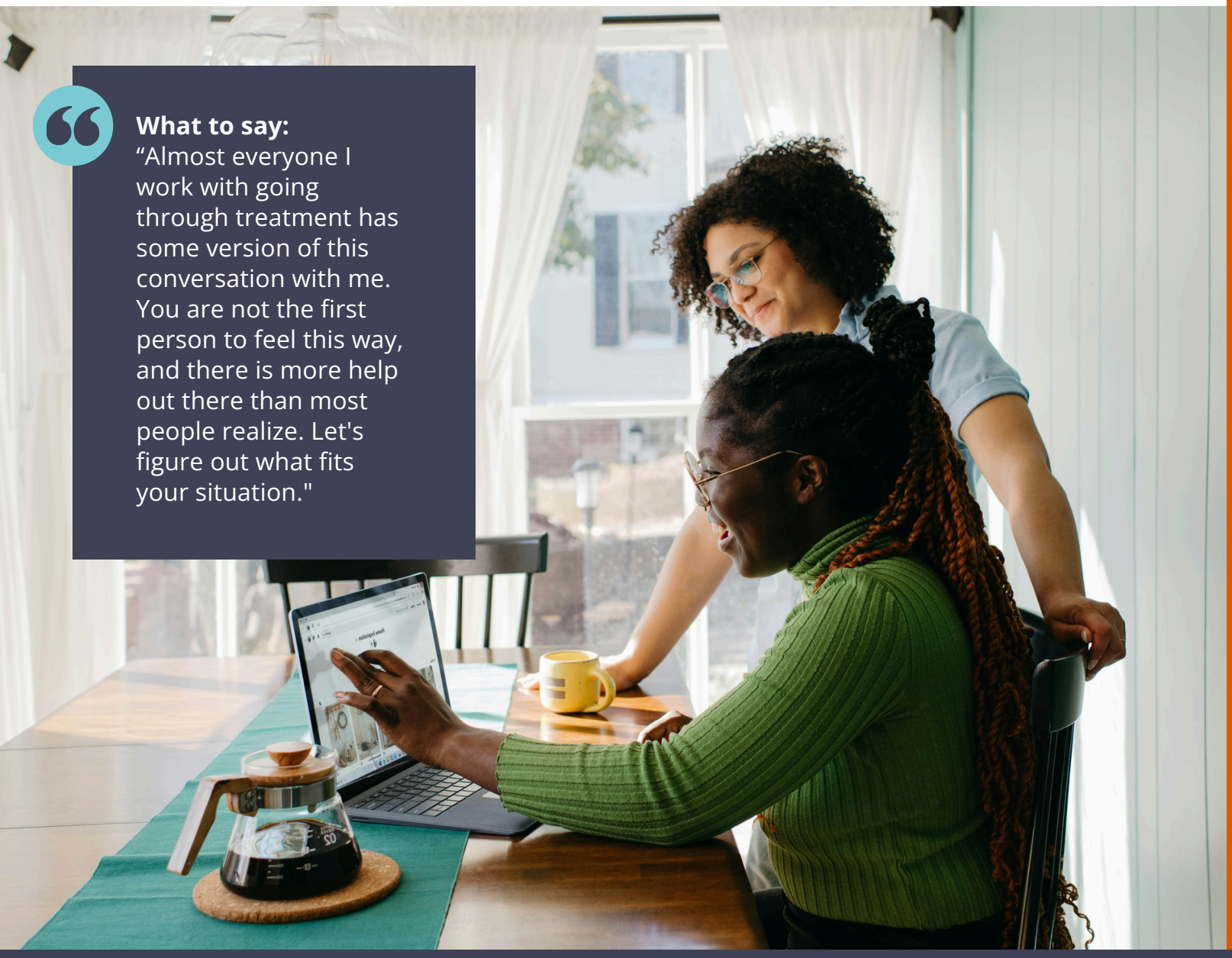
NORMALIZING FINANCIAL CONCERNS

Almost every person going through cancer treatment faces some level of financial stress. It is not a sign of weakness, failure, or poor planning. It is a predictable consequence of an unpredictable illness, and it is one of the most common challenges CHWs will encounter in this role.

Many people affected by cancer stay silent because they feel ashamed, or because they do not believe anything can actually help. Your role is to make sure they know neither of those things is true.

Key messages to share with the person you are supporting:

- It is okay to ask for help, that is exactly what these resources are here for
- Financial stress is one of the most common parts of the cancer experience — they are not alone
- Cost concerns will not result in lesser care, speaking up helps their team find solutions
- You are there to bridge the gap between them and the support that exists



What to say:
"Almost everyone I work with going through treatment has some version of this conversation with me. You are not the first person to feel this way, and there is more help out there than most people realize. Let's figure out what fits your situation."

COMMON COSTS PEOPLE AFFECTED BY CANCER FACE

Help the person you are supporting name what is most concerning.
Costs can come from many directions:

Medical costs

- Doctor visits and specialized fees
- Surgery, chemotherapy, radiation
- Prescription medications
- Insurance premiums and copays
- Deductibles and out-of-pocket costs
- Lab tests and imaging
- Medical equipment and supplies

Daily life costs

- Transporation, gas, and parking
- Lodging for travel to treatments
- Childcare and eldercare
- Lost income from missing work
- Food and household bills
- Utility and housing costs
- Home care and support services

5 TIPS FOR HELPING YOUR THE PERSON YOU ARE SUPPORTING NAVIGATE COSTS

1 **Identify what costs are most pressing**

Is it medication? Transportation? Housing? Copays? Understanding what is most urgent helps you connect to the right resource first.

2 **Connect to the Cancer Support Helpline at the Cancer Support Community**

(CSC) Helpline navigators can help with financial navigation, insurance questions, and referrals. You don't need to have all the answers.

Try saying:
"These navigators are experts in finding financial assistance. Let's call them together if you're comfortable."



3 Ask about support at their treatment center

Most treatment centers have staff who specialize in financial navigation

- Oncology social workers: can help with financial navigation and insurance appeals
- Financial counselors or billing offices: can explain bills and explore payment plans
- Patient navigators: can connect the person you are supporting to internal and external resources



Try saying:
"Does your clinic have an oncology social worker? They can help with insurance appeals and foundation grants. Would you like me to help you ask for a referral?"



4 Share local and community resources

Food banks, transportation programs, utility assistance, and housing support exist in many communities. The Cancer Support Helpline can also help identify local options. Federal and state programs such as SNAP, WIC, LIHEAP, Medicaid, Medicare, and 211 are also important resources.

5 Help your the person you are supporting get organized

Financial stress often comes from an overwhelming pile of bills and paperwork. Help the person you are supporting set up a simple system:

- Create a “Bill Binder”, one place for all bills and Explanation of Benefits (EOB) documents
- Keep a list of all providers and their billing contacts
- Note insurance claim numbers and appeal deadlines

CHW TIP
Keep a local referral list with program names, contact info, languages offered, eligibility rules, and application steps. Update it regularly.

CHW BEST PRACTICE: USE A LAYERED SUPPORT APPROACH

Help the person you are supporting apply for multiple types of support at once rather than one at a time. Financial needs often stack up, and a person affected by cancer may need help with medication AND food AND transportation simultaneously. Work through these categories together:

- **Insurance coverage** — Medicaid, Medicare, Marketplace plans
- **Medication support** — Co-pay foundations, Patient Assistance Programs (PAPs), state programs
- **Food support** — SNAP, WIC, Meals on Wheels, local food banks
- **Utility and rent** — Low Income Home Energy Assistance Program (LIHEAP),, emergency rental assistance, local programs
- **Transportation** — American Cancer Society (ACS), county vouchers, faith-based programs
- **Income replacement** — FMLA, SSI/SSDI, short-term disability, paid family leave
- **Cancer-specific grants** — CancerCare, Family Reach, disease-specific organizations

TYPES OF FINANCIAL ASSISTANCE

Use this table to match what the person you are supporting is saying to the right type of resource:

If the person you are supporting says...	The resource is:	What it does:
"I can't afford the cost of the medicine itself."	**Co-Pay Assistance Foundations**	Nonprofit organizations that cover the patient's share (co-pay) for expensive specialty drugs. Examples: Patient Advocate Foundation (PAF) and Patient Access Network Foundation (PAN Foundation).
"I don't have insurance or my drug isn't covered."	**Patient Assistance Programs (PAPs)**	Programs run directly by pharmaceutical companies that provide medication for free or at very low cost to patients who qualify.
"I don't have a way to get to the hospital."	**Transportation Assistance**	Financial help for getting to and from medical appointments. Common sources include the American Cancer Society, local Area Agencies on Aging, county transportation voucher programs, hospital social work

"I have to choose between food, rent, and my medical bills."	**Living Expense Grants**	One-time financial assistance for non-medical costs such as utilities, groceries, rent, or mortgage. Federal programs like SNAP, WIC, and LIHEAP can also help.
"I just lost my job or had to cut back my hours."	**Income and Employment Support**	When a cancer diagnosis forces a patient to reduce hours or stop working entirely, several protections and income support may be available. FMLA provides up to 12 weeks of unpaid job-protected leave. Short-term disability insurance replaces a portion of income during treatment. SSI and SSDI provide income for patients who cannot work due to disability. Paid family leave is available in some states. An oncology social worker or Helpline navigator can help determine what your patient qualifies for.
"I'm on Medicare and still can't afford my prescriptions."	**State Pharmaceutical Assistance Programs (SPAPs)**	State-run programs that help Medicare beneficiaries pay for prescription drug costs, including premiums, deductibles, and copays. Availability and eligibility vary by state ,not all states offer an SPAP. Patients can also be connected to Medicare's Extra Help program, which provides similar low-income prescription cost assistance nationally.

WHAT CHWS SHOULD NOT DO

- Promise financial help or specific funding amounts
- Give legal or tax advice
- Interpret insurance policies beyond your role
- Handle the personal finances of the person you are supporting unless explicitly authorized by your program





WHEN TO ESCALATE URGENTLY

Refer immediately if the person you are supporting reports:

- Risk of eviction or homelessness
- Utilities are about to be shut off
- No food in the home
- Unable to obtain medications
- Stopping treatment because of cost
- Severe emotional distress or hopelessness

Who to contact and how:

For financial, housing, food, and medication needs: Connect to the Cancer Support Helpline (1-888-793-9355). Dial 211 for local emergency assistance.

For severe emotional distress or hopelessness: Call or text 988 (Suicide and Crisis Lifeline) if in immediate crisis. Notify the the person you are supporting care team.

General escalation steps:

- Listen and stay calm, do not leave the the person you are supporting without a next step
- Identify the most urgent need first
- Make a warm handoff when possible by connecting them directly rather than just giving a number

CHW CONVERSATION GUIDE

Follow the natural progression of your relationship — from first contact to trust-building to education and advocacy.

If you are already in an established relationship with your patient, start at Stage 3. Stages 1 and 2 are included for CHWs who may be introducing this topic during early outreach.

Stage 1 · Outreach **First Contact**	**Stage 2 · Stabilization** **Trust is Forming**	**Stage 3 · Education & Advocacy** **Trust is Established**
Be present. Listen. "Hi, my name is [name] and I'm a Community Health Worker. My job is to be a resource for you — no pressure, no agenda. How are you feeling about everything so far?" "A lot of people I work with are hearing so much new informationat once. Is there anything that's been confusing or hard to follow?" "You don't have to have any questions ready — I'm just here to listen."	**Check in. Identify barriers.** "Since we last connected, has anything come up that's been weighing on you?" "Is there anything getting in the way of you being able to focus on your health right now?" "Have you had a chance to connect with anyone who can help you navigate all of this?"	**Now you can open the financial conversation. Only when the person you are supporting is comfortable.** "Is cost something you've been thinking about? A lot of people find the financial side of treatment catches them off guard." "Are you having any trouble affording medications, getting to appointments, or managing day-to-day costs?" "Would it help if I connected you with someone who specializes in finding financial assistance for people going through cancer treatment?"

ABOUT THE CHW ONCOLOGY-FOCUSED TRAINING PROGRAM

CSC's CHW Oncology-focused Training Program is for community health workers who are interested in gaining skills and knowledge to better assist members of their community impacted by cancer. The program provides free cancer-specific educational resources and intentional opportunities for CHWs to share best practices and build peer connections.

Visit our website: **www.cancersupportcommunity.org/community-health-worker-program**

RESOURCES

RESOURCES FOR CANCER CAREGIVERS

Cancer Support Helpline
1-888-793-9355 — Call, chat, or video in 200 languages, always free.
www.CancerSupportCommunity.org

Open to Options® Helping your patient prepare for their next appointment? Call 1-888-793-9355 or contact your local CSC or Gilda's Club.

MyLifeLine® CSC's online community for anyone impacted by cancer.
www.MyLifeLine.org

Frankly Speaking About Cancer® Plain-language education materials.
orders.cancersupportcommunity.org

Local CSCs and Gilda's Clubs — Free support groups and programs.
CancerSupportCommunity.org/FindLocation-Near-You

NATIONAL FINANCIAL ASSISTANCE RESOURCES

CancerCare — www.cancercare.org

Patient Advocate Foundation (PAF) — www.patientadvocate.org

Patient Access Network (PAN) Foundation — www.panfoundation.org

Family Reach — www.familyreach.org

American Cancer Society — 800-227-2345 | www.Cancer.org

NeedyMeds — www.needymeds.org

GOVERNMENT PROGRAMS

Medicaid/Medicare — www.healthcare.gov

SNAP (food assistance) — www.fns.usda.gov/snap

LIHEAP (utility assistance) — www.liheap.org

211 (local services locator) — www.211.org

Social Security (SSI/SSDI) — www.ssa.gov

Benefits.gov — www.benefits.gov

Meals on Wheels — www.mealsonwheelsamerica.org

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline (CSC-867-5309 or 1-888-793-9355 outside of the U.S.), available in 200 languages.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling CSC-867-5309 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more **www.CancerSupportCommunity.org/FindLocation**.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at **www.CancerExperienceRegistry.org**.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at **www.MyLifeLine.org**.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at **www.CancerSupportCommunity.org/Become-Advocate**.

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