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Distress

People with cancer, as well as their friends and family, can feel distressed after a cancer diagnosis. Distress can be shown in different ways. When cancer is treated or as situations change, learning to cope can be difficult. It's important to know when and where to get help and support.

- Cancer-related Mental Distress
- Coping with Distress

Cancer-related Mental Distress

Cancer doesn't just affect your physical health. For my people it also causes anxiety, depression, PTSD, and other types of mental distress. **Cancer-related mental distress** can happen at any time, even weeks or months after treatment ends.

There are steps you can take to manage your distress.

- What is cancer-related mental distress?
- Types of mental distress
- What causes cancer-related mental distress?
- When does it usually start?
- What are the symptoms of mental distress?
- Who is most at risk?
- Doesn't everyone feel distressed when they have cancer?
- How mental distress affects cancer treatment and side effects

- Screening
- Talking to your health care team
- Treatments
- What caregivers, friends, and family can do
- Find more support

What is cancer-related mental distress?

Cancer-related mental distress is a general term for the many feelings and emotions that come with having cancer.

Mental distress is not the same as having problems or stressors in your life. Stress isn't always negative. It can motivate and focus us. But sometimes, the problems and stressors in your life (like cancer) affect your thoughts and feelings so much that it becomes hard to cope.

People describe mental distress in many ways. If you have mental distress, you might feel:

- · Sad or depressed
- Anxious
- Angry
- Hopeless
- Alone or isolated
- Helpless, or like you have no control
- Unsure of your purpose or meaning in life
- Numb, or nothing at all
- Exhausted

Mental distress can make it hard to function. You might have trouble scheduling appointments, making decisions, or taking medicines that are important for your cancer treatment and survivorship.

You might also struggle with activities not related to your cancer, like doing housework, talking to friends, or taking care of yourself.

Types of mental distress

Some of the most common types of cancer-related mental distress are:

- <u>Anxiety</u>¹
- <u>Depression</u>²
- Stress disorders³ (post-traumatic stress, PTSD, and acute stress disorder)

It's common to have more than one type of mental distress during your cancer treatment and survivorship journey. You might experience these together, or at different times.

What causes cancer-related mental distress?

There are many ways cancer and cancer survivorship can cause mental distress. This includes:

- Worries about the future
- Increased health needs (more appointments, doctors, and medicines)
- Long-term and late side effects⁴
- Concerns about family and relationships
- Insecurity around body image and intimacy
- Fertility concerns and sexual dysfunction⁵
- Money and/or health insurance stress
- Fear of <u>cancer recurrence⁶ (FCR)⁷</u>
- Survivor's guilt

When does it usually start?

Distress can happen at any time. It can also come and go during cancer treatment and survivorship. But there are certain times that often bring feelings of distress.

- When you are first diagnosed
- Before you start a new type of treatment
- When dealing with side effects of cancer treatment⁸
- After treatment ends (<u>survivorship</u>⁹)

Cancer survivors are at greater risk of developing a mental health disorder after treatment ends. This is often due to fear of recurrence, fewer check-up appointments, and less support.

This might take you by surprise. Cancer survivors often say they are surprised at the mental distress they feel after treatment ends.

What are the symptoms of mental distress?

Many of the symptoms of mental distress are hidden, so it can be hard to know if a person is struggling. They might seem "fine" on the outside. You might not even realize when *you* are distressed.

You might feel:

- Guilt, shame, or blame related to your cancer
- Sad, hopeless, or depressed most of the time
- More irritable or angry than usual
- Numb or disconnected from yourself (dissociation)

Other common symptoms are:

- A lack of interest in doing things or seeing people (or self-isolating)
- Avoiding certain people, places, or things
- Nightmares, flashbacks, or intrusive thoughts
- Hypervigilance (extreme caution, attention, or sensitivity to something)
- Wishing or hoping for death
- Having specific thoughts or plans to kill oneself (active suicidal ideation)

988 Suicide & Crisis Lifeline

988 Suicide & Crisis Lifeline provides 24/7, free and confidential support via phone or chat for people in distress, resources for you or your loved ones, and best practices for professionals. Includes information on finding your local crisis center.

Phone: 988

- Interpretation for more than 240 languages
- ASL Videophone for people who are deaf or hard of hearing

Text: 988 (English and Spanish only)

Website: http://suicidepreventionlifeline.org10

To get immediate help, you can also go to the emergency department or call 911.

Who is most at risk?

Some people are more likely to struggle with severe mental distress that prevents them from living their lives.

You might be at greater risk for developing cancer-related mental distress if you have:

- A history of a mental health condition before cancer
- A history of substance use disorder
- A history of abuse or trauma
- Other health conditions

Where you live, grow, work, learn, and play also affects your mental health.

You are more likely to be affected by mental distress if you struggle with basic needs like stable housing, transportation, social support, and access to affordable and nutritious food.

These non-medical needs (**called social determinants of health, or SDOH**) can make a big difference to your physical and mental health.

Some of these things can't easily be changed. But there *are* ways you can get help during your cancer treatment.

Find resources to help you during your cancer treatment:

Cancer Survivors Network

An online community where people with cancer, survivors, and caregivers can connect with others 24/7.

Cancer Help 11

Contact the ACS cancer helpline to get answers and information

MHA - Mental Health America

Find a counselor or mental health provider.

Doesn't everyone feel distressed when they have cancer?

It's common to feel some amount of distress when you or a loved one has cancer. You might feel overwhelmed and anxious about all of the unknowns. It might even feel like your life is out of control. This is normal.

A lot of things can go through your mind during this time. You might wonder:

- Why me?
- Did I do something to cause my cancer?
- What will the future look like for me and my loved ones?

It's also common to feel anxious or worried about:

- Cancer treatments and the possible side effects
- Money, working, insurance, paying bills, or supporting your family
- Helping your friends, family, and caregivers cope
- Spiritual or existential concerns

These are all expected responses to a very distressful and often traumatic event. Just like other side effects, these feelings of distress can usually be managed.

Take steps early to manage your distress

If you feel distressed, don't wait. It's important to take steps early. Don't wait until you reach a level of severe distress before you look for ways to cope. It's much easier (and more effective) to start managing your distress before you get overwhelmed.

Do what you can, when you can

It's not always possible to get help early. That's okay, too. You might not even be aware of your distress until after it becomes unbearable. The most important thing is to get help as soon as you notice it.

Try to do what you can, when you can.

Learn more about coping with mental distress.

How mental distress affects cancer treatment and side effects

Managing your mental distress is also an important part of managing your cancer care.

Mental distress can make some of the <u>physical side effects of cancer¹²</u> and cancer treatment worse. This is especially true of fatigue, nausea and vomiting, sleep problems, and pain.

Studies also show that people with unmanaged mental health conditions are more likely to have worse cancer-related outcomes, including survival and quality of life.

If it seems like you might have severe distress, your doctor or cancer care team may want to rule out other health problems that could be making it worse. They might also offer resources or a referral to a specialist.

Screening

Many experts recommend screening everyone with cancer for anxiety and depression. If your health care team asks you about your mental health, share how you're really feeling.

They might ask questions to learn more about:

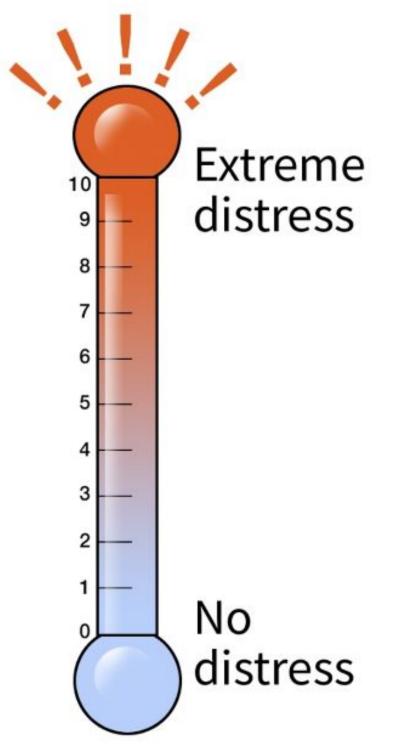
- Thoughts or feelings you are having
- How often you have those feelings, and how intense they are
- Physical symptoms that might be connected to your anxiety
- How these symptoms affect your day-to-day life
- If you're thinking of hurting yourself or anyone else

Measuring distress on a scale

Some cancer care teams measure distress in the same way, using a 0 to 10 scale. A common tool used by many providers is the **distress thermometer**.

The distress thermometer

If your care team uses the distress thermometer, you will be asked to circle the number (0-10) that best describes how much distress you had during the past week, including the present day.



Talking to your health care team

It can be hard to talk about mental health and distress. It might help to write down some

of the symptoms you're having or questions you want to ask. Here are a few ideas:

- Can my symptoms be managed?
- What types of treatments do you recommend?
- Would medication help?
- Can I talk with a therapist or specialist about my symptoms?
- Can you recommend a support group for me?

Treatments

Managing mental distress is very personal and individualized. It depends on each person's specific situation, lifestyle, and needs.

Treatment might include talk therapy, medication, or a combination of both. Sometimes other specialized treatments or <u>integrative therapies</u>¹³ are used along with standard treatment. The goal is to improve your symptoms, reduce your suffering, and improve quality of life.

Examples of therapies that might be used to treat cancer-related mental distress are:

- Psychotherapy (talk therapy)
- Support or peer groups
- Education and resources for lifestyle habits (nutrition, good sleep, physical activity)
- Mindfulness-based activities (meditation, progressive muscle relaxation, yoga, breathwork, imagery)
- Creative therapies or activities (art, writing, dance, music)
- Medicines for specific mental health conditions like anxiety or depression

Learn more in Coping with Distress.

What caregivers, friends, and family can do

Cancer and Mental Health: How Caregivers, Friends, and Family Can Help 14

It's often hard to know how to help a loved one who struggles with their mental health. If you are a friend, family member, or caregiver of someone with cancer, you might also feel like you need to "stay strong" for them. There are many simple, daily ways you can support your loved one, and yourself. Learn more

Find more support

Coping with Distress

Learn more about treatments and coping strategies for cancer-related mental distress.

Cancer Help¹⁵ Contact the ACS cancer helpline to get answers and information

MHA - Mental Health America

Find a counselor or mental health provider.

Hyperlinks

- 1. <u>www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-</u> <u>changes/anxiety.html</u>
- 2. <u>www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-</u> <u>changes/depression.html</u>
- 3. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/post-traumatic-</u> <u>stress-disorder-and-cancer.html</u>
- 4. www.cancer.org/cancer/survivorship/long-term-health-concerns.html
- 5. <u>www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects.html</u>
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- 9. www.cancer.org/cancer/survivorship/be-healthy-after-treatment.html
- 10. suicidepreventionlifeline.org/
- 11. <u>www.cancer.org/about-us/what-we-do/providing-support.html</u>
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Coping with Distress

Many people aren't well-prepared for the mental distress that can come with cancer and cancer treatment. If you or a loved one experiences mental distress, it's important to get support.

There are treatments available and steps you can take to help cope with distress.

- · Learning to cope with distress
- Treatments
- Palliative care and distress
- Tips for coping with distress
- If you have a history of mental health problems
- What caregivers, friends, and family can do
- Find more support

Learning to cope with distress

It's important to find healthy ways of coping with distress. But coping is a skill. Like all skills, it has to be learned. It doesn't come naturally to most people. There are many reasons you might have an easier (or harder) time coping.

- Social support (from friends, coworkers, or others)
- Family relationships
- Worries about money
- Beliefs and values
- Health behaviors
- Access to support and resources

If you don't have the support and coping skills you need, you might end up coping in less healthy ways, like denial.

Denial is one way people often cope with distress. By denying or avoiding a problem, a person might convince theirself and others that they are fine. But even though they seem fine, they are often struggling on the inside.

Learning to manage and cope with your distress during cancer care is especially important. Denial about cancer can lead to delaying care, missing appointments, not getting treatment, or misunderstanding your disease or prognosis.

Denial is a normal response to extreme distress. Our brains actually do this to protect us from potential harm (including emotional and mental harm). It isn't anything to be ashamed of. But it's important to be aware of it so you can learn healthy ways to cope.

Treatments

Mental distress often has more than one single cause. This is why it's so important to use more than one tool to manage it. Treatment for distress works best when more than one strategy is used.

Psychotherapy (talk therapy)

There are many different types of **psychotherapy** (talk therapy). Some of the most common types are:

- **Cognitive behavioral therapy (CBT):** CBT teaches you how to process your feelings instead of avoiding them. You'll learn how to identify automatic negative thoughts. You'll also learn relaxation techniques and healthy coping strategies.
- Acceptance and commitment therapy (ACT): ACT is a sub-type of CBT. You'll learn to use mindfulness as a way to notice and acknowledge your negative thoughts, feelings, and actions without trying to change or get rid of them.
- Interpersonal therapy (IPT): IPT focuses on the connection between your mental distress and your relationships with others.
- Eye movement desensitization and reprocessing (EMDR): EMDR therapy uses directed eye movements along with talk therapy to help your brain heal from past life experiences.
- Exposure therapy: Exposure therapy helps you face your triggers. (A trigger is something that reminds you of a past trauma and causes an emotional reaction.) By facing your triggers, you can learn to cope with them if they come up in the

future.

- **Family and couples therapy:** This type of talk therapy focuses on constructive (positive and productive) communication. It has been shown to improve distress and relationship satisfaction in spouses or family caregivers coping with cancer.
- **Supportive therapy:** This can include group or peer therapy with other people who have, or had, cancer.

Medicines for distress

If you're struggling with mental distress to the point that it affects your everyday life, your doctor might suggest adding medication.

Many types of medicines used for mental distress are also used for other health conditions. For example, certain antidepressants also help improve anxiety.

The most common medicines used for mental distress are described below.

Antidepressants

Antidepressants can help with more than depression. They also help with anxiety, pain, and sleep problems. Antidepressants work by affecting the levels of certain chemicals in your brain, like serotonin and norepinephrine.

Most antidepressants take a few weeks to start working, so it's important to give them time. There are also several different types of antidepressants. Don't get discouraged if the first doesn't work for you.

Learn more about the different types of $\frac{\text{antidepressants}^1}{\text{depression}^2}$ and $\frac{\text{other treatments for}}{\text{depression}^2}$.

Benzodiazepines

Benzodiazepines are used for anxiety. They work much faster than antidepressants. This can be helpful if you are feeling overwhelmed or nervous about a procedure. Benzodiazepines are controlled substances and can be habit-forming.

Talk to your health care team about the risks and benefits of any new medicine.

Support or peer groups

Support or peer groups give you the chance to talk with people who have been through similar experiences. These groups can be helpful even if you have an amazing personal support system. It is often healing to see that you aren't alone in the way you feel.

Complementary therapies

Studies show that some <u>complementary therapies</u>³ improve quality of life and symptoms of mental distress. These therapies are used along with standard medical treatments to help you manage your symptoms.

For example, mindfulness meditation has been shown to improve mental distress.

Mindfulness-based activities

Mindfulness is about noticing and being present with your thoughts, emotions, body, and the world around you. Our minds distract us from the present moment all the time, so it's easy to get caught up in thoughts about the past or future.

Mindfulness takes lots of practice, but it can help you stay connected to the present moment. Noticing more around you (such as in nature, moments of joy, or even moments of grief) can help you feel more connected to the world.

Some common mindfulness-based activities are:

- Meditation
- Body scan
- Yoga
- Tai chi/qui gong
- Breathwork
- Progressive muscle relaxation (PMR)
- Imagery
- Massage
- Music and art therapy
- Hypnosis
- Music and art therapy
- Reflexology
- Acupuncture

Learn more about <u>practicing mindfulness and relaxation</u>⁴.

The following video is brought to you by Healing Works Foundation.

Guided Meditations to Relieve Stress

Explore different ways to be calm when you are feeling anxious. It is best to listen to these meditations in a quiet place without distractions.

Watch on Vimeo 5

Education and resources

Your health care team might give you education and resources about lifestyle habits that can improve mental distress, including mindfulness, meditation, good sleep, and physical activity.

Additional referrals

Your health care team might refer you to additional resources such as patient navigation, social work, counseling, or chaplaincy care.

Palliative care and distress

Your cancer care team might also refer you to <u>palliative care</u>⁶ to help manage your distress.

Palliative care is provided by specialists who work with you and your cancer care team. They can help you find ways to manage many of the things that might be causing your distress or making it worse.

Many people confuse palliative care with hospice care. But they are not the same thing. Palliative care is for anyone with a serious illness, not just people at the end of life. Your care team could refer you to palliative care at any stage of your cancer, cancer treatment, and beyond.

A palliative care team might work with you to manage:

- Physical side effects of cancer and cancer treatment
- Family dynamics and communication
- Caregiver support and respite
- Access to community resources
- Social isolation and loneliness

• Money, insurance, or legal concerns

Studies show that people who get access to palliative care have a better quality of life and may even live longer than people with cancer who don't get this type of care. Learn more about <u>finding palliative care resources</u>⁷.

Tips for coping with distress

Mental health is one of the most difficult topics for many people to talk about. But it affects almost every part of our lives. Just like other health problems, it's important to manage your distress so it doesn't get worse.

Simply naming your distress out loud to another person is often one of the best things you can do to cope. But mental distress is tricky. It distorts (changes) how we think about ourselves. It can also make us think that other people are judging us, or that the feel negatively about us.

This makes it harder to reach out for support. But it's important to keep trying. If you aren't ready to talk about your distress, there are other steps you can take to help yourself cope.

Steps you can take on your own:

Reflect. Think about what helped you in the past during distressing situations.

Take one moment at a time. Also, it's okay if you don't always feel positive. An important part of healing is letting yourself feel all your feelings, good and bad.

Stay informed and ask questions. One of the most distressing things for many people is the unknown.

Take deep, slow breaths. This tells your nervous system you're safe and can relax. Doing this over time can help change your physical reactions to mental distress.

Use a journal. Writing down or recording your thoughts and feelings can help you process what you're going through.

Try complementary therapies. Yoga, massage, imagery, writing, music, and pet therapy have all shown to be helpful. Even getting outside for a walk can make a difference.

Steps you can take with the help of others:

Build a reliable support system. This might be a friend, family member, group, or a pet. Connection, community, and meaningful relationships are what give our lives meaning and connect us to one another.

Find someone you can talk to. A therapist can help you identify and reframe negative thoughts and behaviors and learn new coping skills.

Connect with people who've gone through similar experiences. If you aren't ready to talk in a group, listening to a podcast where other people talk about these experiences is another great option.

Ask a doctor about medication. Antidepressants can also help with depression, anxiety, and sleep problems. Most take a few weeks to start working, so give them time. There are also different types of antidepressants, so don't get discouraged if the first one doesn't work for you.

Get help with the stressors in your life. If you have distress about money, work, school, transportation, or insurance, ask for a referral to a social worker or navigator. They can often find community resources or other support for you.

Figuring out what works for you

Distress is a very real side effect of cancer. You can't just turn it on and off by thinking your way around it. Some days will be better than others. This doesn't mean you've failed, or lost all progress, or gone backward.

Sometimes, there isn't one single fix. A coping method might work one day but not the next. The more tools you have in your toolbox, the better prepared you'll be when you need them.

If you have a history of mental health problems

If you're going through cancer and already coping with mental health problems, you might need extra support.

For someone who is already struggling with mental health problems, the added mental distress of cancer can feel overwhelming or like too much to handle. These are completely valid and normal feelings to have.

You might already be using some of the tips or treatments mentioned here. It's important to continue doing the things that have helped you in the past. It's also important to ask your care team about other things that might be added to help you cope during this time.

This might look like:

- Letting people know you're struggling more than usual and might need extra support or check-ins
- Talking to your therapist or psychologist more frequently
- Reviewing your medicines to make sure they are still working well
- Changing or adding medicines as needed
- Joining a support group
- Getting screened for new or worsening mental illness (such as PTSD or panic disorder)

Even if you are used to coping with mental health issues on your own, you don't need to suffer alone. There are people who have gone through similar experiences. They can share what they learned or what worked best for them.

Managing distress is a normal part of cancer care. It should always be addressed, no matter your history with mental health.

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To get immediate help, you can also go to the emergency department or call 911.

Getting help from your care team

Many doctors and cancer care teams screen for distress, anxiety, and depression. No matter what they screen for, it's important to talk to them about how you're feeling. They can often help treat mild or occasional distress.

You might need more help if your distress is severe, or if it isn't getting better. Your health care team can often connect you with the right resources, referrals, and specialists.

Who can help?

There are many people on your care team who might be able to help you manage your distress:

Nurses and doctors can give you information and education. They can help you understand why distress often affects people with cancer differently. They can also listen and affirm your feelings and experiences.

Psychologists, psychiatrists, therapists, and counselors provide different types of mental health care. This might include talk therapy, medication, and help with building coping skills.

Chaplains provide support no matter what your religious or spiritual beliefs are. They are excellent listeners.

Navigators, social workers, and case managers can help find resources like transportation to appointments, lodging near treatment centers, financial assistance, and more.

Questions to ask

It can be hard to talk about mental health. Sometimes it helps to write down your symptoms or the questions you want to ask. Here are a few ideas:

- Can my symptoms be managed?
- What types of treatments do you recommend?
- Would medication help?
- Can I talk with a therapist or specialist about my symptoms?
- Can you recommend a support group for me?

• Is palliative care a good option for me?

What caregivers, friends, and family can do

Cancer and Mental Health: How Caregivers, Friends, and Family Can Help ⁹

It's often hard to know how to help a loved one who struggles with their mental health. If you are a friend, family member, or caregiver of someone with cancer, you might also feel like you need to "stay strong" for them. There are many simple, daily ways you can support your loved one, and yourself. Learn more

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- 3. <u>www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine.html</u>
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- 5. vimeo.com/920114328/574ae1161a
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8. suicidepreventionlifeline.org/

- 9. www.cancer.org/cancer/caregivers/how-to-help-a-loved-one-in-distress.html
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