Mental Health and Cancer

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 emotional 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. Recognize signs of emotional distress in cancer patients and caregivers at any stage of their cancer experience.
2. Normalize conversations about mental health in a way that feels safe and accessible.
3. Connect people to the right support and know when to escalate.
4. Care for yourself in the process.

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB



MENTAL HEALTH AND CANCER: WHAT YOU NEED TO KNOW

Cancer and mental health are inseparable

A cancer diagnosis affects more than the body. It can shake a person's sense of self, strain relationships, create money worries, and change the future they had imagined. Over time, treatment side effects, fear that the cancer may return, loneliness, and loss of independence can all add to the burden.

Up to **40% of cancer patients experience serious emotional distress,** and caregivers are affected even more often. This is not a weakness. It is a normal response to a very hard experience.

Distress rarely announces itself

Patients and caregivers often do not say "I'm struggling." They show it.

Signs to watch for

- Irritability or anger: snapping at family members or the care team
- Checking out: losing interest in hobbies, treatment, or daily life
- Withdrawal: pulling away from people who care about them
- Physical signs: sleeping too much or not at all, changes in appetite, trouble concentrating
- "I'm fine"- said too quickly, too often, or without eye contact
- Missed appointments or not following through on referrals
- Increased use of alcohol or substances

UNDERSTANDING THE FULL PICTURE



Emotions people with cancer commonly feel:
Cancer brings up a wide range of feelings often all at once. These are normal responses, not signs of weakness:

- Fear and anxiety about the unknown
- Sadness or grief over life changes
- Anger, at the diagnosis, the situation, or others
- Guilt or feeling like a burden
- Loneliness or isolation
- Loss of identity or sense of self
- Hopelessness or depression



How mental health can affect cancer care
Emotional struggles don't stay separate from medical care they show up in it. When someone is overwhelmed, it can be hard to:

- Get to appointments
- Follow or remember a treatment plan
- Take medications the right way
- Eat enough or sleep well
- Speak up, ask questions, or push back when needed
- Stay connected to support

Words can open doors or close them
In many communities, particularly communities of color, "mental health" carries stigma. It can sound like "mental illness," weakness, or something to be ashamed of.

Reframe it:
Call it "the emotional side of cancer," "how you're coping," or "the stress of the experience." Use the language that feels right to the person in front of you.

Know your role and its limits
CHWs do not diagnose mental health conditions. But they can play an important role in their patient's lives by:

- Building trust
- Listening without judgment
- Noticing signs of distress
- Encouraging people to speak with their care team
- Helping connect people to support services

If a patient or caregiver mentions hurting themselves or others, your role shifts immediately from support to emergency referral. Do not hesitate.

For immediate mental health crisis: Call or text 988 (Suicide and Crisis Lifeline, U.S.)

GRIEF AND ANTICIPATORY GRIEF IN CANCER

Grief is a natural response to loss, and it shows up in many ways emotional, physical, and mental ways as people adjust changes in their lives or sense of self. A cancer diagnosis often brings losses that begin well before treatment is over. People may grieve the loss of health, identity, independence, relationships, and the future they imagined for themselves.

This type of grief is called anticipatory grief, and it is one of the most common and least talked about experiences in cancer care.

For patients, anticipatory grief may look like:

- Grieving the person they were before diagnosis, their independence, their body, their sense of self
- Worry about loved ones and how they will cope
- Fear of what their illness will do to the people they love
- Sadness about milestones they worry they may not reach
- Difficulty imagining or planning for the future
- A sense of mourning a life that has already changed, even while still living it
- Feeling guilty for grieving when they are, in their words, "still here"
- Preoccupation with what might happen, even when things are going well right now

For caregivers, anticipatory grief may look like:

- Worry about losing their loved one
- Grieving the person they knew before cancer, their relationship, their shared future
- Pulling away emotionally even while physically present
- Anger or resentment that feels shameful
- Feeling guilty for imagining life after loss
- Exhaustion that goes beyond physical tiredness
- Feeling overwhelmed by responsibility or decision-making
- Quietly mourning plans and milestones that may no longer be possible

There is no right or wrong way to grieve during cancer.

What to say:
"Sometimes people find themselves grieving things that haven't happened yet, the plans that changed, the person they used to be, the future that felt certain. That kind of grief is real, and it makes sense. You don't have to wait until things get harder to feel the weight of what's already changed."



As a CHW, recognizing anticipatory grief is important and creates an opportunity to offer support and help people stay connected to care and to what matters most to them.

What to do:

- Normalize the feeling. Patients and caregivers often feel guilty for grieving. Let them know this grief makes sense, and they do not need to earn the right to feel it.
- Remind them they are not alone. Connect them to a support group through a local CSC or Gilda's Club where others understand this experience firsthand.
- Connect them to the Cancer Support Helpline (1-888-793-9355) for emotional support and counseling resources.
- These conversations can be heavy to carry. After a difficult conversation about grief, give yourself a moment. Talk to a supervisor or trusted colleague if you need to process what came up.

THE EMOTIONAL STAGES OF THE CANCER EXPERIENCE

Grief and distress can show up at any point in the cancer journey. The framework below offers a practical way to understand what a person may be experiencing emotionally—so you can respond with empathy and connect them to the right support.

Every person's emotional experience through cancer is different. The stages below are meant as a guide, not a checklist. Your patient may be in more than one stage at once, may move between stages, or may not identify with a stage at all. Use this as a starting point for conversation.



THE EMOTIONAL STAGES OF THE CANCER JOURNEY

Emotional needs shift at every stage of the cancer journey. Use this as a quick reference to understand where your patient may be – and what kind of support they need most. Caregiver needs are included at every stage.

STAGE 1: Diagnosis

HOW THEY MAY FEEL

Shock and disbelief · Fear and anxiety · Loss of identity · Overwhelmed · Loss of control · Isolation

CAREGIVER

Urgency to fix things · Fear of wrong words · Putting self aside

CHW FOCUS

- Listen and be present
- Normalize emotions
- Help navigate next steps
- Connect to Helpline

STAGE 2: Treatment

HOW THEY MAY FEEL

Exhaustion and fatigue · Irritability · Depression or withdrawal · Uncertainty · Relationship strain · Financial stress

CAREGIVER

Caregiver fatigue · Feeling helpless · Financial pressure

CHW FOCUS

- Check in regularly
- Watch for distress signs
- Support caregivers too
- Connect to resources

STAGE 3: End of Treatment

HOW THEY MAY FEEL

Relief mixed with fear · Loss of structure · Fear of recurrence · "Why am I not happy?" · Identity uncertainty

CAREGIVER

Role uncertainty · Mirrored fear · Complicated relief

CHW FOCUS

- Normalize the transition
- Address fear of recurrence
- Help rebuild routines
- Stay connected

STAGE 4: Survivorship

HOW THEY MAY FEEL

Ongoing fear · New sense of purpose · Changed relationships · Body image concerns · Gratitude and grief

CAREGIVER

Adjusting to new normal · Lingering fear · Relationship shifts

CHW FOCUS

- Long-term check-ins
- Validate ongoing grief
- Connect to support groups
- Watch for signs of depression

STAGE 5: Recurrence

HOW THEY MAY FEEL

Devastation · Loss of trust · Anger · Grief over lost hope · Heightened fear

CAREGIVER

Caregiver fatigue · Feeling helpless again · Fear of the future

CHW FOCUS

- Non-judgmental presence
- Help process the news
- Reconnect to care team
- Explore new options together

STAGE 6: Advanced and end of life

HOW THEY MAY FEEL

Seeking peace · Concern for loved ones · Grief about unfinished things · Moments of acceptance

CAREGIVER

Anticipatory grief · Deep exhaustion · Fear of what comes next

CHW FOCUS

- Honor dignity and comfort
- Connect to pallative support
- Support caregiver grief
- Know when to refer to 988

A note on what this graphic does not capture

Some experiences fall outside these six stages and deserve acknowledgment:

- Patients who are in **active clinical trials** may experience a unique emotional cycle of hope and uncertainty that doesn't map cleanly onto any single stage
- Patients with **chronic or ongoing cancer** who are neither in active treatment nor in remission may feel stuck between stages, with no clear "end of treatment" moment
- **Children and young adults** with cancer face distinct emotional challenges around identity, relationships, and the future that differ significantly from older adults.

A reminder about intersecting identities
A person's emotional experience of cancer is also shaped by who they are. Cultural background, faith, language, immigration status, socioeconomic situation, and prior trauma all affect how someone processes a cancer diagnosis and whether they feel safe expressing distress. As a CHW, your awareness of these layers is one of your greatest strengths.

The tips and conversation guide that follow are designed to help you navigate these emotional stages, wherever your patient is in their experience."

6 TIPS FOR SUPPORTING MENTAL HEALTH IN CANCER

1 **Learn to read the room** Distress may look differently at different stages. Pay attention to where your patient is in their cancer experience, not just what they say.

2 **Name what you see, without diagnosing.** Reflecting back what you observe tells the person they are seen.

What to say: *"I've noticed you seem a little quieter lately than usual. A lot of people find the emotional weight of treatment builds over time. Is that something you've been feeling?"*

3 **Ask the real question.** Surface-level check-ins often get surface-level answers. If they say "I'm fine," pause. Give them space.

Try saying: *"How are you really doing, not just physically, but emotionally?"* or *"Is there anything weighing on you that we haven't talked about yet?"*

If they say they're fine: *"I'm glad to hear that. And I just want you to know that if that ever changes, I'm here."*

4 **Listen to understand, not to respond** Resist the urge to fix, reassure, or move quickly to resources. Before you offer anything, make sure the person feels fully heard.

Validation sounds like: *"That makes complete sense given everything you're going through."*



5 **Know when and how to make the handoff.** Connecting someone to professional support is not giving up on them, it's getting them more.

> **Try saying:** *"I'd like to connect you with someone who specializes in the emotional side of cancer. It's free, confidential, and you can talk by phone, chat, or video. You don't have to commit to anything, it's just a conversation, and you're in control. Would that be okay?"*

6 **Take care of yourself** These conversations are emotionally heavy. Carrying other people's pain without processing your own leads to compassion fatigue, which is a known occupational risk, not a personal failure. Talk to a supervisor or trusted colleague. The Cancer Support Helpline is available to you, too.

WHEN TO REFER, ESCALATING FOR MORE SUPPORT

Refer urgently if your patient or caregiver:

- Mentions thoughts of suicide or harming themselves or others
- Expresses hopelessness about the future or says "there's no point"
- Shows signs of severe disorientation or breaks from reality
- Stops eating, sleeping, or caring for themselves for an extended period
- Is using alcohol or substances to cope to a concerning degree
- Has no support system and is completely isolated

For immediate crisis: If someone is in immediate danger of harming themselves or others, call 911 right away. For someone who is in crisis but not in immediate danger, they can call or text 988, the Suicide & Crisis Lifeline is free, confidential, and available 24/7.

SUPPORTING CAREGIVERS

The caregiver gap is real

Caregivers frequently experience higher levels of distress than patients but are far less likely to seek help. They minimize their own needs to "be strong." Check in with caregivers separately, not just as an extension of the patient.

Caregivers are often invisible patients. They pour everything into the person with cancer and let their own well-being fall to the bottom of the list — or off it entirely. As a CHW, you have a unique opportunity to check in with caregivers directly.

Common questions caregivers carry but rarely say out loud:

- *"How can I keep doing this?"*
- *"Am I allowed to feel angry? Resentful? Exhausted?"*
- *"What happens to me if something happens to them?"*
- *"Who is taking care of me?"*

How you can support caregivers:

- Check in with caregivers one-on-one, not just as part of the patient's support system
- Ask about the basics: Are you eating? Are you sleeping? How is your own health?
- Share the Cancer Support Helpline with caregivers for their own emotional support, it's not just for patients
- Encourage them to connect with a local CSC or Gilda's Club caregiver support group

What to say to a caregiver:
"You cannot pour from an empty cup. Taking care of yourself is what makes it possible for you to keep showing up for your loved one."

A NOTE ON LANGUAGE

Use the words that open doors, not close them. Ask permission before going deeper. What matters most is that the conversation happens.

Instead of saying...	Try saying...	Why it works better
"Do you have depression?"	*"If you're comfortable, can you tell me more about how you've been feeling lately? I may know of some supports that could help."*	Open-ended and permission-based. Does not push toward a yes or no.
"You need a therapist."	*"I'd like to connect you with someone who specializes in the emotional side of cancer — would that be okay?"*	Frames support around cancer, not a personal flaw. Asks permission first.
"You're just stressed."	*"This is a lot for one person to carry. How can I support you right now?"*	Validates the weight of the situation without minimizing it.
"I'm sure you'll be fine."	*"I don't know exactly what's ahead, but I do know you won't have to face it alone."*	Honest and genuinely reassuring without making false promises.
"Try not to worry."	*"It makes complete sense that you're worried. What would feel most helpful right now?"*	Acknowledges the feeling instead of dismissing it. Puts them in control.



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 information at 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 emotional conversation. Only when your patient is comfortable.** "How are you really doing with everything — not just physically, but emotionally?" "A lot of people going through treatment find the emotional weight gets heavier over time. Is that something you've been feeling?" "If you're comfortable, can we talk a little about how you've been coping and whether there's any support that might help lighten that?"

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

CANCER SUPPORT COMMUNITY RESOURCES

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

MENTAL HEALTH AND CRISIS RESOURCES:

988 Suicide and Crisis Lifeline
Call or text 988 (U.S.) — for immediate crisis support

National Alliance on Mental Illness (NAMI)
1-800-950-NAMI (6264) | www.NAMI.org/Help

SAMHSA National Helpline
1-800-662-HELP (4357) | www.SAMHSA.gov/find-support

FOR CAREGIVERS

National Alliance for Caregiving — www.Caregiving.org

Family Caregiver Alliance — 800-445-8106 | www.Caregiver.org

CSC Caregiver Resources — www.cancersupportcommunity.org/caregivers

PROFESSIONAL RESOURCES

Academy of Oncology Nurse and Patient Navigators (AONN+)
aonnonline.org

National Comprehensive Cancer Network — www.nccn.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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