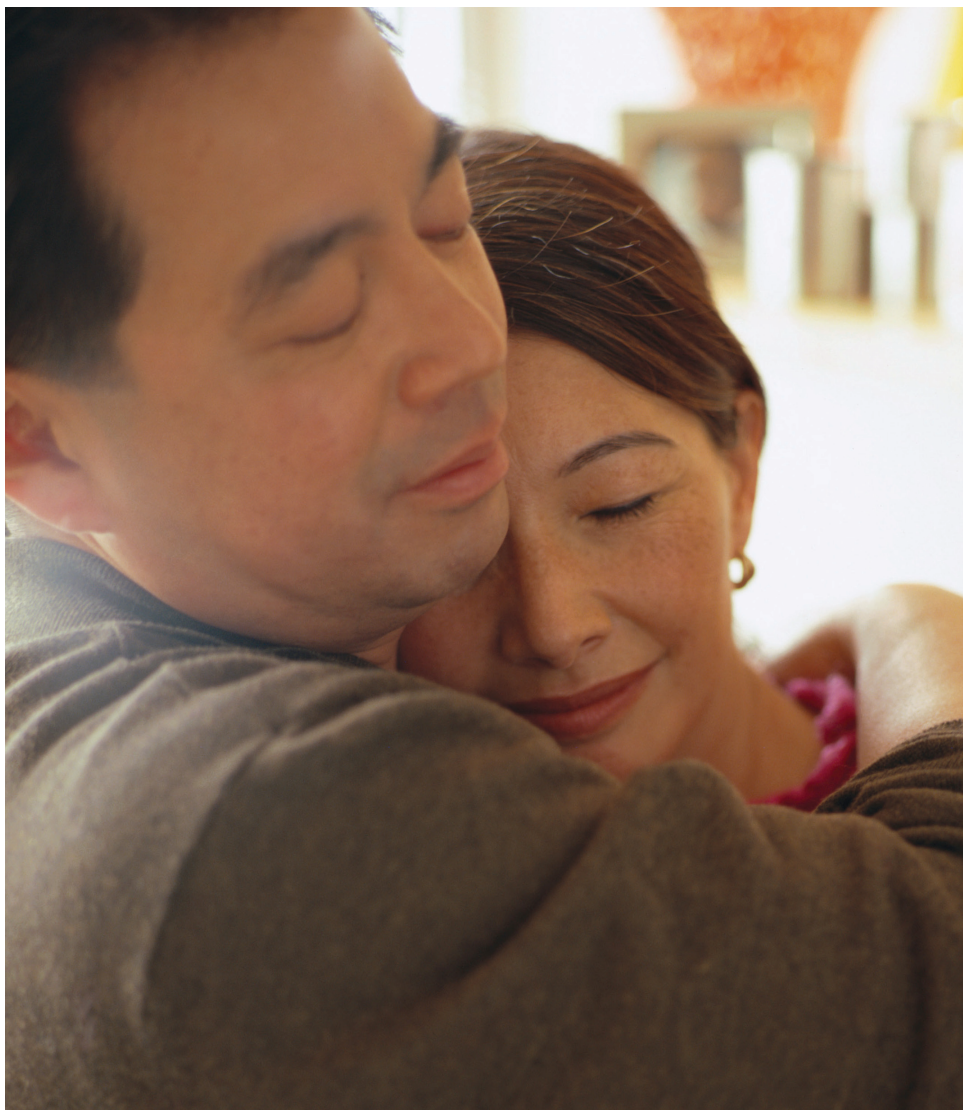


Distress in People With Cancer



What is distress?

Distress is a word that has many meanings. Here, we use “distress” to describe unpleasant feelings or emotions that may cause problems for you as you cope with cancer and its treatment.

Distress is common in people with cancer and in their family members and loved ones. It can make it harder to deal with the changes that come with a cancer diagnosis.

Saying that you are distressed can mean that you feel:

- Sad
- Hopeless
- Powerless
- Afraid
- Guilty
- Anxious
- Panic
- Discouraged
- Depressed
- Uncertain

The stress of dealing with cancer can affect parts of your life other than your feelings. It can affect how you think, what you do, and how you interact with others.

Some distress is normal

A certain amount of distress is normal when you or a loved one has cancer. This distress is caused, in part, because of the attitudes and fears people have about cancer.

People have concerns about what may happen to their bodies. They worry about how the people they care about will cope with cancer and all the things that may happen. And they have fears about what the future will be like. People often wonder, “Am I going to die?” and “Why is this happening to me?”

Once you learn that you or a loved one has cancer, you may no longer feel safe. You may feel afraid, exposed, weak, and vulnerable. Such feelings often last through treatment. Anxiety and sadness are common, too.

Waiting for surgery is another time of major concern. People often worry about the operation itself, but also about whether the cancer is growing while they wait. Fears about the changes that surgery will cause can be a major source of distress, too. Then there are concerns about work and home life and how they may change. Insurance and financial issues often add to the worries.

“

The worst time for me was waiting for that first chemo treatment. Once it was over, and it wasn't as bad as I thought it would be, I was OK. I actually felt better because I was finally doing something about the cancer.

Cancer is stressful

Dealing with the side effects of treatment – such as tiredness (fatigue), hair loss, weight changes, and how your life is disrupted is stressful. Sometimes high levels of distress make it hard to cope. Here, we will try to explain the range of distress – from normal to very high – and offer some tips on how to handle your feelings in healthy ways.

Having a supportive cancer care team can help you cope with distress. Talk to them about how you feel. They can direct you to the help you need.

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 distress you're having and how it's affecting you. There's a distress tool called the Distress Thermometer. It helps measure your distress. Your cancer care team may have asked you similar questions during your cancer visits. (See the example on page 4.)

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.

Another part of the Distress Thermometer 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.

Distress screening tool: the Thermometer and the Problem List

Please circle the number (0-10) that best describes how much distress you’ve had during the past week, including today.



Please read the list below. Have any of the following problems been a cause of your distress in the past week, including today? Be sure to check **NO** or **YES** for each.

NO	YES		NO	YES	
		Practical problems			Physical problems
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue (feeling tired)
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		Family problems	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
		Emotional problems	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Spiritual/religious concerns	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
			<input type="checkbox"/>	<input type="checkbox"/>	Memory or concentration
			<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
			<input type="checkbox"/>	<input type="checkbox"/>	Appearance
			<input type="checkbox"/>	<input type="checkbox"/>	Sexual

Other problems:

Once your cancer care team knows that you're having problems in certain areas, they can work with you to address those concerns. A nurse or social worker will often talk with you in more detail after you've filled out the Distress Thermometer and Problem List. You may be referred to other health care professionals like a counselor, social worker, nutritionist, or chaplain, if needed.

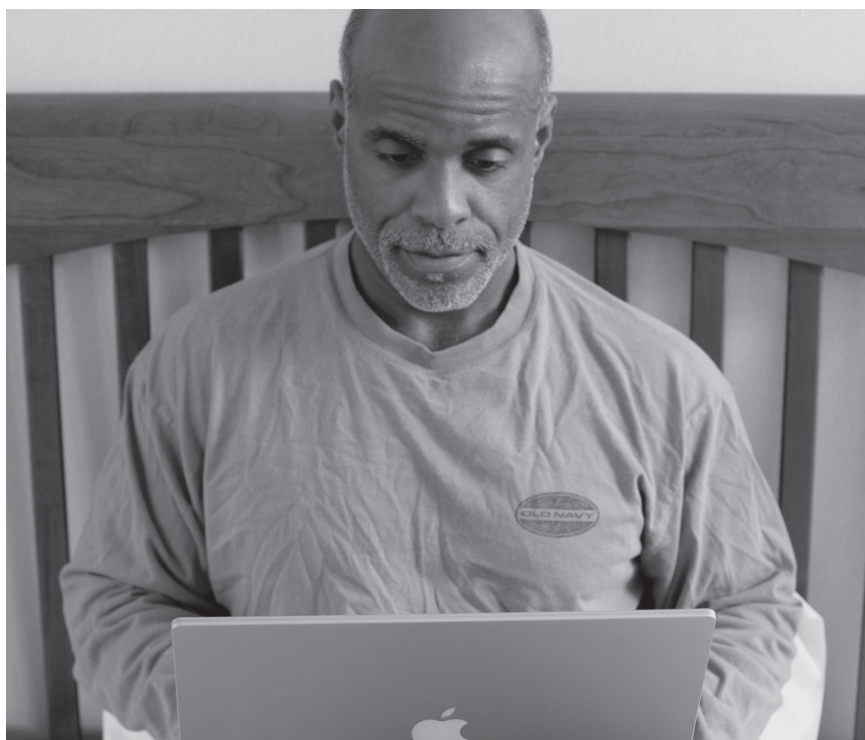
How can I help myself cope with cancer?

People value the care they get from their cancer care team, but many also want to take an active role in dealing with their illness. Dr. Jimmie Holland has spent more than 30 years caring for patients at Memorial Sloan-Kettering Cancer Center in New York, and offers some ideas on helpful ways to cope with cancer. They are listed by those attitudes and beliefs that are helpful (the Do's) and those that are harmful (the Don'ts).

DO

- **Rely on ways of coping that have helped you solve problems and crises in the past.** 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.”** 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 find a 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

- 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 smoking or some other habit, it does not help to blame yourself or beat yourself up.
- Feel guilty if you can't keep a positive attitude all the time. The saying "you have to be positive to beat cancer" is not true. 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 care of yourself better 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 or depression that disrupts your sleep, eating, ability to concentrate, ability to function normally, or if you feel your distress is getting out of control.

Other coping methods: 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.

Most people with cancer can do some form of exercise. 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. If you feel too weak to exercise, your doctor can refer a physical therapist to make a plan that will work for you and is safe.

Treating distress: Who can help?

The kind of problems you have and your level of distress will help decide which services can best help you. These services or referrals are usually covered in part by health insurance. Call your health insurance company to find out which professional services are covered and the dollar amount it will cover. An increasing number of cities and towns have free support groups sponsored by local hospitals, religious organizations, or cancer advocacy groups such as the American Cancer Society.

Social work

When the cancer care team wants to refer you to someone for your distress, a social worker may see you to find out whether your distress falls into the area of psychosocial or practical problems.

Psychosocial problems. The word psychosocial combines psychological, or mental, health with social conditions or aspects. Some psychosocial problems are practical problems.

- Trouble adjusting to illness
- Family and social isolation
- Family conflict
- Problems with treatment decisions
- Concern about the quality of life
- Problems adjusting to changes in care
- Making decisions for future medical care (advance directives)
- 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
- Cultural concerns
- Caregiver issues or the need to prepare for caregiving and set up caregiver support

Practical problems. These can range from day-today needs, such as food and clothing, to professional needs, such as job issues. Listed here are some of the more common practical problems that a social worker can help you and your family or loved ones manage:

- 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 (culture or language not the same as those around you)
- Finding help for family and caregivers

For practical problems that are causing only mild distress, the social worker might use patient and family education, suggest support group sessions, and/or offer resources. For more severe distress due to practical problems, social workers provide patient and family counseling. They may also be able to link people to community agencies, teach problem-solving approaches, help you get needed care, and offer education and support group sessions.

Mental health

Mental health services are used to evaluate and treat distress that's moderate to severe (4 or more on the distress scale). This 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 include:

- Major depression
- Dementia
- Trouble with concentration
- Memory problems
- Anxiety
- Panic attacks
- Mood disorders
- Personality disorders
- Adjustment disorders
- Substance abuse

All of these may be worsened by the distress of cancer.

Mental health professionals use a range of counseling 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.

Pastoral services

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. The clergy are 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 finding out you have cancer can lead to a crisis of faith or belief.

Treatment

Social workers work with patients and families with psychosocial problems by:

- Teaching patients and families
- Offering support and education group sessions for patients and families
- Giving you resource lists and finding community resources where you can get the help you need
- Counseling patients and families about relationships and grief

If the problems are more severe, patient and family counseling or psychotherapy may be used. Patients and/or families or loved ones may also be referred to psychosocial or psychiatric

treatment or pastoral counseling. Certain problems may involve sexual or grief counseling. The social worker may offer community resources that can help families and loved ones with serious issues, such as organizations that help women who are abused at home.

At this level, social workers teach you how to approach and resolve the problem in a way that works best for you. There are also times when the social worker must speak up for the patient who has no close family, or refer a family member to protective services if there's neglect at home. All patients are taught about how to better cope with illness.



Medicines

Usually, psychologists and social workers work with psychiatrists who can prescribe medicines to help manage distress. Sometimes a drug is needed to reduce distress related to cancer, or distress caused by a medicine to treat cancer or another serious symptom.

Choosing the right counselor

When you want to see a counselor, it's important to find one who has had some training and experience in taking care of people with cancer. Your cancer care team is the best way to get names of counselors in your area. Another resource, the American Psychosocial Oncology Society (APOS), can connect you to someone within 2 business days through their toll-free service at **1-866-276-7443** or at www.apos-society.org. They'll help you find a qualified professional in your area who can counsel people with cancer. If you see a counselor and don't feel comfortable or safe talking with them, call APOS and ask for other names.

More resources to help you

Cancer organizations

There's a broad range of psychological support services available for patients. Some provide group and telephone support, as well as information through the internet and written materials.

Internet resources

A large amount of information about cancer is available online. This information can be very useful to those facing cancer. It can help them make decisions about their illness and treatment, and help them find support. But any person or group can post information online, and it's important to look at the source of the information. Always remember, not all information is good or trustworthy. Some information can even be harmful if you act on it.

It's best to stay with websites that are supported by well-known cancer organizations with good reputations, where information is reviewed on a regular basis. Avoid websites that are selling a product or that make claims that can't be proved.



Distress is common in people with cancer and in their caregivers. Here we will help you learn more about distress, what it means, and how you can learn to deal with it.

For cancer information, day-to-day help, and emotional support, visit the American Cancer Society website at **www.cancer.org** or call us at **1-800-227-2345**. We're here when you need us.



cancer.org | 1.800.227.2345

©2018, American Cancer Society, Inc.
No.940405 Rev. 5/18
Models used for illustrative purposes only.