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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.

- [What Is Distress?](#)
- [Tools to Help Measure Distress](#)
- [Managing Distress](#)

What Is Distress?

The word distress has many meanings. Distress is an unpleasant emotion, feeling, thought, condition, or behavior.

Distress can affect the way you think, feel, or act, and can make it hard to cope with having cancer, along with dealing with symptoms, treatment, and side effects. Research shows that distress may affect how you make decisions and take action about health, too. You may have trouble focusing on treatment decisions, making follow-up appointments, or even taking medications that are important for your treatment. People might describe distress as feeling:

- Sad
- Fearful
- Angry

- Helpless
 - Hopeless
 - Out of control
 - Unsure of their faith, purpose, or meaning in life
 - Like they want to pull away from people
 - Concerned about illness
 - Concerned about home or social role (as a father, mother, friend, caregiver, etc.)
 - Depressed, anxious, or panicked
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- [When is distress normal?](#)
 - [When is distress more serious?](#)
 - [What the patient and caregiver can do](#)

When is distress normal?

A certain amount of distress is normal when you or a loved one has cancer. There are many things that suddenly seem uncertain. Distress is common in people with cancer and in their family members and loved ones. In fact, everything about having cancer is stressful. So, a certain amount of distress is normal when you or a loved one has cancer. For example, some people:

- Have concerns about what may happen to their bodies.
- Worry about how the people they care about will cope with cancer and all the things that may happen.
- Have fears about what the future will be like. People often wonder, “Am I going to die?” and “Why is this happening to me?”
- May no longer feel safe, and may feel afraid, exposed, weak, and vulnerable.

Certain times during the treatment or parts of the cancer experience may bring on distress more than others. Some of these times might include:

- Having a new cancer diagnosis
- Having genetic testing
- Waiting for treatment
- Learning more testing or treatment is needed
- Being admitted to or discharged from the hospital
- Finishing treatment
- Learning treatment has stopped working

- Learning cancer has returned or gotten worse
- Starting another type of treatment
- Having advanced cancer
- Having a major side effect or complication
- Nearing the end of life

When is distress more serious?

Sometimes distress can go from an expected level to one that interferes with treatment, makes it hard for you to function or [cope](#)¹, and affects all parts of your life. In some cases, a person with distress may have trouble sleeping, eating, or concentrating. Some might have frequent thoughts of illness and death.

Signs and symptoms of more serious distress:

- Feeling overwhelmed to the point of panic
- Being overcome by a sense of dread
- Feeling so sad that you think you can't go through treatment
- Being unusually irritable and angry
- Feeling unable to cope with pain, tiredness, and nausea
- Poor concentration, "fuzzy thinking," and sudden memory problems
- Having a very hard time making decisions – even about little things
- Feeling hopeless – wondering if there's any point in going on
- Thinking about cancer and/or death all the time
- Having trouble sleeping or getting less than 4 or 5 hours of sleep a night
- Having trouble eating for a few weeks
- Family conflicts and issues that seem impossible to resolve
- Questioning faith and beliefs that once gave you comfort
- Feeling worthless, useless, and like a burden to others

Other things or issues, even those from the past, can increase the risk for distress and signal the need for help. For example, distress can be increased if you have uncontrolled side effects related to cancer, other serious illnesses, financial trouble, limited access to health care, transportation problems, young children at home, or language barriers. Studies also show that women have a higher risk for distress, as well as people who have been physically or sexually abused in the past, or if they have a history of having a mental disorder or drug or alcohol abuse.

What the patient and caregiver can do

- Your first line of defense in coping with distress is **having a cancer care team you feel safe with**. Even if you think your feelings and thoughts are minor, talk to them about how you feel. They can direct you to the help you need. Remember that they are treating YOU, not just the cancer, and they count on you to tell them how you're doing and what you're feeling. Remember, no one can do that except you.
- If you are a loved one or caregiver who is feeling distressed, it's OK to let the cancer care team know that you need help. Even though most of the information here may seem like it's for the person with cancer, it can also be useful to their loved ones and caregivers. These people are a strong source of support, and their well-being is important, too.

Hyperlinks

1. www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes.html

References

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Tools to Help Measure Distress

Sometimes it's hard to talk about distress in a way that helps your cancer care team understand how much you're having and how it's affecting you.

- [Distress screening](#)
- [The distress thermometer](#)
- [The problem list](#)

Distress screening

You've probably been asked to give a pain level based on a scale of 0 to 10 during doctor and hospital visits. The pain scale works like this: You might be asked, "How is your pain right now on a scale from 0 to 10, with 0 being no pain and 10 being the worst pain you can imagine?" This is a helpful way to measure pain. A score above 5 is usually a sign of significant pain, and tells the health care team that the patient needs more help to manage it.

Some cancer care teams measure distress in the same way, using a 0 to 10 scale. A common one used by many cancer care teams is the **Distress Thermometer** (see

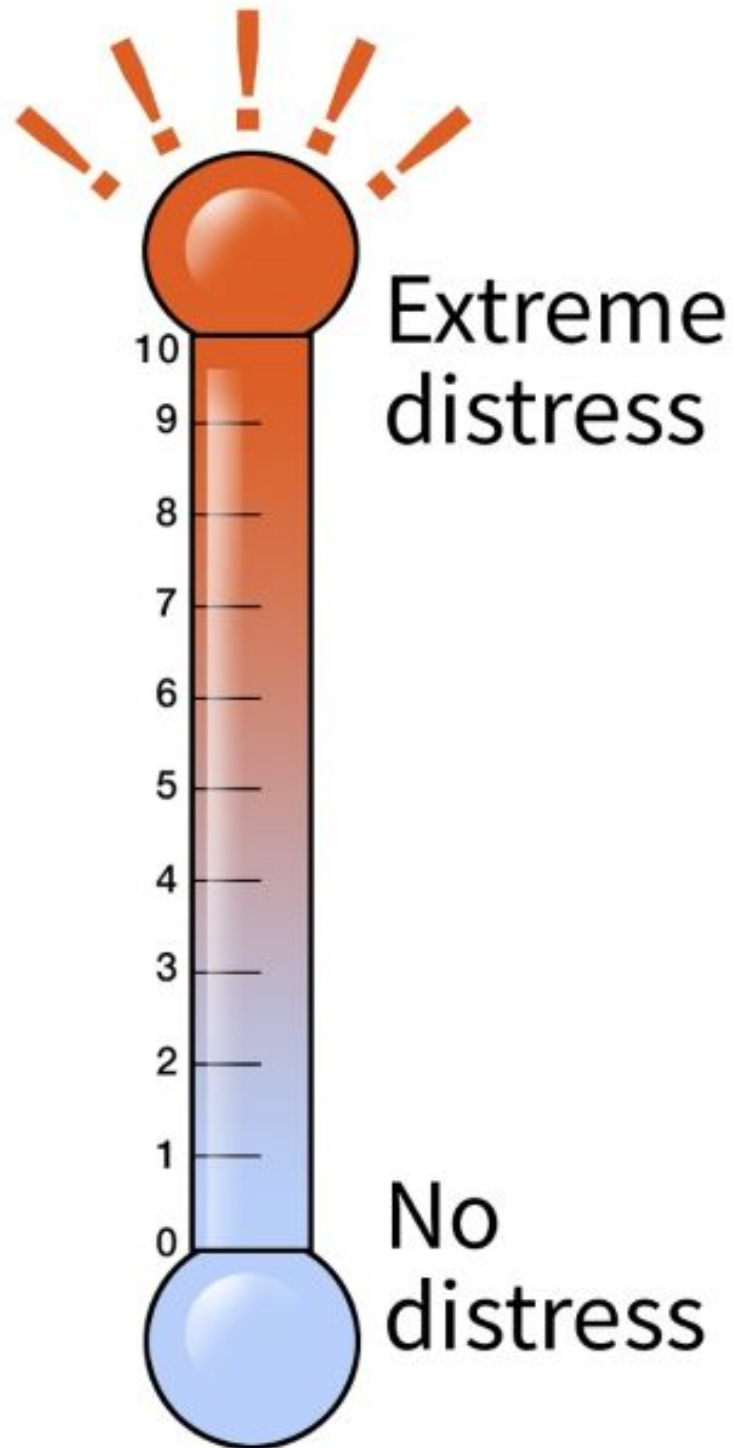
example below). Just as with the pain scale, you're asked to choose a number from 0 to 10 that reflects how much distress you feel today and how much you felt over the past week. Ten is the highest level of distress you can imagine, and 0 is no distress. Most people can use this scale to rate their distress in a way that helps the cancer care team. If your response is 4 or above, you likely have a moderate-to-high degree of distress. Your doctor and/or cancer care team should find out more and offer some help with your distress.

Not only does this tool tell your team about your [emotional health](#)¹, but it also gives you a chance to talk and work out problems during your visit. Surveys done in cancer clinics have shown that up to 4 in 10 patients have significant levels of distress. You are not alone in your distress.

Another part of the distress tool is the **Problem List**, or a list of things that may be causing your distress. For this, you read through a list of common problems and mark possible reasons for your distress. This helps your cancer care team know where you can best get the help you need. The list of physical problems helps you remember those you should tell your treatment team about.

The distress thermometer

You are asked to circle the number (0-10) that best describes how much distress you've had during the past week, including the present day.



The problem list

You are asked to check NO or YES for each problem (physical, emotional, activity,

family, social, or spiritual) that has been a cause of your distress in the past week, including the present day.

You can see and learn more about the Distress Thermometer and Problem List on the [National Comprehensive Cancer Network website](#)².

Hyperlinks

1. www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes.html
2. www.nccn.org/docs/default-source/patient-resources/nccn_distress_thermometer.pdf?sfvrsn=ef1df1a2_4

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Dahlin C. Anxiety. In Camp-Sorrell D, Hawkins RA. *Clinical Manual for the Oncology Advanced Practice Nurse*. 3rd ed. Pittsburgh, PA: Oncology Nursing Society; 2014; 1383-1390.

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Managing Distress

People value the care they get from their cancer care team, but many also want to take an active role in managing their illness. But distress can be hard for some people to manage on their own. Don't hesitate to talk to the cancer care team when you're feeling distress that's hard to handle. Remember that every person is different, and you can work with your cancer care team to find the best action to take based on your own situation.

- [Do's and don'ts](#)
- [Other ways to help manage distress](#)

Do's and don'ts

Here are some thoughts from experts about managing distress that include tips that might be helpful (the Do's) and some actions that could be harmful (the Don'ts).

Do

- **Rely on ways of coping that have helped you solve problems and crises in the past.** Know that almost everyone needs to have people around them they can count on to help when needed. Find someone you feel comfortable talking with about your illness. When you would rather not talk, you may find that relaxation, meditation, listening to music, or other things that calm you are helpful. Use whatever has worked for you before, but if what you're doing isn't working, find a different way to cope, or get professional help.
- **Deal with cancer "one day at a time."** Try to leave worries about the future behind. The task of coping with cancer often seems less overwhelming when you break it up into "day bites," which are easier to manage. This also allows you to focus on getting the most out of each day in spite of your illness.
- **Use support and self-help groups if they make you feel better.** Leave any group that makes you feel worse.
- **Find a doctor who lets you ask all your questions.** Make sure there's a feeling of mutual respect and trust. Insist on being a partner in your treatment. Ask what side effects you should expect and be prepared for them. Knowing what problems may come often makes it easier to handle them if and when they happen.
- **Explore spiritual and religious beliefs and practices, such as prayer, that may have helped you in the past.** If you don't think of yourself as a religious or spiritual person, get support from any belief systems that you value. This may comfort you and even help you find meaning in the experience of your illness.

- **Keep personal records of your doctors' numbers, dates of treatments, lab values, x-rays, scans, symptoms, side effects, medicines, and general medical status.** Information about the cancer and your treatment is important to have, and no one can keep it better than you.
- **Keep a journal if you need to express yourself without holding back.** It can help you process the journey, and you may be amazed by how helpful it can be.

Don't

- **Believe the old saying that “cancer equals death.”** There are more than 16 million people alive in the US today who have had cancer.
- **Blame yourself for causing cancer.** There's no scientific proof linking certain personalities, emotional states, or painful life events to getting cancer. Even if you may have raised your cancer risk through unhealthy habits, it does not help to blame yourself or beat yourself up.
- **Feel guilty if you can't keep a positive attitude all the time.** Low periods will come, no matter how great you are at coping. There is no proof that those times have a bad effect on your health or tumor growth. But if they become frequent or severe, get help.
- **Suffer in silence.** Don't try to go it alone, Get support from your family, loved ones, friends, doctor, clergy, or those you meet in support groups who understand what you're going through. You will likely cope better and take better care of yourself with people around who care about you and can help encourage and support you.
- **Be embarrassed or ashamed to get help from a mental health expert** for [anxiety](#)¹ or [depression](#)² that disrupts your sleep, eating, ability to concentrate, ability to function normally, or if you feel your distress is getting out of control.
- **Keep your worries or symptoms (physical or psychological) secret from the person closest to you.** Ask this person to come with you to appointments and talk about your treatment. Research shows that people don't often hear or absorb information when they are very anxious. A close friend or family member can help you recall and interpret what was said. They can be sure you tell the cancer care team about any changes or new concerns, too. As a practical matter, your friend or loved one can also help you get home from a doctor's visit or medical test.
- **Abandon your regular treatment for an alternative therapy.** If you use treatments that your doctor didn't recommend, use only those that you know do no harm. Find out if the treatment can be safely used along with your regular therapies (as a complementary therapy) to improve your quality of life. Be sure to tell your

doctor which treatments you are using along with medical treatment, since some should not be used during [chemo](#)³ or [radiation treatments](#)⁴. Discuss the pros and cons of any [alternative or complementary therapies](#)⁵ with someone you can trust to look at them more objectively than you may be able to when you are under stress. Psychological, social, and spiritual approaches are often helpful and safe, and doctors generally encourage their use.

Other ways to help manage distress

Support groups and counseling

Finding and going to a support group can help ease feelings of distress by offering support and education for patients and families, and by helping to find community resources. If a support group is not available or does not appeal to someone, a social worker may be able to help find other options. Sometimes group or individual counseling may be a good option, depending on the problem or problems that are most likely causing the feelings of distress. Support groups or counseling may help with:

- Adjusting to illness
- Family problems
- Problems with treatment decisions
- Concern about the quality of life
- Problems adjusting to changes in care
- Making decisions for future medical care (advance directives)
- When there is abuse or neglect in the home
- Trouble coping or problems communicating
- Changes in how you think and feel about your body and your sexual self
- Grief problems
- End-of-life issues
- Cultural concerns
- Caregiver issues or the need to prepare for caregiving and set up caregiver support

Social services

Sometimes having cancer affects your day-to-day needs. These are common, practical problems that a social worker can help you and your family or loved ones manage. They may be able to link people to community agencies, teach problem-solving approaches,

help get needed care, and offer education and support group sessions. Some practical problems they can help with include:

- Transportation problems or other illness-related concerns (for instance, how to get to treatment every day, how to pay for parking, or where to stay for out-of-town overnight hospital visits)
- Financial concerns
- Job concerns
- School concerns
- Food costs and preparation
- Help with daily activities
- Cultural or language differences
- Finding help for family and caregivers

Relaxation, meditation, creative therapies

Therapies and activities that help you relax are often helpful easing some forms of distress. These might include relaxation exercises, yoga, mindfulness, meditation, massage, and guided imagery. Creative therapies like art, dance, and music have also been shown to be helpful for people in some stressful situations. Animal assisted therapy (AAT), also known as pet therapy, involves spending time with therapy animals, is another option that some people might find interesting and worthwhile.

Spiritual support

In a time of crisis, many people prefer to talk with a person from their spiritual or religious group. Today, many clergy have training in pastoral counseling for people with cancer. They're often available to the cancer care team and will see patients who don't have their own clergy or religious counselor. Pastoral services are important because there can be different times during a person's cancer journey when a crisis might lead to questioning their faith or needing to rely on it more.

Exercise

Exercise is not only safe for most people during cancer treatment, but it can also help you feel better. Moderate exercise has been shown to help with tiredness, anxiety, muscle strength, and heart and blood vessel fitness, but even light exercise can be helpful in staying as healthy as possible. For instance, walking is a good way to get started and a good way to keep moving when you're feeling stressed.

Talk with your doctor about your exercise plans before you start. Depending on your level of physical fitness, you may need help from a physical therapist to make a plan that will work for you and is safe.

Keep in mind that even though exercise may help lower distress levels in some people, exercise alone is usually not enough to help people with moderate to severe distress.

Mental health services

Mental health services are used to evaluate and treat distress that's moderate to severe. This type of distress may be caused by other emotional or psychiatric problems the person had before cancer was found. Some problems that can make it harder to cope and may be worsened by the distress of cancer include:

- Major depression
- Dementia
- Anxiety
- Panic attacks
- Mood disorders
- Personality disorders
- Adjustment disorders
- Substance abuse

Mental health professionals use a range of counseling and therapy approaches to help you cope. They often start by helping you figure out what has worked well for you in the past. They will respect your coping style and try to help you strengthen it. They can help you understand how past problems or experiences may be making it harder to deal with cancer. They may also teach you techniques like relaxation and meditation to help control distress.

Medication

Sometimes a drug is needed to reduce distress related to cancer, or distress caused by a medicine to treat cancer or another serious symptom. For example, steroids (like prednisone or Decadron®) may cause mood swings. Opioid pain medicines (like morphine or fentanyl) in higher doses can cause confused thinking. Medicines may be needed to counter these symptoms.

You can work with your cancer care team and a mental health professional to decide if medication might be helpful. Sometimes medicines to treat depression (anti-

depressants) or to treat anxiety (anti-anxiety medicines) are options that may reduce distress and help with poor sleep and appetite.

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](#) ⁶

Hyperlinks

1. www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes/anxiety.html
2. www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes/depression.html
3. www.cancer.org/cancer/managing-cancer/treatment-types/chemotherapy.html
4. www.cancer.org/cancer/managing-cancer/treatment-types/radiation.html
5. www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine.html
6. vimeo.com/920114328/574ae1161a

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