



NCCN
GUIDELINES
FOR PATIENTS®

2024

Distress During Cancer Care



Presented with support from



NATIONAL COMPREHENSIVE CANCER NETWORK®
FOUNDATION
Guiding Treatment. Changing Lives.

Available online at
NCCN.org/patientguidelines



About the NCCN Guidelines for Patients®



National Comprehensive
Cancer Network®

Did you know that top cancer centers across the United States work together to improve cancer care? This alliance of leading cancer centers is called the National Comprehensive Cancer Network® (NCCN®).



Cancer care is always changing. NCCN develops evidence-based cancer care recommendations used by health care providers worldwide. These frequently updated recommendations are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). The NCCN Guidelines for Patients plainly explain these expert recommendations for people with cancer and caregivers.

These NCCN Guidelines for Patients are based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management, Version 1.2024 — October 27, 2023.

View the NCCN Guidelines
for Patients free online
[NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines)

Find an NCCN Cancer
Center near you
[NCCN.org/cancercenters](https://www.nccn.org/cancercenters)

Connect with us



Supporters



NCCN Guidelines for Patients are supported by funding from the
NCCN Foundation®

NCCN Foundation gratefully acknowledges the following corporate supporters for helping to make available these NCCN Guidelines for Patients: AstraZeneca; Baxter International Inc.; Exelixis, Inc.; GSK; Ipsen Biopharmaceuticals, Inc., and Karyopharm Therapeutics.

NCCN independently adapts, updates, and hosts the NCCN Guidelines for Patients. Our corporate supporters do not participate in the development of the NCCN Guidelines for Patients and are not responsible for the content and recommendations contained therein.

To make a gift or learn more, visit online or email

NCCNFoundation.org/donate

PatientGuidelines@NCCN.org

Contents

- 4 About distress
- 7 Screening for distress
- 16 Treatment for distress
- 22 Making treatment decisions
- 31 Words to know
- 32 NCCN Contributors
- 33 NCCN Cancer Centers
- 36 Index

© 2023 National Comprehensive Cancer Network, Inc. All rights reserved. NCCN Guidelines for Patients and illustrations herein may not be reproduced in any form for any purpose without the express written permission of NCCN. No one, including doctors or patients, may use the NCCN Guidelines for Patients for any commercial purpose and may not claim, represent, or imply that the NCCN Guidelines for Patients that have been modified in any manner are derived from, based on, related to, or arise out of the NCCN Guidelines for Patients. The NCCN Guidelines are a work in progress that may be redefined as often as new significant data become available. NCCN makes no warranties of any kind whatsoever regarding its content, use, or application and disclaims any responsibility for its application or use in any way.

NCCN Foundation seeks to support the millions of patients and their families affected by a cancer diagnosis by funding and distributing NCCN Guidelines for Patients. NCCN Foundation is also committed to advancing cancer treatment by funding the nation's promising doctors at the center of innovation in cancer research. For more details and the full library of patient and caregiver resources, visit [NCCN.org/patients](https://www.NCCN.org/patients).

National Comprehensive Cancer Network (NCCN) and NCCN Foundation
3025 Chemical Road, Suite 100, Plymouth Meeting, PA 19462 USA

1

About distress

5 What is distress?

5 How can I get help?

6 Key points

Everyone with cancer becomes distressed at some point in time.

Distress is normal. There are standards of care for distress to help you get the resources you need.

the changes in your life. Distress is to be expected.

Cancer brings on many challenges. It affects your body but may also affect your relationships, work, and finances, just to name a few. These challenges are harder if distress is causing problems, too. Distress can affect a person's self-care, social life, mood, or faith.

What is distress?

Distress includes common feelings like sadness, worry, and anger but is much broader. It is defined as an unpleasant experience of a mental, physical, social, or spiritual nature. Distress can affect the way you think, feel, or act.

Distress is very common among people with cancer. It is normal to be concerned about

How can I get help?

If your cancer care team isn't asking about distress, let them know how you feel. Once your team knows your situation, they can help.

This book explains how your team can refer you to resources and what resources may be available to you. It includes expert recommendations for managing distress.

NCCN experts recommend care that is based on the latest science and practices at top

Distress and cancer

Distress among people with cancer varies greatly.
What causes distress for one person may not be a trigger for someone else.
Distress also affects people in different ways. There are many symptoms (shown here), and levels of distress range from mild to severe.



cancer centers. They emphasize several standards of care for distress, including:

- Distress should be routinely assessed with a screening tool. Screening tools are quick and simple. The screening tool developed by NCCN, called the NCCN Distress Thermometer and Problem List, is explained in Chapter 2.
- Screening tools should measure the level and nature of your distress. This information helps your care team know if you need help and if so, what kind of help you need. Distress can be caused by many things, such as cancer symptoms, work concerns, and grief.
- Qualified care providers should work together to provide help for distress. Types of trained providers are described in Chapter 2, and types of help that may be available to you are described in Chapter 3.

NCCN experts recently added a new standard of care. This new standard is a welcoming and fair system for managing cancer-related distress. Some people with cancer have experienced prejudice and discrimination because of their age, gender, mental health, or other factors. Such experiences may cause major distress and should not occur at cancer centers.

Read this book to learn more about distress. You may learn about help specific to your needs. In Chapter 4, there is a list of suggested questions to ask your care team. You're more likely to get the care you want by asking questions and making decisions with your team.

Key points

- Distress is normal, common, and expected among people who have cancer.
- Being distressed can make it harder to cope with cancer.
- You should expect to receive distress screening and help at cancer care visits.



I talk with people every day who are in a place of despair. When they call us, they've usually just experienced a one-two punch. First, they've been told they have cancer. Second, after receiving encouraging news that there is medication that can potentially save their lives, they are devastated to discover the out-of-pocket cost of the medication is beyond their financial means, because insurance won't pay the full amount."

2

Screening for distress

- 8 When to get screened
- 9 NCCN Distress Thermometer and Problem List
- 12 What to expect after screening
- 12 Referral to experts
- 15 Key points

Screening for distress is a key part of cancer care. This chapter describes the screening process and who can help you. Distress screening, when paired with getting help, improves lives.

When to get screened

Screening is a quick assessment of your level of distress and what is causing distress. Ideally, you would be screened at every health visit because distress can occur at any time. If that's not possible, screening should occur routinely and when you are likely to be distressed. **See Guide 1** for a list of times when distress is more likely.

Guide 1

Times when distress is more likely to start or worsen

During diagnosis

- A new symptom occurs, prompting testing
- Being tested for a health problem
- Finding out the diagnosis, such as cancer
- Getting a diagnosis of and living with advanced cancer
- Learning that a risk of cancer runs in your family

Before and during treatment

- Waiting for treatment to start
- Symptoms get worse
- Having a health problem that is caused by cancer treatment
- Starting another type of treatment
- Learning that treatment didn't work
- Being admitted to or discharged from a hospital

End of treatment

- Switching from active treatment to only survivorship care
- Getting cancer tests and other health care
- Learning that the cancer returned or worsened
- Starting end-of-life care
- Loss and grieving of family member, friend, or pet

During testing

You may become distressed when getting tests. An example is being distressed when getting tests for a lump or other symptom. After getting tested, you may need to wait for the results, which can be hard.

The first response to learning of a cancer diagnosis is often shock. You may also be worried, fearful, or sad. Further testing may be needed to learn more about the cancer that was found.

When cancer appears cured or well-controlled, people get tests on a regular basis. Going to check-up visits and waiting again for test results can be stressful. Distress is also common if the cancer returns or worsens.

During treatment

Waiting for treatment to start can trigger distress. Cancer treatment may cause distressing health problems (that is, complications and side effects). Distress is also common after learning that treatment didn't work.

During transitions in care

Distress can occur during transitions in care. Such transitions include being discharged from the hospital or finishing treatment. Shifting from frequent treatment visits to less frequent follow-up visits is a big change.

NCCN Distress Thermometer and Problem List

The NCCN Distress Thermometer and Problem List is a well-known screening tool among cancer care providers. It has been shown in many studies to work well.

The Distress Thermometer measures distress on a 0 to 10 scale. Higher scores mean greater distress.

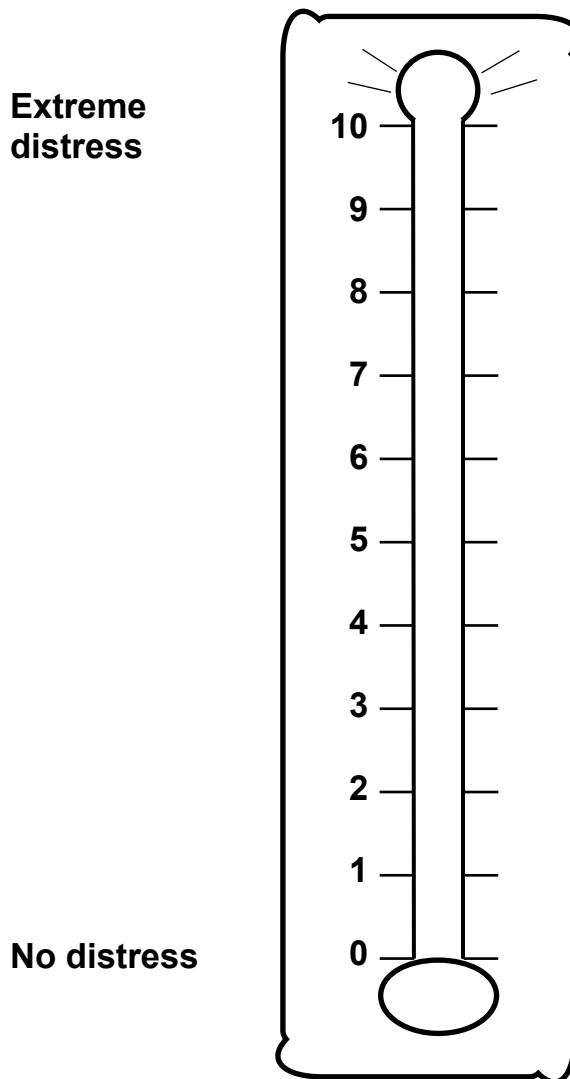
The Problem List includes problems from different areas of life. It can be changed to fit the hardships of a particular group of people. The Problem List will help your care team learn what is causing your distress and ask better follow-up questions. You will be referred to helpful resources.

If you aren't screened for distress at appointments, you can show your team your responses to the NCCN Distress Thermometer and Problem List that are on the next page.

NCCN Distress Thermometer

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.



Problem List

Have you had concerns about any of the items below in the past week, including today?
(Mark all that apply)

Physical Concerns

- Pain
- Sleep
- Fatigue
- Tobacco use
- Substance use
- Memory or concentration
- Sexual health
- Changes in eating
- Loss or change of physical abilities

Emotional Concerns

- Worry or anxiety
- Sadness or depression
- Loss of interest or enjoyment
- Grief or loss
- Fear
- Loneliness
- Anger
- Changes in appearance
- Feelings of worthlessness or being a burden

Social Concerns

- Relationship with spouse or partner
- Relationship with children
- Relationship with family members
- Relationship with friends or coworkers
- Communication with health care team
- Ability to have children
- Prejudice or discrimination

Practical Concerns

- Taking care of myself
- Taking care of others
- Work
- School
- Housing
- Finances
- Insurance
- Transportation
- Child care
- Having enough food
- Access to medicine
- Treatment decisions

Spiritual or Religious Concerns

- Sense of meaning or purpose
- Change in faith or beliefs
- Death, dying, or afterlife
- Conflict between beliefs and cancer treatment
- Relationship with the sacred
- Ritual or dietary needs

Other Concerns

What to expect after screening

Distress screening is usually fast. A member of your cancer care team will discuss the results with you. Your results will be used to get you the help you need.

Some types of distress may be managed by your cancer care team. Your team has a wide range of knowledge and skills. For some types of distress, they may refer you to people with a different set of knowledge and skills. After you complete screening of distress, a member of your team may:

- Assess your distress further
- Treat ongoing physical symptoms
- Manage mild distress symptoms
- Refer you to experts in distress

“

It's hard to deal with all of the things that happen at once, and not to just collapse and worry and stress.”

Referral to experts

There are providers who have completed special training for treating distress. Your cancer care team may refer you to one or more of these experts based on your screening results. In this section, some of the experts in distress are described. Their qualifications and the issues they treat are explained.

Chaplains

You may mark on a screening tool that you have spiritual or religious concerns. Many cancer centers have a chaplain on staff. If not, your cancer care team will likely know of one in the community. Many people who are distressed are interested in meeting with a chaplain.

Many chaplains are certified and have finished a specific course of training to provide chaplaincy services. They are certified as either board-certified chaplains or associate certified chaplains.

Chaplains help people of any faith or no faith. They provide care for issues like:

- Conflicts between beliefs and treatment
- Concerns or needs relating to faith, purpose, or meaning of life
- Concerns about dying or the afterlife
- Relationship with the sacred
- Ritual or dietary needs

Social workers

Social workers help people cope with life challenges. They have earned either a bachelor's or master's degree in social work. Some go on to earn a doctoral degree.

Social workers can choose a specific area of practice. Oncology social workers provide a range of services to the cancer community. Clinical social workers are mental health professionals and must obtain a state license to practice.

Social workers provide help for practical and psychosocial problems, such as:

- Housing, food, and transportation
- Insurance and bills
- Assistance with self-care and dependent care
- Coping with a cancer diagnosis and treatment
- Treatment decisions and advance directives
- Grief, loss, and adjusting to changes in one's health and body
- Anxiety, trauma, depression, and thoughts of suicide
- Family, social, and cultural issues

Early distress screening leads to timely management of distress. Better management of distress in turn improves self-care and health outcomes.



Psychologists

Psychologists are experts in how people think, feel, and behave. Most have a doctoral degree. Some pursue more training in a post-doctoral fellowship, obtain board certification, or both.

Psychologists who provide clinical services include clinical psychologists, counseling psychologists, health psychologists, neuropsychologists, and school psychologists.

A state license is required to provide clinical services. In some states, psychologists can prescribe medications for mental health after obtaining the proper education, training, and state certification.

Depending on their training, psychologists provide treatment for the following:

- Health issues, such as pain, weight, sleep, sex, and taking medications as prescribed
- Cognitive problems, such as dementia and chemo brain
- Mood and anxiety problems, such as depression, panic, and worry
- Substance use, such as drugs, alcohol, and smoking
- Thoughts of suicide
- Relationship issues, such as caregiving strains and social conflicts

Psychiatrists

Psychiatrists are licensed medical doctors who specialize in mental health. They are experts in how the body and mind affect each other. They are able to assess both physical and mental health.

Most psychiatrists become board-certified in psychiatry. They can obtain more training and become certified in a particular area. These areas include child and adolescent psychiatry, geriatric psychiatry, addiction psychiatry, and consultation-liaison psychiatry. Some consultation-liaison psychiatrists specialize in working with patients with cancer.

Psychiatrists are trained to treat mental, emotional, and addictive disorders. Some of the common disorders treated by psychiatrists include depression, general anxiety, bipolar, panic, psychotic, eating, and substance use disorders. Psychiatrists may be particularly helpful for mental disorders that:

- Are hard to diagnose
- Occur with physical conditions
- Require medication to manage
- Need treatment in a hospital
- Occur suddenly or over a long period of time
- Are not responding to standard treatment

Nurses

There are many types of nurses who care for people with cancer. A registered nurse (RN) is the most common type. Nurses need a state license to practice.

Another type of nurse is an advanced practice registered nurse (APRN). An APRN is an RN who has earned at least a master's degree in nursing. APRNs can prescribe medication.

Nurses can also obtain certification in specialty areas. Examples of certification include oncology and psychiatry. Oncology nurses provide a high quality of care to people with cancer. Psychiatric nurses are mental health experts.

Nurses are on the front line of cancer care. They are often the first to detect that a person is distressed. They may be the one to screen you for distress. Across the many types of nursing, nurses provide help for a wide range of problems related to distress, such as:

- Practical matters like needing a ride to appointments
- Lack of knowledge about cancer
- Physical symptoms and illnesses
- Complex health care systems
- Mental health symptoms and disorders

Key points

- Screening for distress is quick and should be done routinely.
- The NCCN Distress Thermometer and Problem List assess the level and nature of your distress.
- Your cancer care team will treat mild distress or refer you to experts in distress.
- Experts in distress have obtained education, training, and credentials to conduct evaluations and provide treatment.



share with us.

Take our survey,
and help make the
NCCN Guidelines for Patients
better for everyone!

[NCCN.org/patients/comments](https://www.nccn.org/patients/comments)

3

Treatment for distress

- 17 Cancer care team
- 18 Chaplaincy care
- 18 Social work and counseling services
- 19 Mental health services
- 21 Key points

There is a wide range of help for distress. This chapter is an overview of the common types of help for people with cancer.

Cancer care team

The cancer care team often manages mild distress. Mild distress is also called expected distress. It includes worry about the future and concerns about treatment. Your team can manage mild distress by:

- Explaining that distress is normal and what to expect
- Providing education on cancer and its treatment
- Discussing advance care planning
- Prescribing medication for symptoms
- Preventing gaps in care between health care providers
- Teaching new or better ways to cope
- Sharing information about resources at your cancer center and in your community



Cancer education

Having cancer is very stressful. One stressor is the need to learn about cancer. Your care team can answer questions and direct you to trusted educational resources. Learning from trusted educational resources can be very helpful and reduce stress.

There may be a learning center at your cancer center. The learning center may have printed materials or have access to online resources. Health educators can help you find trusted information.

Your cancer center may have a patient navigator program. Patient navigators educate. They can explain your plan of care. They can tell you what to expect at appointments and from treatment. They can give you educational materials.

NCCN has a growing library of NCCN Guidelines for Patients®. These resources are a good starting point from which to learn the best options for cancer care. Your cancer care team can provide more information to help you make treatment decisions. The entire library of NCCN Guidelines for Patients can be found at [NCCN.org/patientguidelines](https://www.NCCN.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.

Chaplaincy care

Many people with cancer find spirituality or religion helpful. People use spiritual or religious resources to cope with cancer. Receiving spiritual support may improve quality of life and satisfaction with care.

A chaplain can help whether you have strong beliefs, different beliefs, conflicted beliefs, or no beliefs. Chaplains provide a range of services, including:

- Spiritual or existential support to foster peace and comfort
- Counseling in line with your faith or beliefs
- Guidance to discover spirituality or purpose
- Prayer
- Guided meditation
- Spiritual or religious rituals
- Serving as a liaison between patients and spiritual communities
- Referral to health care providers

Social work and counseling services

Social workers provide services for practical or psychosocial problems. Patient navigators and case managers may be of help, too. Practical problems commonly relate to illness, food, money, work, school, language, and caregiving. Psychosocial problems include mental and social effects of cancer.

People with practical and psychosocial problems are often helped by social work and counseling services. Otherwise, some of these problems may be addressed by mental health services, which are described in the next section. Social workers address practical and psychosocial problems by:

- Connecting patients to resources
- Advocating on behalf of patients
- Teaching patients and families
- Leading support groups
- Counseling patients, couples, and families
- Contacting protective services
- Giving a referral to a mental health provider
- Giving a referral to a chaplain

Mental health services

There are many types of mental health providers. The work of these providers overlaps, but their expertise varies. You should be referred to a provider who is a good fit for your needs. Examples of mental health providers include:

- Clinical social workers
- Psychologists
- Advanced practice clinicians
- Psychiatric nurses
- Addiction medicine specialists
- Psychiatrists

Evaluation

The first step of care is often an evaluation to assess the problem. Evaluations differ between people based on the type of distress. You may be evaluated for:

- Changes in behavior
- Pain, fatigue, or lack of sleep
- Sexual health
- Current and past mental health
- Treatment history
- Medical causes
- Alcohol and drug use
- Cognitive problems
- Body image
- Suicidal thoughts and plan
- Safety



Counseling and psychotherapy

Some people think of psychotherapy and counseling as the same thing. Both help people feel better, solve problems, and achieve life goals. Both are sometimes called “talk therapy.”

Many providers think of these as two distinct treatments. Counseling is often thought of as short-term help for outward behaviors. In contrast, psychotherapy is in-depth, sometimes long-term, help that addresses the inner person. The differences between the two treatments have lessened over time.

Counseling often focuses on a specific issue. Examples include adjusting to illness, grief, and stress management. The methods used in counseling vary based on the issue.

Psychotherapy can help with a broad range of mental health needs. Cognitive behavioral therapy (CBT) focuses on changing thoughts and actions that contribute to poor mental health. It can help with depression, anxiety, pain, and fatigue among people with cancer.

Supportive psychotherapy uses a flexible approach to meet people’s changing needs. It is widely used to help people with cancer. Subtypes of this psychotherapy include supportive-expressive, cognitive-existential, and meaning-centered psychotherapy.

Treatment

There are many types of mental health treatment. Based on the evaluation, your provider will make a treatment plan tailored to you. Mental health treatment works well to reduce distress and improve quality of life among people with cancer.

Types of mental health treatment include:

- Watchful waiting on level of distress
- Education on mental health issues
- Psychotherapy or counseling; also called “talk therapy”
- Cognitive rehabilitation to improve brain functioning
- Behavioral management
- Suicide prevention
- Psychiatric medication
- Medications for drug detoxification and to prevent relapse
- Electroconvulsive therapy
- Hospital care, residential treatment, and specialized programs
- Exercise
- Integrative (or complementary) therapy like yoga or meditation



Psychiatric medications

Psychiatric (or psychotropic) medications are drugs that improve mental health. Psychiatric medications are grouped by how they are commonly used.

Antidepressants are commonly used to treat depression. Depression is often experienced as feeling down or irritable most of the day for weeks. Antidepressants are also used to treat anxiety and certain physical problems like pain.

Anxiolytics may be used with psychotherapy to treat anxiety. Key features of anxiety include severe fear or worry, panic attacks, and strong behavioral impulses.

Mood stabilizers treat bipolar-related disorders. The key feature of bipolar disorders is an episode of elevated mood called mania.

Antipsychotics treat psychotic disorders. Features of psychotic disorders include perceiving unreal sensations, fixed false beliefs, and disorganized thinking.

Antipsychotics treat other health conditions, too. They may be used to treat anxiety if other medications did not work. Antipsychotics are also used to treat delirium—a short-term disturbance in mental abilities. Delirium occurs in people with advanced cancer. It can also be triggered by some types of medicines.

Key points

- The cancer care team often treats mild distress.
- A chaplain can help people of any faith or no faith. Chaplains provide support, counseling, and guidance to people in need.
- Social workers provide help for practical or psychosocial problems. These problems may be relieved by learning new information or skills, counseling, attending support groups, or community resources.
- Mental health providers perform evaluations to inform treatment planning. Common mental health services include education, psychotherapy, and prescribing medications.



Let us know what you think!

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.

[NCCN.org/patients/response](https://www.nccn.org/patients/response)

4

Making treatment decisions

23 It's your choice

23 Questions to ask

29 Resources

It is important to be comfortable with the health care you choose.

This choice starts with having a candid conversation with your care team.

It's your choice

In shared decision-making, you and your care team share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your team.

Care decisions are very personal. What is important to you may not be important to someone else. Some things that may play a role in your decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments
- Your feelings about pain or side effects
- Cost of treatment, travel to treatment centers, and time away from school or work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from cancer care including care for distress. Discuss openly

the risks and benefits of your options. Share concerns with your care team.

Second opinion

It is normal to want to get help as soon as possible. While mental health should not be ignored, there is time to have another provider suggest a treatment plan. This is called getting a second opinion, and it's a normal part of medical care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see providers who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the provider you will see for your second opinion.

Questions to ask

Possible questions to ask your cancer care team are listed on the following pages. Feel free to use these or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment.

Questions about distress

1. Is my symptom(s) part of being distressed?
 2. Will my distress just go away in time?
 3. How can you help me?
 4. How can I help myself?
 5. What help will my insurance cover?
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-

Questions about cancer

1. What tests will I have?
 2. Does any treatment option offer a cure or long-term cancer control?
 3. What are the possible complications and side effects of treatment?
 4. What does each option require of me in terms of travel, time off, costs, and so forth?
 5. What can be done to prevent or relieve side effects?
 6. What are my chances that the cancer will return or worsen?
 7. What resources and support are available to me and my caregivers?
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-

Questions about spiritual care

1. What do chaplains do?
 2. Are chaplains of a specific faith?
 3. Can a chaplain help me if we're not of the same faith or if I have no faith?
 4. Can a chaplain help other family members?

Questions about social work and counseling

1. What do social workers do?
 2. Can you help me find a local support group?
 3. Is there help for the high costs of cancer care?
 4. Can you show me how to talk with my children, family, and friends?
 5. How do I deal with people who are treating me differently?
 6. How can counseling help with intimacy?
 7. Can you help me get an advance directive?
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-

Questions about mental health services

1. What's the difference between the different types of mental health providers?
2. What's your expertise?
3. What are you testing me for? How long does testing take?
4. How will psychoeducation help me?
5. Will psychiatric medicine affect my cancer treatment? How long until the medicine works? What are the side effects of psychiatric medicine? How long do I need to take psychiatric medicine?
6. How does talk therapy help with distress? How do I choose a therapist?
7. Is there proof that complementary therapy or exercise helps distress?

Resources

AIM at Melanoma
aimatmelanoma.org

Bag It
bagitcancer.org

Be the Match
BetheMatch.org/one-on-one

Breastcancer.org
Breastcancer.org

Breast Cancer Alliance
breastcanceralliance.org

Cancer Hope Network
canceropennetwork.org

DiepC Foundation
DiepCfoundation.org

FORCE: Facing Our Risk of Cancer Empowered
facingourrisk.org

Ovarian Cancer Research Alliance
ocrahope.org

Overcome
Overcome.org



We want your feedback!

Our goal is to provide helpful and easy-to-understand information on cancer.

Take our survey to let us know what we got right and what we could do better.

NCCN.org/patients/feedback

Sharsheret
sharsheret.org

Triage Cancer
triagecancer.org

Unite for HER
Uniteforher.org



Words to know

addiction medicine specialist

A medical doctor who's an expert in unhealthy use of substances.

APRN

Advanced practice registered nurse

CBT

Cognitive behavioral therapy

chaplain

A trained expert in providing spiritual care.

diagnosis

To identify a disease.

distress

An unpleasant experience of a mental, physical, social, or spiritual nature.

NCCN®

National Comprehensive Cancer Network®

RN

Registered nurse

psychiatrist

A medical doctor who's an expert in mental health.

psychologist

A trained expert in the human mind and behavior.

screening tool

A short assessment for a condition.

side effect

An unplanned physical or emotional response to treatment.

social worker

An expert in meeting people's social and emotional needs.

substance use disorder

Repeated use of alcohol, drugs, or tobacco that causes major life problems.

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management, Version 1.2024. It was adapted, reviewed, and published with help from the following people:

Dorothy A. Shead, MS
*Senior Director
 Patient Information Operations*

Laura J. Hanisch, PsyD
Patient Information Program Manager

Laura Phillips
Graphic Artist

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management, Version 1.2024 were developed by the following NCCN Panel Members:

*Michelle B. Riba, MD, MS/Chair
University of Michigan Rogel Cancer Center

Jessica Vanderlan, PhD/Vice-Chair
Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

Kristine A. Donovan, PhD, MBA/Immediate Past Vice-Chair
Moffitt Cancer Center

Kauser Ahmed, PhD
UCLA Jonsson Comprehensive Cancer Center

Barbara Andersen, PhD
The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute

Ilana Braun, MD
Dana-Farber/Brigham and Women's Cancer Center

William S. Breitbart, MD
Memorial Sloan Kettering Cancer Center

Benjamin W. Brewer, PsyD
University of Colorado Cancer Center

*Cheyenne Corbett, PhD
Duke Cancer Institute

Jesse Fann, MD, MPH
Fred Hutchinson Cancer Center

Jill Farabelli, LCSW, APHSW-C
Abramson Cancer Center at the University of Pennsylvania

Stewart Fleishman, MD
Consultant

Sofia Garcia, PhD
Robert H. Lurie Comprehensive Cancer Center of Northwestern University

Donna B. Greenberg, MD
Mass General Cancer Center

*Rev. George F. Handzo, MA, MDiv
Consultant

Laura Herald Hoofring, MSN, APRN
The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

Amy Horyna, MSW, LCSW, OSW-C
Huntsman Cancer Institute at the University of Utah

Chao-Hui Huang, PhD, MEd, MA
O'Neal Comprehensive Cancer Center at UAB

Sean Hutchinson, MD
UT Southwestern Simmons Comprehensive Cancer Center

Shelley Johns, PsyD
Indiana University Melvin and Bren Simon Comprehensive Cancer Center

*Jennifer Keller, LSW, MSS
Fox Chase Cancer Center

Sheila Lahijani, MD
Stanford Cancer Institute

Sara Martin, MD
Vanderbilt-Ingram Cancer Center

Shehzad K. Niazi, MD
Mayo Clinic Comprehensive Cancer Center

Megan Pailler, PhD
Roswell Park Comprehensive Cancer Center

*Francine Parnes, JD, MA
Patient Advocate

Vinay Rao, DO
Yale Cancer Center/Smilow Cancer Hospital

Xiomara Rocha-Cadman, MD
City of Hope National Medical Center

Eli Scher, DO
Case Comprehensive Cancer Center/University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute

Jessica Schuster, MD
University of Wisconsin Carbone Cancer Center

Melissa Teply, MD
Fred & Pamela Buffett Cancer Center

Lora Thompson, PhD
Moffitt Cancer Center

Angela Usher, PhD
UC Davis Comprehensive Cancer Center

Alan D. Valentine, MD
The University of Texas MD Anderson Cancer Center

NCCN

Susan Darlow, PhD
Manager, Guidelines Information Standardization

Sarah Montgomery, BA
Guidelines Layout Specialist

* Reviewed this patient guide. For disclosures, visit [NCCN.org/disclosures](https://www.NCCN.org/disclosures).

NCCN Cancer Centers

Abramson Cancer Center
at the University of Pennsylvania
Philadelphia, Pennsylvania
800.789.7366 • pennmedicine.org/cancer

Case Comprehensive Cancer Center/
University Hospitals Seidman Cancer Center and
Cleveland Clinic Taussig Cancer Institute
Cleveland, Ohio
UH Seidman Cancer Center
800.641.2422 • uhhospitals.org/services/cancer-services
CC Taussig Cancer Institute
866.223.8100 • my.clevelandclinic.org/departments/cancer
Case CCC
216.844.8797 • case.edu/cancer

City of Hope National Medical Center
Duarte, California
800.826.4673 • cityofhope.org

Dana-Farber/Brigham and Women's Cancer Center |
Mass General Cancer Center
Boston, Massachusetts
617.732.5500 • youhaveus.org
617.726.5130 • massgeneral.org/cancer-center

Duke Cancer Institute
Durham, North Carolina
888.275.3853 • dukecancerinstitute.org

Fox Chase Cancer Center
Philadelphia, Pennsylvania
888.369.2427 • foxchase.org

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska
402.559.5600 • unmc.edu/cancercenter

Fred Hutchinson Cancer Center
Seattle, Washington
206.667.5000 • fredhutch.org

Huntsman Cancer Institute at the University of Utah
Salt Lake City, Utah
800.824.2073 • healthcare.utah.edu/huntsmancancerinstitute

Indiana University Melvin and Bren Simon
Comprehensive Cancer Center
Indianapolis, Indiana
888.600.4822 • www.cancer.iu.edu

Mayo Clinic Comprehensive Cancer Center
Phoenix/Scottsdale, Arizona
Jacksonville, Florida
Rochester, Minnesota
480.301.8000 • *Arizona*
904.953.0853 • *Florida*
507.538.3270 • *Minnesota*
mayoclinic.org/cancercenter

Memorial Sloan Kettering Cancer Center
New York, New York
800.525.2225 • mskcc.org

Moffitt Cancer Center
Tampa, Florida
888.663.3488 • moffitt.org

O'Neal Comprehensive Cancer Center at UAB
Birmingham, Alabama
800.822.0933 • uab.edu/onealcancercenter

Robert H. Lurie Comprehensive Cancer Center
of Northwestern University
Chicago, Illinois
866.587.4322 • cancer.northwestern.edu

Roswell Park Comprehensive Cancer Center
Buffalo, New York
877.275.7724 • roswellpark.org

Siteman Cancer Center at Barnes-Jewish Hospital
and Washington University School of Medicine
St. Louis, Missouri
800.600.3606 • siteman.wustl.edu

St. Jude Children's Research Hospital/
The University of Tennessee Health Science Center
Memphis, Tennessee
866.278.5833 • stjude.org
901.448.5500 • uthsc.edu

Stanford Cancer Institute
Stanford, California
877.668.7535 • cancer.stanford.edu

The Ohio State University Comprehensive Cancer Center -
James Cancer Hospital and Solove Research Institute
Columbus, Ohio
800.293.5066 • cancer.osu.edu

The Sidney Kimmel Comprehensive
Cancer Center at Johns Hopkins
Baltimore, Maryland
410.955.8964
www.hopkinskimmelcancercenter.org

The UChicago Medicine Comprehensive Cancer Center
Chicago, Illinois
773.702.1000 • uchicagomedicine.org/cancer

The University of Texas MD Anderson Cancer Center
Houston, Texas
844.269.5922 • mdanderson.org

UC Davis Comprehensive Cancer Center
Sacramento, California
916.734.5959 • 800.770.9261
health.ucdavis.edu/cancer

UC San Diego Moores Cancer Center
La Jolla, California
858.822.6100 • cancer.ucsd.edu

UCLA Jonsson Comprehensive Cancer Center
Los Angeles, California
310.825.5268 • cancer.ucla.edu

UCSF Helen Diller Family
Comprehensive Cancer Center
San Francisco, California
800.689.8273 • cancer.ucsf.edu

University of Colorado Cancer Center
Aurora, Colorado
720.848.0300 • coloradocancercenter.org

University of Michigan Rogel Cancer Center
Ann Arbor, Michigan
800.865.1125 • rogelcancercenter.org

University of Wisconsin Carbone Cancer Center
Madison, Wisconsin
608.265.1700 • uwhealth.org/cancer

UT Southwestern Simmons
Comprehensive Cancer Center
Dallas, Texas
214.648.3111 • utsouthwestern.edu/simmons

Vanderbilt-Ingram Cancer Center
Nashville, Tennessee
877.936.8422 • vicc.org

Yale Cancer Center/Smilow Cancer Hospital
New Haven, Connecticut
855.4.SMILOW • yalecancercenter.org

Notes

Index

- addiction medicine specialist** 19, 31
- cancer education** 17
- chaplaincy** 12, 18
- counseling** 18–21, 27
- distress**
 - experts** 12–15
 - screening** 6, 8–9, 12–13
 - symptoms** 5
- NCCN Distress Thermometer and Problem List** 7, 9, 15
- exercise** 28
- health educator** 17
- integrative therapy** 20
- nurse** 15, 19
- patient navigator** 17
- psychiatric medicine** 20, 28
- psychiatrist** 14, 19
- psychologist** 14, 19
- psychotherapy** 19–21
- social worker** 13, 19, 27





NCCN
GUIDELINES
FOR PATIENTS®

Distress During Cancer Care

2024

To support the NCCN Guidelines for Patients, visit

NCCNFoundation.org/Donate



National Comprehensive
Cancer Network®

3025 Chemical Road, Suite 100
Plymouth Meeting, PA 19462
215.690.0300

NCCN.org/patients – For Patients | NCCN.org – For Clinicians