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

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 treatment 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

References


Mehta RD, Roth AJ. Psychiatric Considerations in the Oncology Setting. CA Cancer J Clin. 2015;65:300-314.


References


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