



NCCN
GUIDELINES
FOR PATIENTS®

Version 1.2017

Please complete
our online survey at
NCCN.org/patients/survey

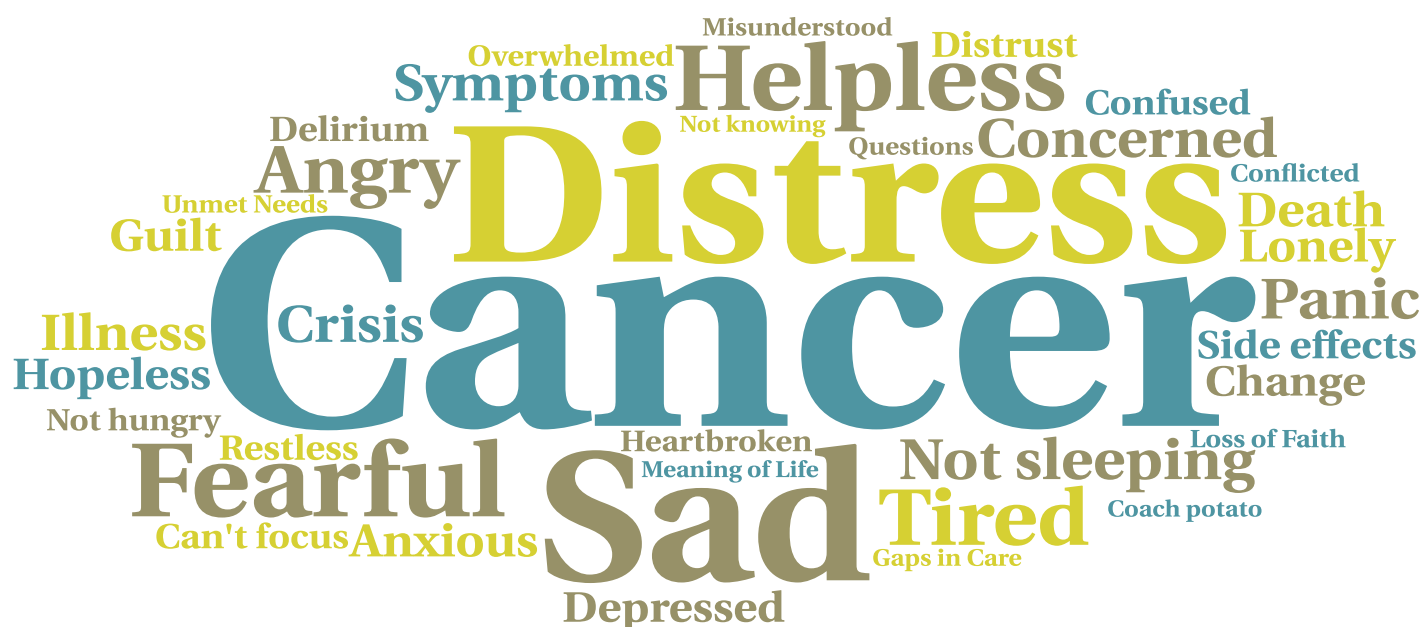
Distress

SUPPORTIVE CARE BOOK SERIES

Presented with support from:



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



Available online at NCCN.org/patients



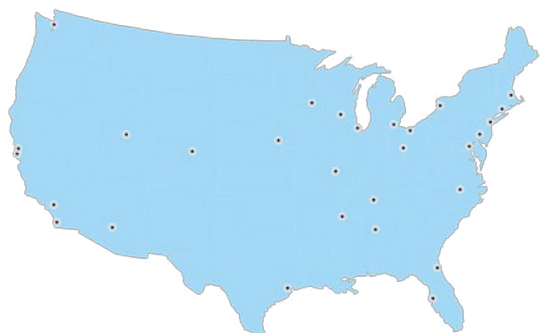
EVERYONE with cancer has some level of distress at some point in time.

The first goal of this book is to help you and your cancer care team talk about distress throughout your cancer journey. The second goal is to help you get relief from distress if needed.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world's leading cancer centers. Experts from NCCN have written guidelines on distress management for cancer care teams and psychosocial professionals. These guidelines suggest the best practice for distress management. The information in this patient book is based on the guidelines written for health care workers.

This book focuses on distress management. Key points of the book are summarized in the related [NCCN Quick Guide™](#). NCCN also offers patient resources on nausea and vomiting, adolescents and young adults with cancer, lung cancer screening, and treatment for many types of cancer. Visit [NCCN.org/patients](https://www.nccn.org/patients) for the full library of patient books, summaries, and other resources.

About



These patient guides for cancer care are produced by the National Comprehensive Cancer Network® (NCCN®).

The mission of NCCN is to improve cancer care so people can live better lives. At the core of NCCN are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN Guidelines® contain information to help health care workers plan the best cancer care. They list options for cancer care that are most likely to have the best results. The NCCN Guidelines for Patients® present the information from the NCCN Guidelines in an easy-to-learn format.

Panels of experts create the NCCN Guidelines. Most of the experts are from NCCN Member Institutions. Their areas of expertise are diverse. Many panels also include a patient advocate. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors.

For more information about the NCCN Guidelines, visit NCCN.org/clinical.asp.

Dorothy A. Shead, MS
*Director, Patient and
Clinical Information
Operations*

Alycia Corrigan
Medical Writer

Susan Kidney
*Graphic Design
Specialist*

Laura J. Hanisch, PsyD
*Medical Writer/Patient
Information Specialist*

Rachael Clarke
*Guidelines Data and
Layout Coordinator*

Kimberly Williams
*Graphic Design and
Production Specialist*



NCCN Foundation was founded by NCCN to raise funds for patient education based on the NCCN Guidelines. NCCN Foundation offers guidance to people with cancer and their caregivers at every step of their cancer journey. This is done by sharing key information from the world's leading cancer experts. This information can be found in a library of NCCN Guidelines for Patients® and other patient education resources. NCCN Foundation is also committed to advancing cancer treatment by funding the nation's promising doctors at the center of cancer research, education, and progress of cancer therapies.

For more information about NCCN Foundation, visit NCCNFoundation.org.

© 2017 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.

National Comprehensive Cancer Network (NCCN) • 275 Commerce Drive, Suite 300 • Fort Washington, PA 19034 • 215.690.0300

Endorsed and sponsored in part by



Good Days

Good Days is proud to support this educational resource for patients and their families and offers unwavering commitment to those who struggle with chronic disease, cancer, and other life-altering conditions.

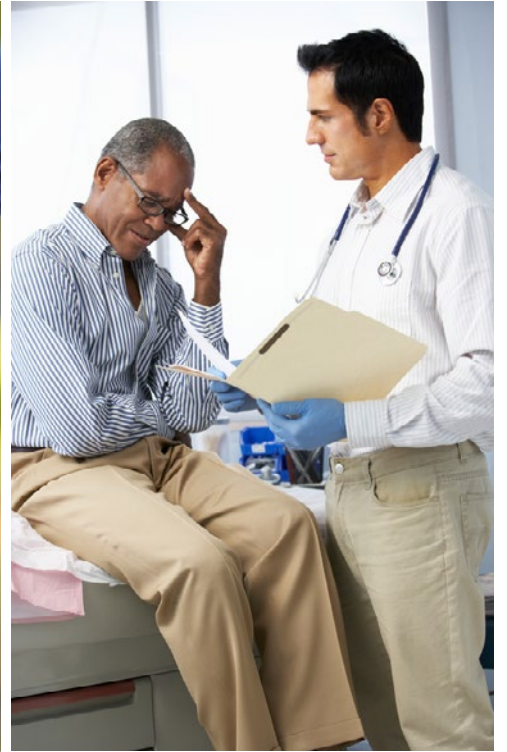
Good Days is a national, independent 501(c)(3) non-profit charitable organization that provides financial assistance to patients so that they do not have to choose between getting the treatment they need and affording the necessities of everyday living.

www.mygooddays.org

Endorsed by

American Psychosocial Oncology Society

American Psychosocial Oncology Society (APOS) is pleased to endorse the NCCN Guidelines for Distress. APOS stands behind early psychosocial distress screening and distress management of cancer patients as an integral part of comprehensive cancer care. Education about distress management for those affected by cancer and all who support them will prove most valuable throughout the cancer journey. The NCCN guidelines provide this resource in an easily navigated document. apos-society.org



Contents

- 6 How to use this book
- 7 Part 1
What is distress?
Explains why distress is important in cancer care.
- 13 Part 2
How distressed are you?
Describes the tools used to assess distress.
- 22 Part 3
What help is there?
Explains the types of treatment for distress.
- 28 Part 4
Have you received help?
Provides information to make getting help easier.
- 36 Glossary
Dictionary
Acronyms
- 40 NCCN Panel Members
- 41 NCCN Member Institutions
- 42 Index

Who should read this book?

Distress is very common among people with cancer. Patients and those who support them—caregivers, family, and friends—may find this book helpful. It may help you talk with your cancer care team about your distress and get help if needed.

Where should you start reading?

Part 1 is a good starting point to learn what distress is. In **Part 2**, the tools used to assess for distress are described, and in **Part 3**, the types of help for distress are described. **Part 4** provides information to help you talk with your health care providers and obtain help.

Does the whole book apply to you?

This book includes information for many people. Your cancer care team can point out what parts of the book apply to you. They can also give you more information. As you read through this book, it may help to make a list of questions to ask your health care providers.

Help! What do the words mean?

In this book, medical words are included. Some of these words may be new to you. Don't be shy to ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the *Dictionary*. Acronyms are also defined when first used and are in the *Glossary*. Acronyms are short words formed from the first letters of several words. One example is CBT for **cognitive behavioral therapy**.

1

What is distress?

8 Distress defined

9 Outcomes

10 Causes and risks

10 Triggers

12 Review



Part 1 explains the basics about distress. You can learn what distress is and how it may affect your life. Part 1 also describes who may have higher levels of distress. Likewise, the time points at which distress is more likely are listed.

Distress defined

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.

Distress occurs across a range of experience. It can be mild and consist of common feelings like sadness, fear, and helplessness. On the other hand, it can be more severe. Higher levels of distress can cause problems in one or more areas of life. You may struggle with taking care of yourself, your social life, emotions, faith, and so forth.

Everyone with cancer has some distress at some point in time. It is normal to feel sad, fearful, and helpless. You are not “crazy” if you are distressed. Distress is expected.

There are many symptoms of distress. See [Guide 1](#). The type and number of symptoms differ between people. Certain symptoms can be caused by things other than distress. Thus, it is important to tell your treatment team if you have any of these symptoms. Tips for talking with your cancer care team are given in Part 4.

Guide 1. Symptoms of distress

Some symptoms of distress are:

- Sadness, fear, and helplessness
- Anger, feeling out of control
- Questioning your faith, your purpose, the meaning of life
- Pulling away from too many people
- Concerns about illness
- Concerns about your social role (ie, as mother, father, caregiver)
- Poor sleep, appetite, or concentration
- Depression, anxiety, panic
- Frequent thoughts of illness and death

Outcomes

Distress is linked with a number of negative factors. This section describes some of the outcomes of distress and other factors that are linked to distress. These negative factors are some of the reasons why distress screening and treatment are so important.

By definition, being distressed isn't pleasant.

Feeling lousy doesn't make coping with cancer any easier. You have enough on your plate learning about cancer, going through treatment or follow-up care, and doing your everyday duties.

Distress may affect how well you function. It can interfere with sleep. You might sleep less or more than normal. Distress may affect how well you can focus. You may need to ask people to repeat what they said because you lost track. Distress may affect how well you relate to people. You may pull away from others. If you have children, you may have trouble taking care of them.

Distress may interfere with your health decisions or actions. Research found that people who are distressed are less likely to take their medicines as their doctor prescribed. Likewise, distressed people are less likely to attend their follow-up visits. As a result, you may make extra visits to the doctor's office and emergency room. If you're distressed, you may also have trouble making treatment decisions and be less likely to exercise and quit smoking.

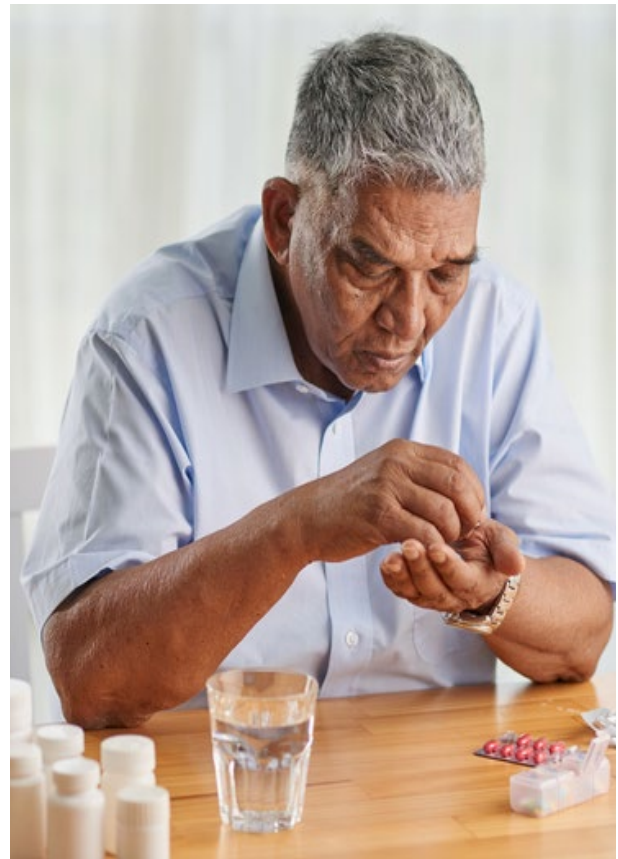
Distress may worsen your health. Distress leads to poorer quality of life. It may even have a harmful impact on your length of life (survival). Keep reading this book to learn about distress screening and getting help.



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

–Pauline

Wife of a Cancer Survivor



Causes and risks

There isn't one cause of distress. What causes distress for one person with cancer may not be the same for another person. For example, people who are distressed may feel overwhelmed. Some have many side effects from treatment. Others struggle with worries or have money problems. Even if you have been wise with your money, the costs related to cancer can add up.

Anyone can become distressed but research has found that some people are more likely than others. The risk factors for higher levels of distress are listed in [Guide 2](#). A risk factor is anything that increases the chance of an event. There is a wide range of risk factors for distress.

You may have health-related risk factors. Some people have symptoms from the cancer, from the cancer treatment, or both. If your symptoms are severe or long lasting, your chance of becoming distressed is increased. Having another severe illness, cognitive impairment, or limited access to health care can also lead to distress.

You may have personal risk factors. Such factors include being young, being a woman, and having problems with communication. It may be a shock to learn that you have cancer. Likewise, it may be too much to deal with cancer and your everyday duties. Your chance for becoming distressed is also increased if you don't know the words your treatment team uses or you don't have access to information.

Money may get even tighter. You may have less money due to travel costs, insurance co-payments, and missing work. With less money, your chance of becoming distressed is increased.

Spiritual and social factors can contribute to distress. You may have long-standing or new spiritual or religious concerns in the context of having cancer.

Family conflicts, a lack of family support, and living alone may increase the burden of having cancer and lead to distress. Having young children is an important responsibility. Raising children and dealing with cancer at the same time can be very hard to do.

Higher levels of distress are linked to sexual and physical abuse, substance use disorders (ie, alcohol, drugs), and other mental disorders. If you have been abused, you are more likely to become distressed at some point during your cancer care. If you have had a mental or substance use disorder, your chance of being distressed is higher than someone who has not.

Triggers

Distress can occur at any point in time during your cancer journey. However, there are times when being distressed is more likely. Read [Guide 3](#) for a list of times of when you are more likely to be distressed.

Distress may result from learning you have cancer. It may also occur beforehand when being assessed for cancer. Transitions in care can also lead to distress. Examples of a transition include being discharged from the hospital or finishing all treatment. It can be a big change when shifting from frequent doctor visits during active treatment to less frequent visits during follow-up care. Another common time point for being distressed is learning that your health has worsened.

Ideally, you would be screened for distress at every health care visit. However, it is very important that you be assessed for distress at the time points listed in [Guide 3](#). Screening tools for distress are described in Part 2 along with some of the benefits of distress screening.

Guide 2. Risk factors for higher distress

You are more likely to be distressed if you:	
• Have uncontrolled symptoms	• Have spiritual or religious concerns
• Have a severe illness other than cancer	• Have family conflicts
• Have cognitive impairment	• Have a lack of social support
• Have limited access to health care	• Live alone
• Are younger in age	• Have young children
• Are a woman	• Have been physically or sexually abused
• Have barriers to communicating	• Have had a substance use disorder (ie, alcohol, drugs)
• Have money problems	• Have had a mental disorder (eg, anxiety, depression)

Guide 3. Vulnerable periods for distress

You are more likely to become distressed if you:	
• Learn a symptom needs more testing	• Were just admitted to or discharged from the hospital
• Are being assessed for cancer	• Recently finished treatment
• Just learned the diagnosis	• Are in follow-up care
• Are undergoing genetic testing	• Learn treatment didn't work
• Are waiting for treatment	• Learn the cancer has returned or progressed
• Are starting another type of treatment	• Have advanced cancer
• Have a major treatment-related complication	• Are near to the end of life

Review

- Distress is an unpleasant experience of a mental, physical, social, or spiritual nature.
- Everyone with cancer has some level of distress at some point in time.
- Distress may limit how well you function, interfere with your health decisions and self-care, and worsen your health.
- You may be more likely to be distressed than other people. Having uncontrolled symptoms, money problems, a lack of support, and other factors increases the likelihood for being distressed.
- There will be times during your cancer journey when being distressed is more likely. A change in your health, treatment, or health providers may lead to distress.



I worried how we would survive this financially.

—Carol

Survivor, Multiple Myeloma

2

How distressed are you?

14 Screening tools

14 Screening benefits

18 Role of cancer team

19 Experts in distress

21 Review



Assessing distress is a key part of cancer care. Part 2 is a review of the screening process for distress. Screening tools are described and the benefits of screening are explained. You can also learn who can help you with reducing distress.

Screening tools

A screening tool is a short assessment for a condition. For distress, screening tools prompt you to respond to one or more verbal statements or questions. Distress screening tools have been tested in research studies. They have been found to work well for detecting who is distressed and pinpointing people's psychosocial needs.

There is more than one screening tool for distress. Screening tools are often paper-based surveys. However, hand-held devices, interactive voice responses, and internet-based programs have also been used. The screening tools created by NCCN experts in distress are described next.

The Distress Thermometer and Problem List

The Distress Thermometer is a well-known screening tool among cancer care providers. It has been shown in many studies to work well. It measures distress on a 0 to 10 scale. See page 16. To report your distress, circle the number that matches your level of distress in the past week.

The Problem List is completed along with the Distress Thermometer. It will help your cancer care team learn what is causing your distress. In turn, your team can ask better follow-up questions and refer you to the right help if needed.

You may receive a screening tool for distress at your next doctor's visit. You may complete the screen

while in the waiting room. If you are not screened for distress, share this book and your scores with your cancer care team.

Your cancer care team will discuss your scores with you. Some types of distress may be managed by your cancer care team. Other types may be better addressed by people with a different set of knowledge and skills. The experts in distress are described later in this chapter.

Screening benefits

Distress screening is usually a quick process. If paired with getting help as needed, it can yield major benefits. Some of the benefits of distress screening are listed next.

Detects who is distressed. Without standard screening, less than half of distressed people are identified and get the help they need. Often, doctors don't ask and patients don't tell their doctors about their distress. Screening tools empower doctors to inquire about distress and empower patients to share how they are feeling. Read Part 4 to learn about distress screening becoming a standard of care for people with cancer.

Detailed evaluations. You may receive an in-depth assessment depending on what is bothering you. An example is memory testing if you say your memory is a big problem. Another example is a clinical assessment for high distress about sexual problems or pain. A clinical assessment may consist of one or more of the following: an interview, survey, or health tests.

Better distress management. Early distress screening leads to timely management of distress. A study of routine screening showed that distressed people referred to help as needed were less

distressed 3 months later. Better management of distress in turn improves self-care and health outcomes.

Improved self-care. Treating distress makes it easier to stay on track with your cancer treatment. You will be less likely to miss doctor's visits and skip taking your medicines. In turn, you won't feel the need to call and visit your doctor more often. Furthermore, it is easier to communicate with your treatment team when not distressed.

Improved health outcomes. Treating distress early helps to prevent emotional problems from becoming severe. You likely won't be angry all the time or be intensely angry. Severe anxiety and depression may also be avoided. In addition to mental health, treating distress may help your physical health. One study suggests that decreasing distress may lead to better survival for people with cancer.



You just can't imagine how much fear and anxiety builds up.

–Dan

Survivor, Non-Small Cell Lung Cancer



NCCN Distress Thermometer

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

Extreme distress**No distress**

A vertical thermometer-style scale with numbers 0 through 10. The number 10 is at the top, with a bulb and radiating lines above it. The number 0 is at the bottom, with a bulb below it. Horizontal tick marks are present for each integer. The scale is enclosed in a rounded rectangular frame.

Problem List

Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems

- | | | |
|--------------------------|--------------------------|---------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Child care |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/financial |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions |

Family Problems

- | | | |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues |

Emotional Problems

- | | | |
|--------------------------|--------------------------|--------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Depression |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry |
| <input type="checkbox"/> | <input type="checkbox"/> | Loss of interest in usual activities |

- | | | |
|--------------------------|--------------------------|-------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual/religious concerns</u> |
|--------------------------|--------------------------|-------------------------------------|

YES NO Physical Problems

- | | | |
|--------------------------|--------------------------|------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Diarrhea |
| <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| <input type="checkbox"/> | <input type="checkbox"/> | Feeling swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration |
| <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| <input type="checkbox"/> | <input type="checkbox"/> | Nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested |
| <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse |
| <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |

Other Problems:

Role of cancer team

Learning that you have cancer and all the events that follow is a difficult time. Distress is a normal reaction and is to be expected. Distress screening tools can be used by your cancer care team to make a plan to meet your needs.

Your cancer care team can monitor your distress level. They can screen you for distress at future visits. They can also alert you of times when being distressed is more likely.

Your cancer care team can help to reduce your distress. Your team can manage expected distress symptoms, such as:

- Fear, worry, and uncertainty about the future,
- Concerns about cancer,
- Sadness about loss of health,
- Poor sleep, appetite, and concentration,
- Frequent thoughts of illness, treatment, side effects, or death; and
- Concerns about social roles (eg, mother, father, caregiver).

Your team can help by giving you information on cancer. They can also help by preventing gaps in care between health care providers. Some cancer centers have patient navigators that will guide you through the health care system. Another way your cancer team can help is to tell you about resources in your cancer center and community. They may refer you to an expert in distress.

“

On a daily basis I come across patients who are being absolutely drained of the resources they need.

–Dr. Fahd
Oncologist



Experts in distress

There are professionals who have completed special training for treating distress. Some of these experts are described next. They may work at your cancer center or work within your community.

Chaplains

You may note on the Problem List that you have spiritual or religious concerns. Some cancer centers have a chaplain on staff. If not, your cancer care team may know of one in the community. Many distressed people are interested in meeting with a chaplain.

A certified chaplain has finished a specific course of training to provide chaplaincy services. They are certified as either board-certified chaplains or associate certified chaplains. They provide care for issues like grief, guilt, loss of faith, and spiritual concerns. Read Part 3 to learn more about chaplaincy care.

Social workers

Social workers have earned either a bachelor's or master's degree in social work. Some go on to earn a doctoral degree. Oncology social workers have been educated about cancer and trained to provide a range of services to the cancer community.

Social workers provide help for practical and psychosocial problems. Practical problems include concerns about cancer, concrete needs (eg, housing, food), concerns about school or your job, language or cultural issues, and caregiver issues. Psychosocial problems may be related to changes in your body, your quality of life, family and friends, making tough decisions, and end-of-life issues. Read Part 3 to learn more about social work and counseling.

Psychiatric social workers are mental health professionals. They are also called clinical social workers. They must obtain a state license to practice. The services provided by clinical social workers include:

- Mental health assessments,
- Education to patients and families,
- Leading support groups,
- Psychotherapy, and
- Linking patients with community resources.

[illegible]

Psychologists

Psychologists are also mental health professionals. Most psychologists have a doctoral degree in psychology. The two doctoral degrees that can be earned are a PhD and PsyD in psychology. All psychologists complete an internship. Some psychologists pursue more training in a post-doctoral fellowship, obtain board certification, or both.

There are different fields of psychology. Clinical psychologists, counseling psychologists, health psychologists, neuropsychologists, and school psychologists are some of the types of psychologists that provide clinical services. A state license is required to provide clinical services.

Psychologists provide a range of services. Examples include in-depth mental health and neurocognitive assessments. Many also provide psychotherapy. Depending on their training, psychologists provide treatment for the following:

- Health issues (eg, pain, weight, sleep, sex, taking medications)
- Cognitive problems (eg, dementia, chemo brain)
- Mood and anxiety problems (eg, depression, panic, worry)
- Substance use (eg, drugs, alcohol, smoking)
- Relationship issues (eg, caregiving strains, social conflicts).

Read Part 3 to learn about mental health services. In some states, psychologists can prescribe medications after obtaining the proper education, training, and state certification.

Psychiatrists

Psychiatrists are medical doctors who specialize in mental health. They first have to obtain either an MD or DO degree. Afterward, they obtain a state license to practice and complete a 4-year residency program in psychiatry. Some become board certified, obtain more training, or both.

Psychiatrists assess the physical and mental aspects of mental health. They can order lab tests as well as give psychological tests. Their training enables them to understand relationships between medical processes and psychological issues (eg, genetics, depression).

Psychiatrists provide different types of treatment. They are experts in prescribing psychiatric medicines. Depending on their training, they may conduct neurocognitive assessments and provide psychotherapy. Read Part 3 to learn more about mental health services provided by psychiatrists.



Nurses

The field of nursing greatly varies. The nurse on your cancer care team is likely an RN (registered nurse). RNs have earned at least an associate's degree or a diploma from a hospital-based program. All RNs are licensed to practice.

Some RNs go on to earn a master's or doctoral degree in nursing. They can also obtain certification to become an expert in certain areas. Examples of certification include oncology and psychiatry.

You may receive care from an NP (nurse practitioner). An NP has earned at least a master's degree in nursing, is licensed, and has passed a national certification exam. NPs provide more comprehensive care than RNs. In some states, they can prescribe medicines.

Nurses are often the first to detect that a person is distressed. They may be the one to screen you for distress. They will also inform your cancer care team of your state.

Nurses also provide a range of services for distress treatment. They can help with practical matters, provide counseling, and refer you to other experts.

- Your cancer care team can assess you for distress at future visits and provide help for mild distress.
- Experts in distress have obtained education, training, and credentials to conduct evaluations and provide treatment. Depending on your needs, you may be referred to a chaplain, social worker, psychologist, psychiatrist, psychiatric nurse, or other mental health professional.



Cancer and my health situation have given me a new perspective. For one thing, I don't take any day for granted.

—Leonard

Survivor, Multiple Myeloma

Review

- A screening tool for distress is a brief survey of your perceived distress. The Distress Thermometer and Problem List were created by NCCN experts to assess the level and nature of your distress.
- Distress screening that is paired with help for related problems can be very helpful.

3

What help is there?

23 Cancer education

23 Chaplaincy care

24 Social work and counseling

25 Mental health services

27 Review



The cause of distress greatly differs across people. In turn, the help for distress varies based on need. Part 3 is an overview of the common types of help for distress among people with cancer.

Cancer education

Having cancer is very stressful. While absorbing the fact that you have cancer, you have to learn about tests and treatments. This information is important, as you will be deciding a treatment plan with your doctor. After treatment, you may have more doctor's visits and tests for a long time.

Learning about cancer and its treatment may reduce your distress. During your cancer journey, your cancer care team will likely use many medical words. Most of these words may be new to you, and it may seem like a lot to learn. Don't be shy to ask your team to explain a word or phrase that you do not understand.

There are many resources to help you learn about cancer. Your cancer center may have an information center that can provide information. Some cancer centers have a patient navigator program. Patient navigators sometimes help people learn more about cancer.

NCCN has a growing library of patient resources. This library includes the [NCCN Guidelines for Patients®](#) and the [NCCN Quick Guide™](#). 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. Visit [NCCN.org/patients](https://www.nccn.org/patients) for resources on cancer screening, cancer treatment, and supportive care.

Chaplaincy care

Spirituality or religion is important to many people. People use spiritual and religious resources to cope with cancer. Furthermore, there is a link between health and spirituality and religion. Data from multiple studies showed that spirituality and religion are related to better mental health. Also, attending religious services was related to fewer deaths from any cause including cancer.

Many people with cancer have spiritual needs. A chaplain can help you whether you have strong beliefs, different beliefs, conflicted beliefs, or no beliefs. Chaplains provide help for grief, guilt, and hopelessness. They can also address concerns about treatment, death, the afterlife, the Divine, and the meaning and purpose of life. You may want a chaplain to help you talk with your religious community, family, or treatment team.

Chaplains provide a range of services. They provide spiritual counseling. Your chaplain will listen to your concerns and provide advice and guidance as needed. You may receive more guidance or comfort through reading. Your chaplain may suggest a good reading resource to you.

Many people say prayer is a major help with dealing with cancer. Your chaplain can pray with you and pray on your behalf. Likewise, he or she can help get your ritual needs met. Your chaplain may be able to perform a ritual such as communion (Eucharist). If not, he or she can contact clergy of your faith.

Chaplains can serve as a contact between you and others. If you want, your chaplain can help you talk with your faith community. If you are not a member somewhere, your chaplain can help you connect with a local community.

Social work and counseling

This section describes services for practical or psychosocial problems. Social workers are the main providers of these services. However, patient navigators provide help for certain practical problems at some cancer centers. The mental health services described in the next section may also be of help for practical or psychosocial problems.

Practical problems

As described in Part 2, practical problems may relate to illness, food, money, work, school, language, and caregiving. Education, support groups, and a resource list may be enough help for mild problems. Read Part 4 for a list of online resources. At support groups, you will hear about the experiences of other people with cancer. You may learn some new ways to deal with practical problems.

For complex practical problems, education may be very helpful to you and your family. You may also benefit from learning problem-solving skills and receiving counseling. In addition, your social worker may take a very active role in linking you with community resources and be your advocate. He or she can help you obtain the support you need from other organizations.

Psychosocial problems

Psychosocial problems include a wide range of issues. You may have trouble adjusting to being sick or with making decisions. Cancer may worsen your quality of life or cause unwanted changes to your body. Having cancer may also force the need to get an advance directive and deal with end-of-life issues. Psychosocial problems can also involve conflicts within your family or with others.

You and your family may find it helpful to learn more about the problem you are dealing with. Your social worker may have information for you or may refer you to an educational group. Likewise, counseling

and support groups that provide guidance may be of help. Counseling may focus on a specific topic like sex or grief. Like practical problems, help for psychosocial problems may come from community resources. For complex psychosocial problems, your social worker may refer you for chaplaincy care or mental health services.



Initially you're doing everything you can to survive and you can kind of get used to that and you're constantly fighting and then after a while, you get a chance to pop your head above water for a little bit, and look around, and you see all the people who are trying to throw you flotation, trying to help you keep your head above water and not sink and yelling out words of encouragement to you – and so ... you keep going.

–Steve

Brother of a Cancer Survivor

Mental health services

Your cancer care team may refer you to a mental health professional. There are many types of mental health professionals. Examples include clinical social workers, psychologists, advanced practice clinicians, psychiatric nurses, and psychiatrists. The work of these professionals overlap but their expertise varies. Your cancer care team will refer you to someone who is a good fit.

The first step of care is often an evaluation to assess the problem. Evaluations differ between people based on the type of distress. Evaluations can consist of one or more of the following: interviews, surveys, and testing.

Based on the evaluation, your provider will make a treatment plan for you. Research has shown that mental health treatment works well to reduce distress and improve quality of life among people with cancer. The common types of mental health treatment are described next.

Psychoeducation

Psychoeducation is a learning event for people with specific types of distress or health conditions. The focus of the event may be general, such as on stress management. Other events may have a specific focus, such as sun protection for people with melanoma.

There are many methods to deliver psychoeducation. One method is one-to-one teaching. Group psychoeducation is also common. Besides in-person learning, you may receive reading materials, DVDs, and online resources.

Medicine

Some people need eyeglasses to function better. Likewise, some people need medicines to function better. Psychiatric (or psychotropic) medicines are drugs that improve mental health. These medicines



work by changing the amount of certain chemicals in the brain. Psychiatric medicines can be prescribed by psychiatrists, nurse practitioners, oncologists, and in some states, psychologists.

There are different types of psychiatric medicine. They are grouped by how they are commonly used. However, be aware that some medicines have other uses. An example is an antidepressant that can also help some women with hot flashes. The common classes of psychiatric medicines are listed next.

Antidepressants. These medicines treat depression. Two key features of depression are feeling down or irritable and losing interest in things that you used to like. Depression that is present at cancer diagnosis or during treatment may last a long time. There is strong proof that antidepressants work well to treat depression.

Antidepressants may be used with psychotherapy to treat depression. Antidepressants also treat anxiety and certain physical problems. Such physical problems include nausea, hot flashes, pain, and sleep problems. Read *Anxiolytics* to learn more about anxiety.

Anxiolytics. These medicines may be used with psychotherapy to treat anxiety. They are also called anti-anxiety medicines. Key features of anxiety

include severe fear or worry, panic attacks, and strong behavioral impulses. Anxiolytics are also helpful for anxiety related to stress or trauma.

Mood stabilizers. These medicines treat bipolar-related disorders. The key feature of bipolar disorders is an episode of elevated mood called mania. There is strong proof that mood stabilizers work well to treat mania.

Psychostimulants. These medicines help with alertness, attention, and energy. They treat attention deficit hyperactivity disorder and improve fatigue. Fatigue is an extreme tiredness despite getting enough sleep. A drug named methylphenidate seems to help cancer-related fatigue but more research is needed.

Antipsychotics. These medicines treat psychotic disorders. Features of psychotic disorders include perceiving unreal sensations (hallucinations), fixed false beliefs (delusions), and disorganized thinking (thought disorders). The stress of having cancer can trigger or worsen psychotic features. Some types of cancer or treatment can also cause or worsen psychosis.

Antipsychotics treat other health conditions, too. Your health provider may advise an antipsychotic for anxiety if other medicines did not work. Antipsychotics also treat delirium. Delirium is a short-term disturbance in mental abilities. It occurs in about 43 out of every 100 persons with advanced cancer. Some types of medicines that help people with cancer cause the delirium.

Psychotherapy

Psychotherapy is a treatment for distress. It is also known as “talk therapy.” Despite this name, only a professional trained in specific methods can provide psychotherapy. Psychotherapy is provided one-on-one between patient and provider or in a group setting with other patients.



I was overwhelmed with anxiety about my future. Imagine if you have to work to maintain yourself, plus you have extreme fatigue and then the side effects of the medication, it's very difficult to cope.

—Gwen

Survivor, Non-Small Cell Lung Cancer

There are different types of psychotherapy. CBT (cognitive behavioral therapy) 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.

Cancer affects the whole family. Any family member can experience distress. Individual counseling may help. However, family and couples therapy may reduce distress better than treatment for one person. Some research has been done but more is needed to learn how well family and couples therapy works for families affected by cancer.

Substance use disorder treatment

The word “substance” refers to alcohol, drugs, or tobacco. Disorders of these substances are defined by repeated use that causes major life problems.

Your chances for a substance use disorder are very low if you haven't had a problem before. Poor control of cancer-related symptoms may increase your chances of developing a substance problem.

You should have a thorough evaluation if you have had substance use disorder. Current use of some substances may require detox. After detox, specialized treatment programs to help you stay clean or sober are advised. If you haven't had a recent problem, be aware that relapse may occur under the stress of cancer. Joining a risk reduction program may be a good option.

Complementary and integrative therapies

Complementary therapies are non-standard treatments given with standard treatments. An example is yoga given with psychotherapy. Some people call complementary therapies by a different name—integrative therapies. Others refer to the practice of providing both complementary and standard treatments as integrative therapy (or integrative medicine).

There is proof that complementary therapies improve mental health among people with cancer. One study reviewed 203 clinical trials. The study found that meditation, yoga, relaxation with imagery, massage, and music therapy might be helpful for depression among women with breast cancer. Music therapy, meditation, and yoga may also reduce anxiety.

Exercise

Some people know that exercise can improve health among people with cancer. Fewer people know that exercise may also improve quality of life and mental health. More research is needed to learn how well exercise treats mental health among people with cancer.

Review

- Learning more about cancer may reduce distress.
- A chaplain can meet your spiritual needs through counseling, prayer, and other services.
- Practical problems in life may be solved by learning new information or skills, counseling, attending support groups, and connecting with community resources.
- Psychosocial problems may be relieved by new information, counseling and supportive groups, and community assistance.
- Mental health services for distress are based on an evaluation. Psychoeducation may be helpful for some people while others greatly benefit from medication, psychotherapy, or both. People struggling with drugs, alcohol, or tobacco problems need substance treatment. Complementary therapy and exercise appear to improve mood and reduce anxiety.

4

Have you received help?

29 It's a standard of care

30 Questions to ask

34 Websites

35 Review



Every distressed person with cancer should receive help. Part 4 gives a history of how distress management has become a standard of cancer care. It also provides a list of questions and websites for you to use.

This history is important to know. You should expect to receive distress screening and help at your cancer care visits. If your distress isn't addressed, ask for help.



Hope is a huge part of the cancer process because if you lose that, you don't have the inner strength you need to fight.

—Kris

Survivor, Multiple Myeloma

It's a standard of care

Everyone with cancer has some distress at some point in time. However, distressed people with cancer have been underserved for decades. In 1997, NCCN made a groundbreaking step by forming a panel to develop treatment guidelines for distress. The first guidelines for distress were completed in 1999. This book is based on the most current version of the guidelines.

The IOM (Institute of Medicine) is a nonprofit group that provides advice to the nation. Its aim is to help people make good health decisions. IOM is greatly respected among health care professionals.

In 2007, IOM released a report called *Cancer Care for the Whole Patient*. In this report, a treatment model for distress was proposed. The model is based on the work of the NCCN panel. It includes routine distress screening, treatment planning, referrals to experts in distress, and re-evaluation. The IOM report made distress management a new standard of quality cancer care.

The Commission on Cancer is a program of the American College of Surgeons. It grants accreditation to cancer centers that apply and meet their standards of quality cancer care. In 2015, new standards went into effect for cancer centers. These new standards included distress screening.

Questions to ask

Ask your health care providers questions about distress. Being informed will help you make decisions. The questions below are in regard to the care you read about in this book. Feel free to use them or ask your own questions.

It may help to prepare questions before your visit. At the visit, repeat the answers given to you to confirm what you heard. You can also take notes and record your visit so you can later review what was said. Many people bring their spouse, partner, friend, or other family member for support.

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?

Cancer information

1. What type of cancer do I have? Will it grow fast?
2. What tests do I need? How often are these tests wrong?
3. What options do I have? What will happen if I do nothing?
4. What are the pros and cons of each option? What are the side effects of treatment? 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?
7. Are you board certified? If yes, in what area? How many people like me have you treated?

Spiritual care

1. What do chaplains do?
2. Are chaplains ministers or priests?
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?

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?

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?

Websites

Distress is to be expected when facing cancer. There are community resources that can help. Free online information can be found at the websites listed next.

Cancer information

NCCN

NCCN.org/patients

National Cancer Institute (NCI)

cancer.gov/resources-for/patients

Distress

Alliance for Quality Psychosocial Cancer Care

wholecancerpatient.org

American Psychosocial Oncology Society

apos-society.org

Fertility

MyOncofertility.org

myoncofertility.org

NCCN

NCCN.org/patients

Spirituality

National Cancer Institute (NCI)

cancer.gov/cancertopics/pdq/supportivecare/spirituality/Patient

Support services

CancerCare

cancercare.org

Cancer Support Community

cancersupportcommunity.org

Good Days

mygooddays.org

National Coalition for Cancer Survivorship

canceradvocacy.org/resources/cancer-survival-toolbox

Review

- Distress management is a new standard of quality cancer care. Expect and ask for help from your cancer care team.
- Ask your health care providers questions about distress. Being informed will help you make decisions.
- There are community resources that can help. Many of these resources can be found online.



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.

-Fran

Patient Care Specialist

Glossary

37 Dictionary

37 Acronyms

Dictionary

chaplain

A trained expert in providing spiritual care.

cognitive impairment

Trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.

diagnosis

To identify a disease.

distress

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature.

oncologist

A medical doctor who's an expert in the treatment of cancer.

psychiatrist

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

psychologist

A trained expert in the human mind and behavior.

risk factor

Anything that increases the chance of an event.

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.

Acronyms

CBT

Cognitive behavioral therapy

IOM

Institute of Medicine

NCCN®

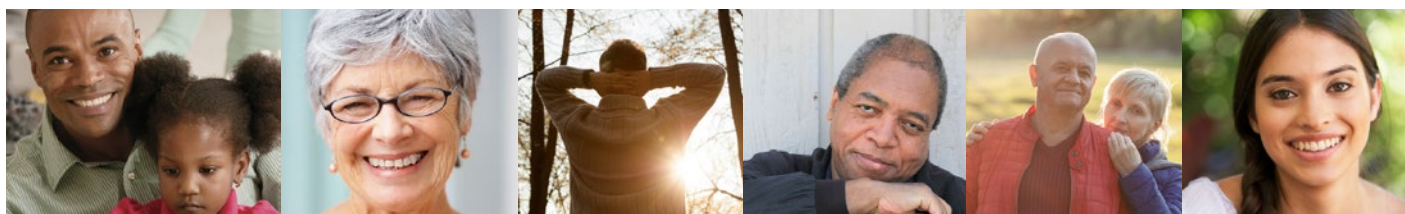
National Comprehensive Cancer Network®

NP

Nurse practitioner

RN

Registered nurse



NCCN
GUIDELINES
FOR PATIENTS®

PROVIDING TRUE INSIGHT TO PEOPLE LIVING WITH CANCER

NCCN GUIDELINES FOR PATIENTS® PROVIDE TREATMENT GUIDANCE
FROM THE WORLD'S LEADING CANCER EXPERTS

Acute Lymphoblastic Leukemia

Adolescents and Young Adults
(AYAs) with Cancer

Brain Cancer – Gliomas

Breast Cancer

Carcinoma in Situ (Stage 0)

Early-Stage (Stages I and II)

Stage III Breast Cancer

Stage IV Breast Cancer

Chronic Lymphocytic Leukemia

Chronic Myelogenous Leukemia

Colon Cancer

Distress (Supportive Care Series)

Esophageal Cancer

Hodgkin Lymphoma

Kidney Cancer

Lung Cancer (Non-Small Cell
Lung Cancer)

Lung Cancer Screening

Malignant Pleural Mesothelioma

Melanoma

Multiple Myeloma

Myelodysplastic Syndromes

Nausea and Vomiting

(Supportive Care Series)

Non-Hodgkin's Lymphomas

Diffuse Large B-cell Lymphoma

Follicular Lymphoma

Mantle Cell Lymphoma

Mycosis Fungoides

Peripheral T-cell Lymphoma

Ovarian Cancer

Pancreatic Cancer

Prostate Cancer

Soft Tissue Sarcoma

Stomach Cancer

Thyroid Cancer – *Coming Soon!*

Waldenström's

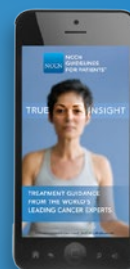
Macroglobulinemia/

Lymphoplasmacytic Lymphoma

New!

**NCCN
Patient Guides
for Cancer**

MOBILE APP



AVAILABLE FREE ONLINE AT **NCCN.org/patients** OR IN PRINT AT **Amazon.com**

HELP US MAKE A TRUE IMPACT
IN THE LIVES OF PEOPLE LIVING
WITH CANCER >

DONATE NOW
nccnfoundation.org

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

As of February 23, 2017

State Fundraising Notices

FLORIDA: A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION OF NCCN FOUNDATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE WITHIN THE STATE 1-800-HELP-FLA. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THE STATE. FLORIDA REGISTRATION #CH33263.

GEORGIA: The following information will be sent upon request:

(A) A full and fair description of the programs and activities of NCCN Foundation; and (B) A financial statement or summary which shall be consistent with the financial statement required to be filed with the Secretary of State pursuant to Code Section 43-17-5. **KANSAS:** The annual financial report for NCCN

Foundation, 275 Commerce Drive, Suite 300, Fort Washington, PA 19034, 215-690-0300, State Registration # 445-497-1, is

filed with the Secretary of State. **MARYLAND:** A copy of the NCCN Foundation financial report is available by calling NCCN Foundation at 215-690-0300 or writing to 275 Commerce Drive, Suite 300, Fort Washington, PA 19034. For the cost of copying and postage, documents and information filed under the Maryland charitable organizations law can be obtained from the Secretary of State, Charitable Division, State House, Annapolis, MD 21401, 1-410-974-5534. **MICHIGAN:** Registration Number MICS 45298. **MISSISSIPPI:** The official registration and financial information of NCCN Foundation may be obtained

from the Mississippi Secretary of State's office by calling 888-236-6167. Registration by the Secretary of State does not imply endorsement by the Secretary of State. **NEW JERSEY:** INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING (973) 504-6215 AND IS AVAILABLE ON THE INTERNET AT www.njconsumeraffairs.gov/ocp.htm#charity. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT. **NEW YORK:**

A copy of the latest annual report may be obtained from NCCN Foundation, 275 Commerce Drive, Suite 300, Fort Washington, PA 19034, or the Charities Bureau, Department of Law,

120 Broadway, New York, NY 10271. **NORTH CAROLINA:**

FINANCIAL INFORMATION ABOUT THIS ORGANIZATION AND A COPY OF ITS LICENSE ARE AVAILABLE FROM THE STATE SOLICITATION LICENSING BRANCH AT 888-830-4989 (within North Carolina) or (919) 807-2214 (outside of North Carolina). THE LICENSE IS NOT AN ENDORSEMENT BY THE STATE. PENNSYLVANIA: The official registration and

financial information of NCCN Foundation may be obtained from the Pennsylvania Department of State by calling toll-free within Pennsylvania, 800-732-0999. Registration does not imply endorsement. **VIRGINIA:** A financial statement for

the most recent fiscal year is available upon request from the State Division of Consumer Affairs, P.O. Box 1163, Richmond, VA 23218; 1-804-786-1343. **WASHINGTON:** Our charity is registered with the Secretary of State and information relating to our financial affairs is available from the Secretary of State, toll free for Washington residents 800-332-4483. **WEST VIRGINIA:** West Virginia residents may obtain a summary of

the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. Registration does not imply endorsement.

Consult with the IRS or your tax professional regarding tax deductibility. REGISTRATION OR LICENSING WITH A STATE AGENCY DOES NOT CONSTITUTE OR IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THAT STATE. We care about your privacy and how we communicate with you, and how we use and share your information. For a copy of NCCN Foundation's Privacy Policy, please call 215.690.0300 or visit our website at www.nccn.org.

NCCN Panel Members for Distress Management

Jimmie C. Holland, MD/Chair
Memorial Sloan Kettering Cancer Center

Teresa L. Deshields, PhD/Vice Chair
Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

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

Ilana Braun
Dana-Farber/Brigham and Women's Cancer Center | Massachusetts General Hospital Cancer Center

William S. Breitbart, MD
Memorial Sloan Kettering Cancer Center

Benjamin W. Brewer, PsyD
University of Colorado Cancer Center

Luke O. Buchmann, MD
Huntsman Cancer Institute at the University of Utah

Matthew M. Clark, PhD
Mayo Clinic Cancer Center

Molly Collins, MD
Fox Chase Cancer Center

Cheyenne Corbett, PhD
Duke Cancer Institute

Kristine Donovan, PhD, MBA
Moffitt Cancer Center

Stewart Fleishman, MD
Continuum Cancer Centers of New York Consultant

Donna B. Greenberg, MD
Massachusetts General Hospital Cancer Center

Rev. George F. Handzo, MA, MDiv
HealthCare Chaplaincy Network Consultant

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

Elizabeth Kvale, MD
University of Alabama at Birmingham Comprehensive Cancer Center

Lisa McGuffey, PhD
University of Wisconsin Carbone Cancer Center

William Mitchell, MD
UC San Diego Moores Cancer Center

Laura J. Morrison, MD
Yale Cancer Center/Smilow Cancer Hospital

Oxana Palesh, PhD, MPH
Stanford Cancer Institute

Francine Parnes, JD, MA
Patient Advocate

Janice P. Pazar, RN, PhD
St. Jude Children's Research Hospital/The University of Tennessee Health Science Center

Timothy P. Pearman, PhD, MS
Robert H. Lurie Comprehensive Cancer Center of Northwestern University

Michelle B. Riba, MD, MS
University of Michigan Comprehensive Cancer Center

Rosa Scrivani, LCSW
Roswell Park Cancer Institute

Moreen M. Shannon-Dudley, MSW
Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance

Kimberly Shapiro, MD
City of Hope Comprehensive Cancer Center

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

Elizabeth Weinstein, MD
Case Comprehensive Cancer Center/University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute

NCCN Staff

Susan Darlow, PhD
Oncology Scientist, Medical Writer

Nicole McMillian, MS
Guidelines Coordinator

For disclosures, visit www.nccn.org/about/disclosure.aspx.

NCCN Member Institutions

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska
800.999.5465
nebraskamed.com/cancer

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

City of Hope Comprehensive
Cancer Center
Los Angeles, California
800.826.4673
cityofhope.org

Dana-Farber/Brigham and
Women's Cancer Center
Massachusetts General Hospital
Cancer Center
Boston, Massachusetts
877.332.4294
dfbwc.org
massgeneral.org/cancer

Duke Cancer Institute
Durham, North Carolina
888.275.3853
dukecancerinstitute.org

Fox Chase Cancer Center
Philadelphia, Pennsylvania
888.369.2427
foxchase.org

Huntsman Cancer Institute
at the University of Utah
Salt Lake City, Utah
877.585.0303
huntsmanccancer.org

Fred Hutchinson Cancer
Research Center/
Seattle Cancer Care Alliance
Seattle, Washington
206.288.7222 • seattlecca.org
206.667.5000 • fredhutch.org

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

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

Mayo Clinic Cancer Center
Phoenix/Scottsdale, Arizona
Jacksonville, Florida
Rochester, Minnesota
800.446.2279 • Arizona
904.953.0853 • Florida
507.538.3270 • Minnesota
mayoclinic.org/departments-centers/mayo-clinic-cancer-center

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

Moffitt Cancer Center
Tampa, Florida
800.456.3434
moffitt.org

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

Roswell Park Cancer Institute
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
888.226.4343 • stjude.org
901.683.0055 • westclinic.com

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

University of Alabama at Birmingham
Comprehensive Cancer Center
Birmingham, Alabama
800.822.0933
www3.ccc.uab.edu

UC San Diego Moores Cancer Center
La Jolla, California
858.657.7000
cancer.ucsd.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
Comprehensive Cancer Center
Ann Arbor, Michigan
800.865.1125
mcancer.org

The University of Texas
MD Anderson Cancer Center
Houston, Texas
800.392.1611
mdanderson.org

Vanderbilt-Ingram Cancer Center
Nashville, Tennessee
800.811.8480
vicc.org

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

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

Index

cancer education 23

chaplaincy 23–24

Commission on Cancer 29

complementary therapy 27, 33

counseling 23–24, 26–27, 32

distress 6, 8–12, 14–21, 23, 25–27, 29–30, 32–35

- causes** 10
- experts** 19–21
- outcomes** 9
- risks** 10–11
- symptoms** 8
- triggers** 10

NCCN Distress Thermometer and Problem List 14, 16–17, 19, 21

exercise 27

Institute of Medicine 29

integrative therapy 27

patient navigator 18, 23–24

psychiatric medicine 20, 25

psychiatrist 20–21, 25

psychoeducation 25, 27

psychologist 20–21, 25

psychotherapy 19–20, 25–27

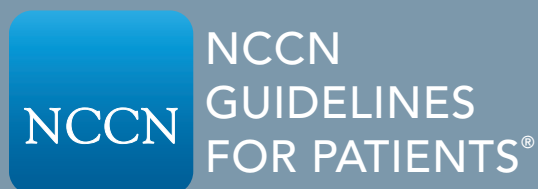
screening 14–18, 29

- benefits** 14–15
- tools** 14, 16–18

social worker 19, 21, 24–25, 32

substance use disorder 10–11, 26–27





Distress

Version 1.2017

NCCN Foundation® gratefully acknowledges our Advocacy supporter Good Days for its support in making available these NCCN Guidelines for Patients®. NCCN independently develops and distributes the NCCN Guidelines for Patients. Our industry supporters do not participate in the development of the NCCN Guidelines for Patients and are not responsible for the content and recommendations contained therein.



National
Comprehensive
Cancer
Network®

275 Commerce Drive
Suite 300
Fort Washington, PA 19034
215.690.0300

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