



National Comprehensive  
Cancer Network®

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

# Distress Management

Version 3.2019 — May 6, 2019

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

**\*Kristine A. Donovan, PhD, MBA/Vice-Chair**  $\theta$   
Moffitt Cancer Center

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

**Ilana Braun, MD**  $\theta$   
Dana-Farber/Brigham and Women's  
Cancer Center  
**William S. Breitbart, MD**  $\theta$   $\text{P}$   $\text{E}$   
Memorial Sloan Kettering Cancer Center

**Benjamin W. Brewer, PsyD**  $\theta$   
University of Colorado Cancer Center

**Luke O. Buchmann, MD**  $\text{¶}$   
Huntsman Cancer Institute  
at the University of Utah

**Matthew M. Clark, PhD**  $\theta$   $\text{E}$   
Mayo Clinic Cancer Center

**Molly Collins, MD**  $\text{E}$   
Fox Chase Cancer Center

**Cheyenne Corbett, PhD**  $\text{E}$   
Duke Cancer Institute

**Stewart Fleishman, MD**  $\text{E}$   $\theta$   
Consultant

**Sofia Garcia, PhD**  $\theta$   
Robert H. Lurie Comprehensive Cancer  
Center of Northwestern University

**Donna B. Greenberg, MD**  $\theta$   $\text{P}$   
Massachusetts General Hospital  
Cancer Center

**Rev. George F. Handzo, MA, MDiv**  $\text{E}$   
Consultant

**Laura Hoofring, MSN, APRN**  $\#$   $\theta$   $\text{†}$   
The Sidney Kimmel Comprehensive  
Cancer Center at Johns Hopkins

**Chao-Hui Huang, PhD**  $\theta$   
University of Alabama at Birmingham  
Comprehensive Cancer Center

**Robin Lally, PhD, MS, RN**  $\#$   
Fred & Pamela Buffett Cancer Center

**Sara Martin, MD**  $\text{E}$   
Vanderbilt-Ingram Cancer Center

**Lisa McGuffey, PhD, JD**  $\theta$   
University of Wisconsin  
Carbone Cancer Center

**William Mitchell, MD**  $\text{†}$   $\text{E}$   
UC San Diego Moores Cancer Center

**Laura J. Morrison, MD**  $\text{E}$   
Yale Cancer Center/Smilow Cancer Hospital

**Megan Pailler, PhD**  $\theta$   
Roswell Park Comprehensive  
Cancer Center

**Oxana Palesh, PhD, MPH**  $\theta$   $\text{E}$   
Stanford Cancer Institute

**Francine Parnes, JD, MA**  $\text{¥}$   
Patient Advocate

**Janice P. Pazar, RN, PhD**  $\theta$   $\text{E}$   
St. Jude Children's Research  
Hospital/The University of Tennessee  
Health Science Center

**Laurel Ralston, DO**  $\theta$   
Case Comprehensive Cancer Center/  
University Hospitals Seidman Cancer  
Center and Cleveland Clinic Taussig  
Cancer Institute

**Jaroslava Salman, MD**  $\theta$   
City of Hope  
National Medical Center

**Moreen M. Shannon-Dudley, MSW**  $\text{E}$   
Fred Hutchinson Cancer Research Center/  
Seattle Cancer Care Alliance

**Alan D. Valentine, MD**  $\theta$   
The University of Texas  
MD Anderson Cancer Center

**NCCN**  
**Susan Darlow, PhD**  
**Nicole McMillian, MS**

$\xi$ Bone marrow transplantation	$\text{E}$ Supportive care including palliative, pain management,
$\text{P}$ Internal medicine	pastoral care, and
$\text{†}$ Medical oncology	oncology social work
$\#$ Nursing	$\text{¶}$ Surgery/Surgical oncology
$\text{¥}$ Patient advocacy	Discussion Section
$\theta$ Psychiatry, psychology, including* health behavior	Writing Committee

[NCCN Guidelines Panel Disclosures](#)

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### [NCCN Distress Management Panel Members](#) [Summary of the Guidelines Updates](#)

#### **Key Terms:**

- [Distress \(DIS-1\)](#)
- [Definition of Distress in Cancer \(DIS-2\)](#)
- [Standards of Care for Distress Management \(DIS-3\)](#)

### [Overview of Evaluation and Treatment Process \(DIS-4\)](#) [Management of Expected Distress Symptoms \(DIS-5\)](#)

### [NCCN Distress Thermometer and Problem List \(DIS-A\)](#) [Psychosocial Distress Patient Characteristics \(DIS-B\)](#)

### [Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

### [Social Work and Counseling Services: Practical Problems \(DIS-24\)](#)

### [Social Work and Counseling Services: Psychosocial Problems \(DIS-25\)](#)

### [Chaplaincy Care \(DIS-26\)](#)

### [Principles for Implementation of Standards and Distress Management Guidelines \(DIS-27\)](#)

### [Institutional Evaluation of Standards of Care \(DIS-28\)](#)

**For End-of-Life Issues,** [See the NCCN Guidelines for Palliative Care](#)  
**For Cancer Pain,** [See the NCCN Guidelines for Adult Cancer Pain](#)

**Clinical Trials:** NCCN believes that the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

To find clinical trials online at NCCN Member Institutions, [click here:](#)  
[nccn.org/clinical\\_trials/clinicians.aspx](http://nccn.org/clinical_trials/clinicians.aspx).

**NCCN Categories of Evidence and Consensus:** All recommendations are category 2A unless otherwise indicated.

See [NCCN Categories of Evidence and Consensus](#).

The NCCN Guidelines® are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2019.



Updates in Version 3.2019 of the NCCN Guidelines for Distress Management from Version 2.2019 include:

- The Discussion has been updated to reflect the changes in the algorithm. ([MS-1](#))

Updates in Version 2.2019 of the NCCN Guidelines for Distress Management from Version 1.2019 include:

#### [DIS-27](#) Principles for Implementation of Standards and Distress Management Guidelines

- This is a new section that provides recommendations to support standards and implementation of the Distress Management Guidelines. This section replaces the “Recommendations for Implementation of Standards and Guidelines” and “Recommended Readings for Implementation of Psychosocial Care into the Routine Care of Patients with Cancer” that were previously in the guidelines.

Updates in Version 1.2019 of the NCCN Guidelines for Distress Management from Version 2.2018 include:

#### [DIS-4](#) Overview of Evaluation and Treatment Process

- Evaluation: “...by primary oncology team of oncologist, nurse, advanced practice oncology nurse professional, and...”

#### [DIS-5](#) Management of Expected Distress Symptoms

- Expected distress symptoms: *Financial worries* added.
- Interventions:
  - ▶ Sub-bullet added, *Discuss advance care planning*
  - ▶ Eighth bullet revised, “Family/couple/caregiver support...”
  - ▶ Build trust removed.

#### [DIS-B](#) Psychosocial Distress Patient Characteristics

- Patients at increased risk for distress: Sub-bullet revised, “History of *trauma and/or abuse...*”
- Periods of increased vulnerability: This section was extensively revised.
- Footnote 1: Reference was updated.

#### [DIS-6](#) Psychological/Psychiatric Treatment Guidelines

- Evaluation for: *Suicide risk* added.

#### [DIS-9](#) Neurocognitive Disorders: Delirium

- Treatment: Revised, “~~Antipsychotics~~ + Behavioral management + family support/education environment ± *pharmacotherapy*”

#### [DIS-10](#) Depressive Disorders

- Evaluation: *Demoralization* added as a sub-bullet.
- Treatment: (Same changes below also made on DIS-12 for Bipolar and Related Disorders)

- ▶ No danger to self or others: Bullet revised, *Psychiatric Mental health* treatment and follow-up/patient and family education. Change also made in pathway below.
- ▶ Danger to self or others: Sub-bullet revised, “Remove *guns/* dangerous objects.”

#### [DIS-17](#) Trauma and Stressor-Related Disorders

- Evaluation: Last bullet revised, Assess for past trauma *and/or cancer-related post-traumatic stress*.

#### [DIS-18](#) Trauma and Stressor-Related Disorders: Adjustment Disorders

- No danger to self or others: After treatment revised, “Medications prescribed and/or psychotherapy.”
- Danger to self or others: Sub-bullet revised, “Remove *guns/* dangerous objects.”

#### [DIS-21](#) Substance-Related and Addictive Disorders

- First column revised: “Signs, symptoms, and history of dependence, active *substance abuse* disorder, or addiction (~~See NCCN Guidelines for Adult Cancer Pain~~).”
- Footnote g revised: Opioids, alcohol, tobacco, or other. *For opioids, also see Opioid Principles, Prescribing, Titration, Maintenance, and Safety in the NCCN Guidelines for Adult Cancer Pain (PAIN-E). For tobacco use see the NCCN Guidelines for Smoking Cessation.*

#### [DIS-22](#) Substance-Related and Addictive Disorders

- First column: Revised to, “Following appropriate detoxification regimen *appropriate treatment and/or management program*.”

[Continued](#)



### **DIS-23 Personality Disorders**

- ***Schizotypal*** added as a sign and symptom.
- Evaluation: Sub-bullet revised, **Fearful**

### **DIS-24 Social Work and Counseling Services**

- Practical problems
  - ▶ Bullet revised, “**Concrete Basic needs, including housing, food, financial/insurance concerns assistance programs, assistance with activities of daily living (ADLs), and ...**”
  - ▶ Grief and loss was removed.
- Footnote i revised: “Social work and counseling services include mental health ~~services using care as described in the psychological/psychiatric treatment guidelines...~~” (Also on DiS-25)

### **DIS-25 Social Work and Counseling Services**

- Psychosocial problems; Type of problem
  - ▶ Eighth bullet revised: **Functional Changes regarding body image and sexuality sexual health**
  - ▶ Ninth bullet revised: **End-of-life Grief, bereavement, and coping with loss**
  - ▶ Bullets added: **Depressive symptoms, Suicidal ideation, Anxiety (ie, fears, nervousness, worry)**
- Social work and counseling interventions
  - ▶ Mild psychosocial problems: **Strengthen coping strategies** added.
  - ▶ Severe/moderate psychosocial problems: Last bullet revised, **Consider referral for chaplaincy counseling care**

### **DIS-26 Chaplaincy Care**

- The Chaplaincy Care treatment algorithms were extensively revised.

### **DIS-29 Institutional Evaluation of Standards of Care**

- Interventions: Second bullet revised, **Distress Thermometer (0–10) and Problem List** screening tool in clinics and inpatient setting.
- Patient Outcomes: Revised to, “**Reduced distress, satisfaction (CQI survey of impact).**”



### “DISTRESS”

**The term “distress” was chosen because it:**

- Is more acceptable and less stigmatizing than “psychiatric,” “psychosocial,” or “emotional”
- Sounds “normal” and less embarrassing
- Can be defined and measured by self-report

### [Definition of Distress in Cancer \(DIS-2\)](#)

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### DEFINITION OF DISTRESS IN CANCER

**Distress is a multifactorial unpleasant experience of a psychological (ie, cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.**

### [Standards of Care for Distress Management \(DIS-3\)](#)

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### STANDARDS OF CARE FOR DISTRESS MANAGEMENT

- **Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.**
- **Screening should identify the level and nature of the distress.**
- **Ideally, patients should be screened for distress at every medical visit as a hallmark of patient-centered care. At a minimum, patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status (ie, remission, recurrence, progression, treatment-related complications).**
- **Distress should be assessed and managed according to clinical practice guidelines.**
- **Interdisciplinary institutional committees should be formed to implement standards for distress management.**
- **Educational and training programs should be developed to ensure that health care professionals and certified chaplains have knowledge and skills in the assessment and management of distress.**
- **Licensed mental health professionals and certified chaplains experienced in psychosocial aspects of cancer should be readily available as staff members or by referral.**
- **Medical care contracts should include adequate reimbursement for services provided by mental health professionals.**
- **Clinical health outcomes measurement should include assessment of the psychosocial domain (eg, quality of life and patient and family satisfaction).**
- **Patients, families, and treatment teams should be informed that distress management is an integral part of total medical care and is provided with appropriate information about psychosocial services in the treatment center and the community.**
- **Quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.**

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### MANAGEMENT OF EXPECTED DISTRESS SYMPTOMS

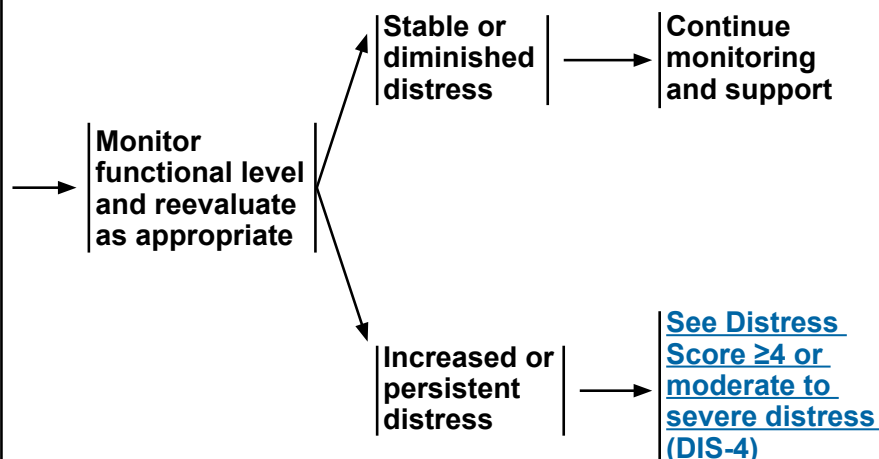
#### EXPECTED DISTRESS SYMPTOMS<sup>d</sup>

- Fear and worry about the future
- Concerns about illness
- Sadness about loss of usual health
- Anger, feeling out of control
- Poor sleep
- Poor appetite
- Poor concentration
- Preoccupation with thoughts of illness and death
- Concerns with disease or treatment side effects
- Concerns about social role (ie, as father, mother)
- Spiritual/existential concerns
- Financial worries

#### INTERVENTIONS

- Acknowledge/validate distress
- Clarify diagnosis, treatment options, and side effects
  - ▶ Be sure patient understands disease and treatment options
  - ▶ Discuss advance care planning
  - ▶ Refer to appropriate patient education materials (eg, [NCCN Guidelines for Patients](#))
- Educate patient that points of transition may bring increased vulnerability to distress
- Ensure continuity of care
- Mobilize resources
- Consider medication to manage symptoms:
  - ▶ Analgesics ([See NCCN Guidelines for Adult Cancer Pain](#))
  - ▶ Anxiolytics
  - ▶ Hypnotics
  - ▶ Antidepressants
  - ▶ Psychostimulants
- Support groups and/or individual counseling
- Family/couple/caregiver support and counseling
- Relaxation, meditation, creative therapies (eg, art, dance, music)
- Spiritual support
- Exercise
- Assess and strengthen coping strategies

#### RE-EVALUATION



<sup>d</sup>[See Psychosocial Distress Patient Characteristics \(DIS-B\).](#)

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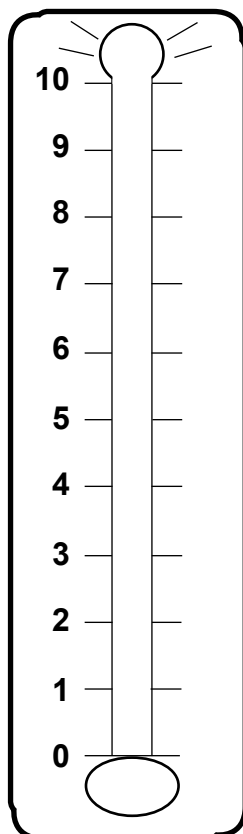
# NCCN Guidelines Version 3.2019

## Distress Management

### 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**

### 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                       | <u>Practical Problems</u>           | YES                      | NO                       | <u>Physical Problems</u> |
|--------------------------|--------------------------|-------------------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Child care                          | <input type="checkbox"/> | <input type="checkbox"/> | Appearance               |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing                             | <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing         |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/financial                 | <input type="checkbox"/> | <input type="checkbox"/> | Breathing                |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation                      | <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination     |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school                         | <input type="checkbox"/> | <input type="checkbox"/> | Constipation             |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions                 | <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"/> | Dealing with children               | <input type="checkbox"/> | <input type="checkbox"/> | Fevers                   |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner                | <input type="checkbox"/> | <input type="checkbox"/> | Getting around           |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children            | <input type="checkbox"/> | <input type="checkbox"/> | Indigestion              |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues                | <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 use            |
|                          |                          |                                     | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet   |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual/religious concerns</u> |                          |                          |                          |

**Other Problems:** \_\_\_\_\_

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### PSYCHOSOCIAL DISTRESS PATIENT CHARACTERISTICS<sup>1</sup>

#### PATIENTS AT INCREASED RISK FOR DISTRESS<sup>2</sup>

- History of psychiatric disorder or substance use disorder
- History of depression/suicide attempt
- Cognitive impairment
- Communication barriers<sup>3</sup>
- Severe comorbid illnesses
- Social issues
  - ▶ Family/caregiver conflicts
  - ▶ Inadequate social support
  - ▶ Living alone
  - ▶ Financial problems
  - ▶ Limited access to medical care
  - ▶ Young or dependent children
  - ▶ Younger age<sup>4</sup>
  - ▶ History of trauma and/or abuse (physical, sexual, emotional, verbal)
  - ▶ Other stressors
- Spiritual/religious concerns
- Uncontrolled symptoms
- Cancer type associated with risk of depression (eg, pancreatic cancer, head and neck cancer)

#### PERIODS OF INCREASED VULNERABILITY

- Finding and investigating a suspicious symptom
- During diagnostic workup
- Finding out the diagnosis
- Advanced cancer diagnosis
- Learning about genetic/familial cancer risk
- Awaiting treatment
- Increase in symptom burden
- Significant treatment-related complication(s)
- Admission to/discharge from hospital
- Change in treatment modality
- Treatment failure
- End of active treatment
- Medical follow-up and surveillance
- Transition to survivorship
- Recurrence/progression
- Transition to end-of-life care

<sup>1</sup>For site-specific symptoms with major psychosocial consequences, see Holland JC, Golant M, Greenberg DB, et al. Psycho-oncology: A quick reference on the psychosocial dimensions of cancer symptom management. Oxford University Press, 2015.

<sup>2</sup>From the [NCCN Guidelines for Palliative Care](#).

<sup>3</sup>Communication barriers include language, literacy, and physical barriers.

<sup>4</sup>See [NCCN Guidelines for Adolescent and Young Adult \(AYA\) Oncology](#).

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### PSYCHOLOGICAL/PSYCHIATRIC TREATMENT GUIDELINES

Referral by  
oncology team  
to mental  
health team<sup>e</sup>

- Evaluation for:
- Distress
  - Problematic behaviors
  - Psychiatric history/medications
  - Substance use disorder
  - Pain and symptom control
    - ▶ [NCCN Guidelines for Adult Cancer Pain](#)
    - ▶ [NCCN Guidelines for Palliative Care](#)
  - Fatigue  
([NCCN Guidelines for Cancer-Related Fatigue](#))
  - Body image
  - Sexual health ([See NCCN Guidelines for Survivorship](#))
  - Impaired cognitive capacity
  - Safety
  - Suicide risk
  - Psychological/psychiatric disorder
  - Medical causes  
(refer to primary oncology team)

[Neurocognitive Disorders: Dementia \(DIS-7\)](#)

[Neurocognitive Disorders: Delirium \(DIS-9\)](#)

[Depressive Disorders \(DIS-10\)](#)

[Bipolar and Related Disorders \(DIS-12\)](#)

[Schizophrenia Spectrum and Other Psychotic Disorders \(DIS-14\)](#)

[Anxiety Disorders \(DIS-16\)](#)

[Trauma and Stressor-Related Disorders \(DIS-17\)](#)

[Trauma and Stressor-Related Disorders: Adjustment Disorders \(DIS-18\)](#)

[Obsessive Compulsive and Related Disorders \(DIS-20\)](#)

[Substance-Related and Addictive Disorders \(DIS-21\)](#)

[Personality Disorders \(DIS-23\)](#)

Follow-up and  
communication  
with primary  
oncology team,  
primary care  
physician, and  
family/  
caregivers

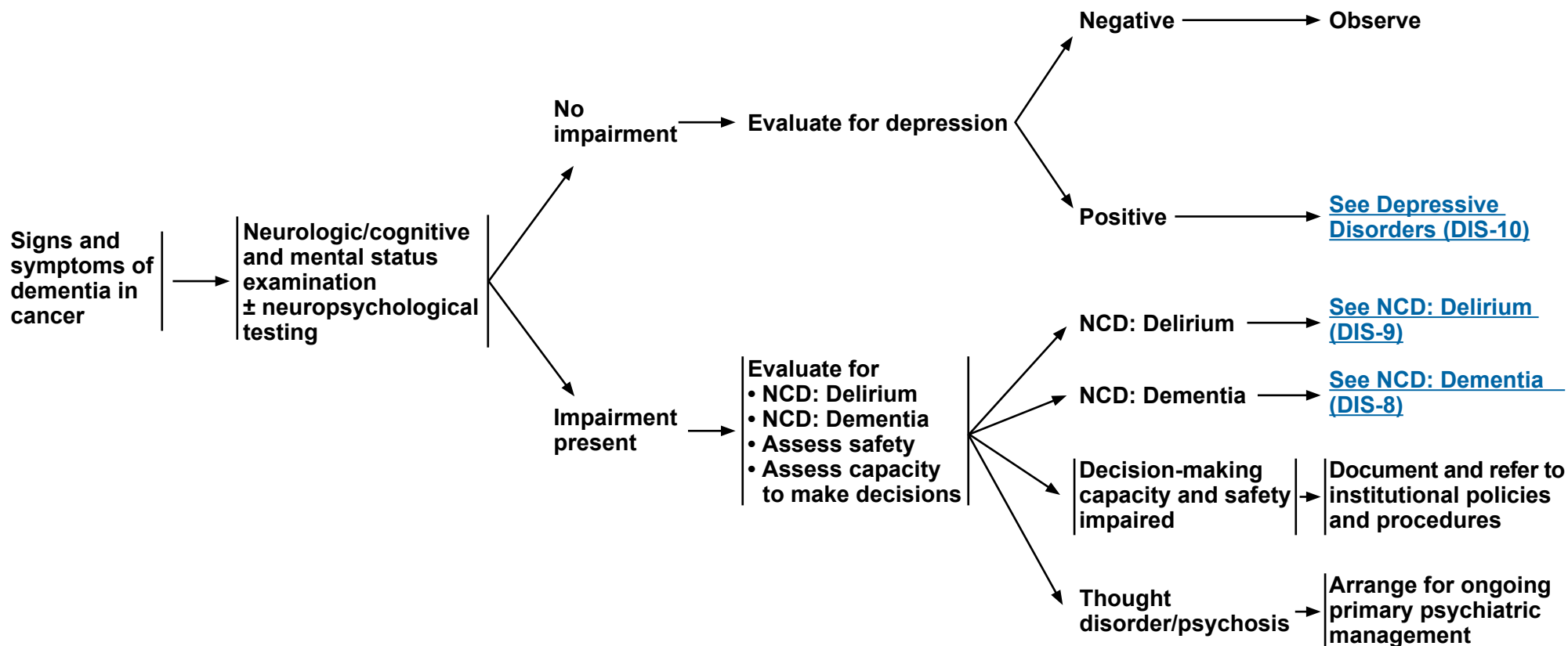
<sup>e</sup>Psychiatrist, psychologist, advanced practice clinicians, and/or social worker.

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### NEUROCOGNITIVE DISORDERS (NCD): DEMENTIA

### EVALUATION



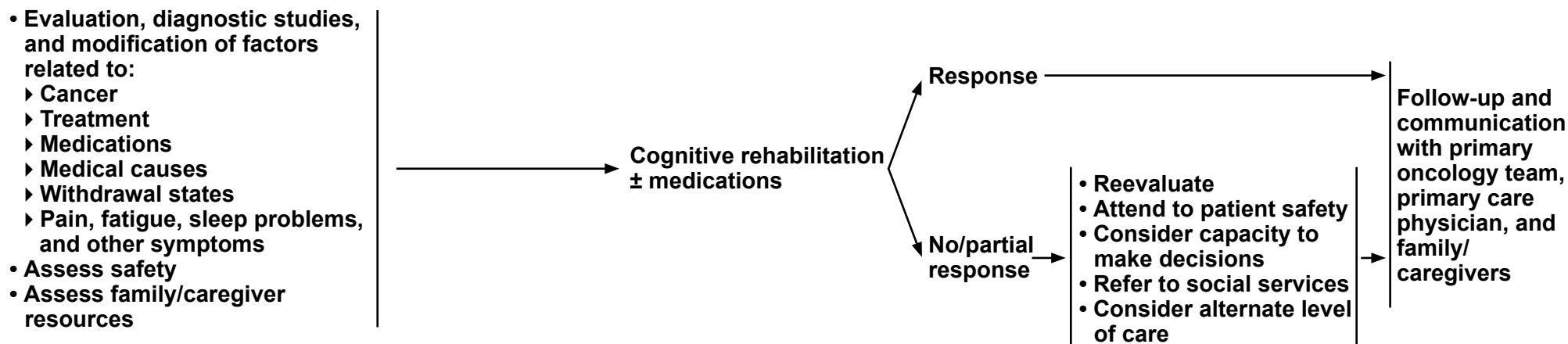
[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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### NCD: DEMENTIA

### TREATMENT

### FOLLOW-UP



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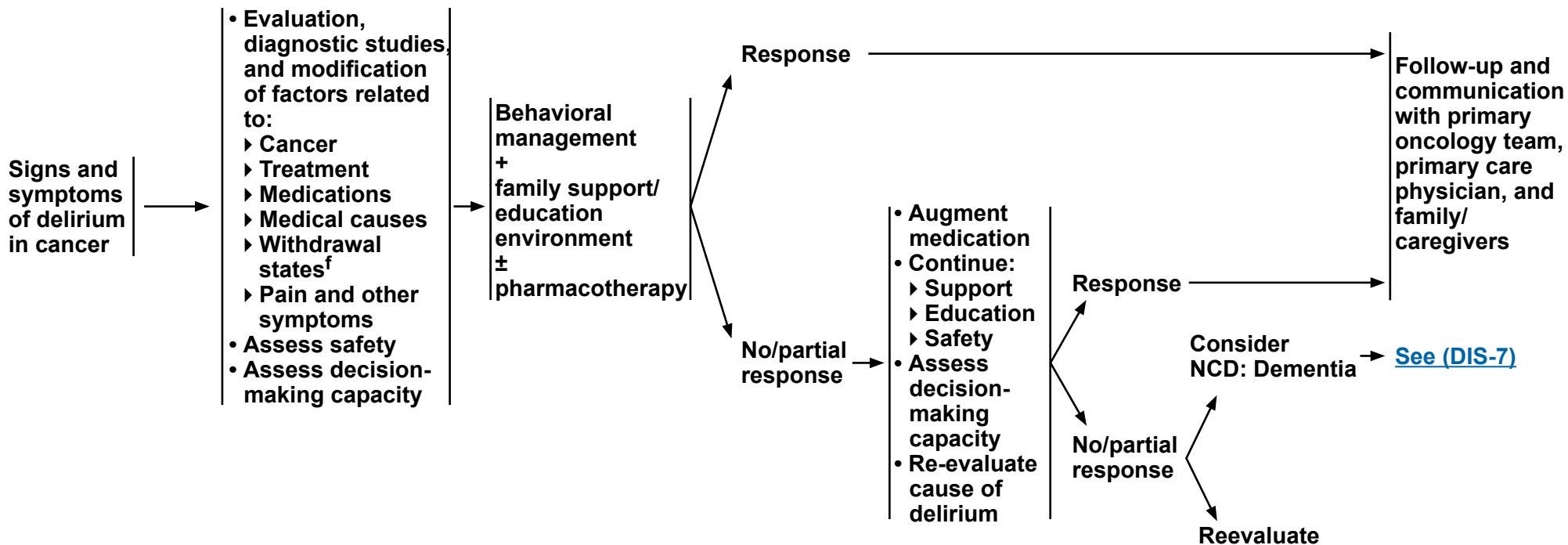


**NCD: DELIRIUM**

**EVALUATION**

**TREATMENT**

**FOLLOW-UP**



<sup>f</sup>Management of withdrawal states may vary depending upon the substance.

[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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# NCCN Guidelines Version 3.2019

## Distress Management

### DEPRESSIVE DISORDERS

Signs and symptoms of depressive disorders in cancer including:

- Depressive disorders related to medical illness
- Major depressive disorders
- Persistent depressive disorder

### EVALUATION

- Evaluation, diagnostic studies, and modification of factors related to:
  - Cancer
  - Treatment
  - Medications
  - Medical causes
  - Withdrawal states
  - Pain
  - Fatigue
  - Sleep disruption
  - Anorexia
  - Anhedonia
  - Decreased interest in activities
  - Wish to die
  - Suicidal thoughts
  - Mood swings
  - Poor concentration
  - Demoralization
- Consider psychosocial and spiritual concerns
- Assess decision-making capacity
- Assess safety
- Evaluate family/home environment
- Evaluate alcohol and recreational drug use
- Evaluate using PHQ-2 or PHQ-9

No danger to self or others →

Danger to self or others →

### TREATMENT

- Psychotherapy
- Psychotropic medication (category 1)
- Mental health treatment and follow-up/patient and family education
- Consider referral to social work services or chaplaincy care [See Social Work and Counseling Services \(DIS-24\) or Chaplaincy Care \(DIS-26\)](#)

- Evaluate suicide and homicide risk
- Consider hospitalization
- Assure patient safety:
  - Order psychiatric consultation
  - Increase monitoring
  - Remove guns/dangerous objects
- Assure safety of others
- Consider referral to social work services or chaplaincy care [See Social Work and Counseling Services \(DIS-24\) or Chaplaincy Care \(DIS-26\)](#)

Response →

No/partial response →

### FOLLOW-UP

Follow-up and communication with primary oncology team, primary care physician, and family/caregivers

[See \(DIS-11\)](#)

Follow-up and communication with primary oncology team, primary care physician, and family/caregivers

Mental health treatment and follow-up/patient and family education

[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

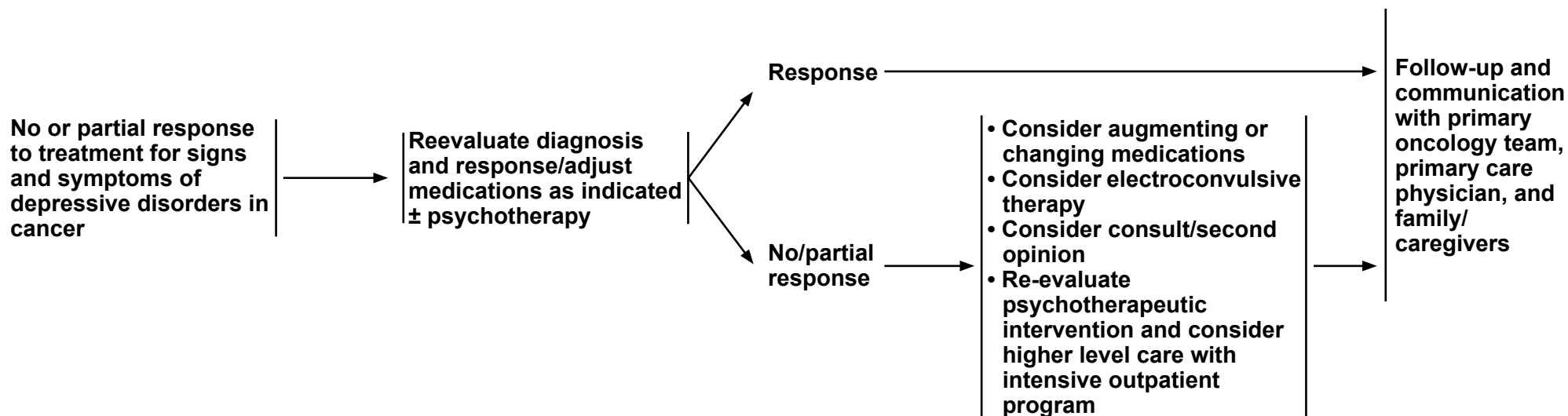
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**DEPRESSIVE DISORDERS**  
(continued)

**EVALUATION**

**TREATMENT**

**FOLLOW-UP**

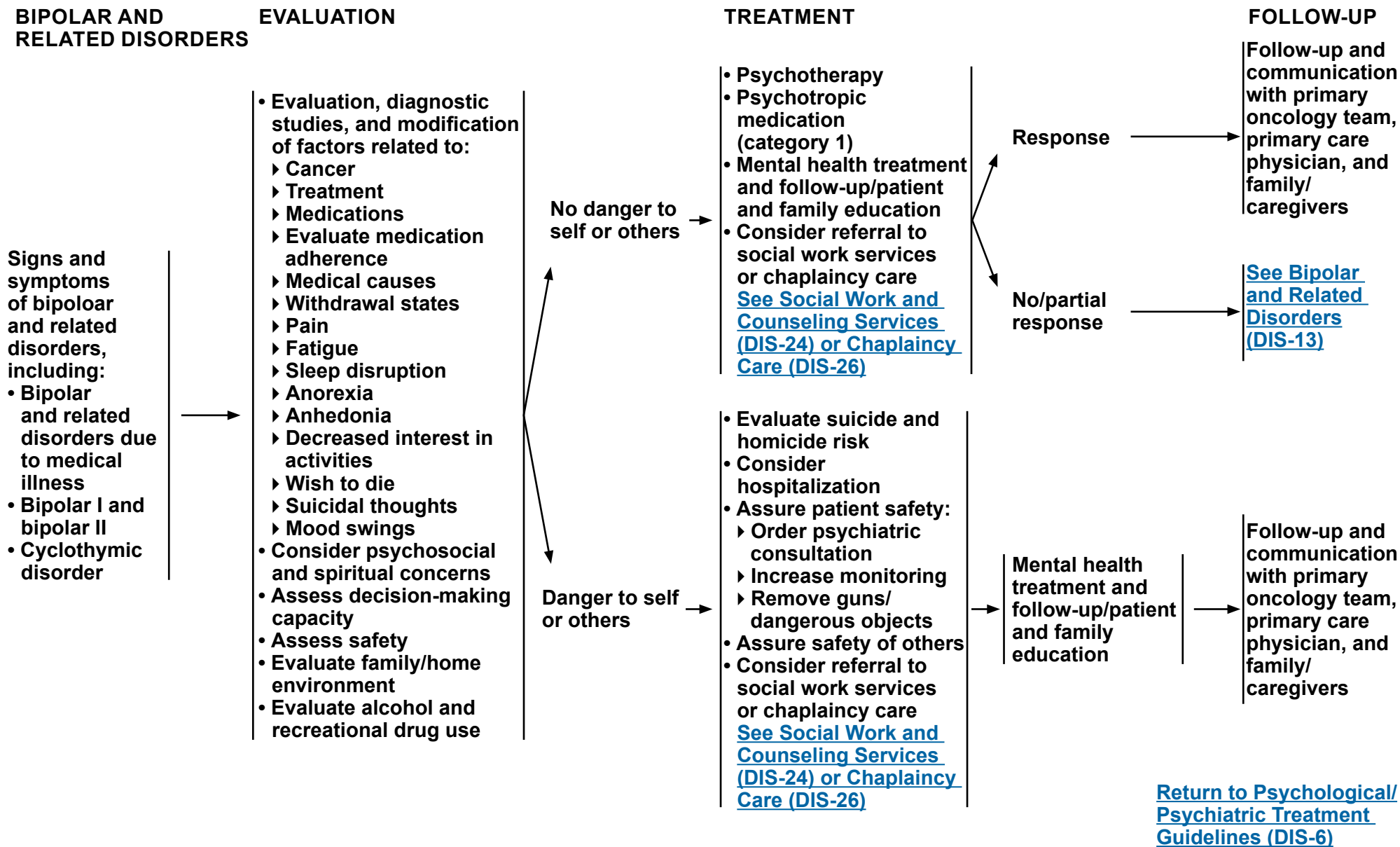


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[Return to Psychological/ Psychiatric Treatment Guidelines \(DIS-6\)](#)

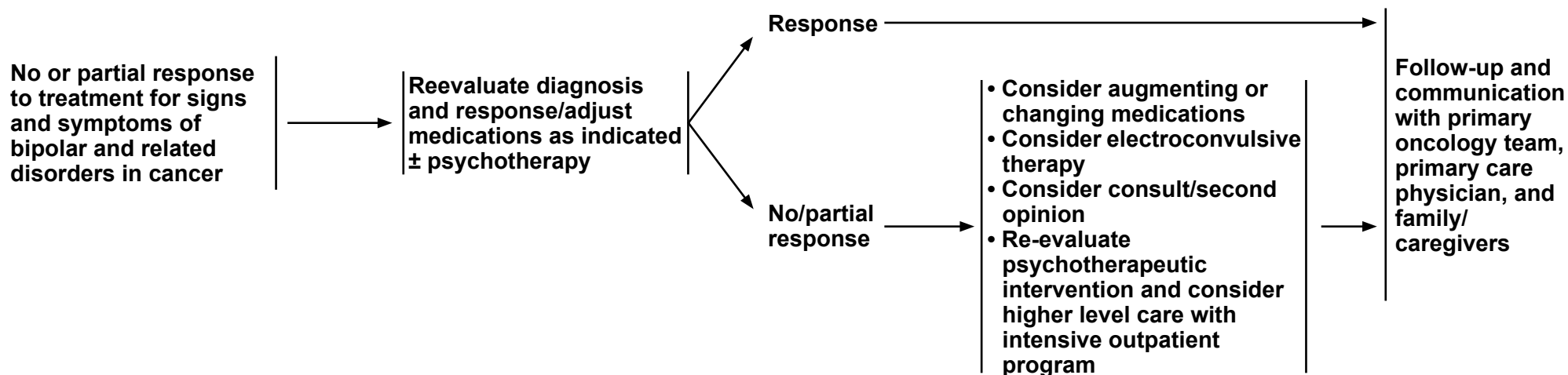
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**BIPOLAR AND RELATED  
DISORDERS  
(continued)**

**EVALUATION**

**TREATMENT**

**FOLLOW-UP**



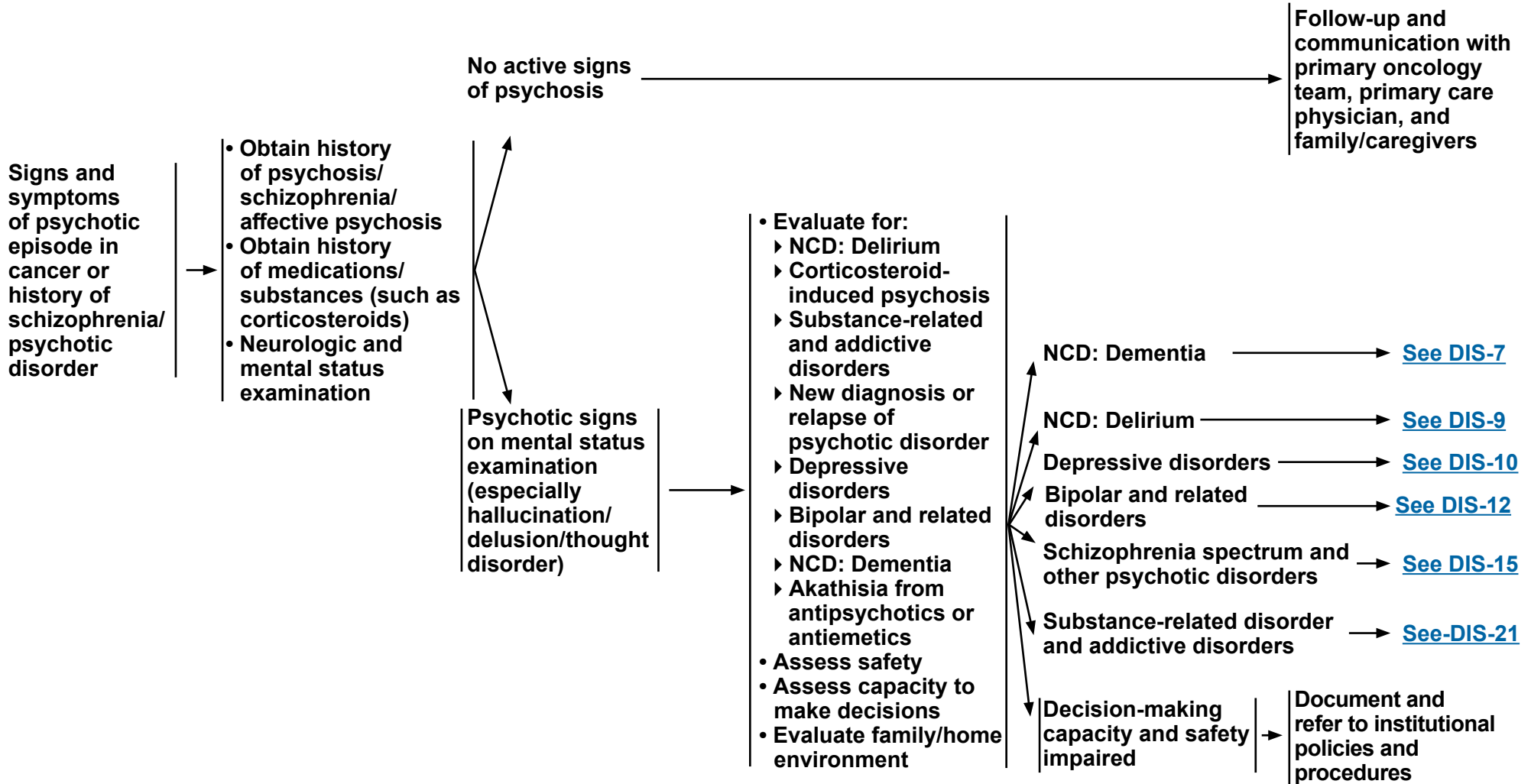
[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

**Note: All recommendations are category 2A unless otherwise indicated.**  
**Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.**



### SCHIZOPHRENIA SPECTRUM AND OTHER PSYCHOTIC DISORDERS

### EVALUATION



[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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### SCHIZOPHRENIA SPECTRUM AND OTHER PSYCHOTIC DISORDERS (continued)

### TREATMENT

### FOLLOW-UP

- Evaluation, diagnostic studies, and modification of factors related to:
  - ▶ Cancer
  - ▶ Treatment
  - ▶ Medications (particularly steroids)
  - ▶ NCD: Delirium
  - ▶ NCD: Dementia
  - ▶ Withdrawal states or substance use disorder
  - ▶ New diagnosis of psychotic disorder
  - ▶ Relapse of psychotic disorder (eg, not taking maintenance anti-psychotic medications)
    - ◊ Evaluate medication adherence
- Assess safety
- Assess capacity to make decisions
- Assess family/caregiver resources including inpatient psychiatry hospitalization and community mental health team

- Secure safety
- Consider anti-psychotic medications (urgently administer)
- Consider medications for mood
- Consider transfer to psychiatric unit/hospital
- Consider role of electroconvulsive therapy in psychotic depression/mania, catatonia

Response

No/partial response

- Reevaluate
- Attend to patient safety
- Consider capacity to make decisions
- Maintain communication with team for chronic psychotic disorder/psychiatric service
- Consider alternate level of care

Follow-up and communication with primary oncology team, primary care physician, and family/caregivers

[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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# NCCN Guidelines Version 3.2019

## Distress Management

### ANXIETY DISORDERS

Signs and symptoms of anxiety disorder in cancer:

- Anxiety due to general medical condition
- Generalized anxiety disorder
- Panic disorder
- Specific phobia
- Agoraphobia
- Substance/medication-induced anxiety disorder
- Conditioned nausea/vomiting ([See NCCN Guidelines for Antiemesis](#))

### EVALUATION

- Evaluation, diagnostic studies, and modification of factors related to:
  - Cancer
  - Treatment
  - Nausea/vomiting
  - Medications
  - Medical causes
  - Withdrawal states
  - Pain
  - Poor concentration
  - Sleep disruption
  - Anxiety or panic attacks
  - Hypervigilance
  - Fears
  - Irritability
- Assess safety
- Assess decision-making capacity
- Evaluate family and home environment
- Evaluate alcohol and recreational drug use
- Consider spiritual/religious concerns ([see Chaplaincy Care DIS-26](#))

### TREATMENT

Psychotherapy (category 1)  
 ± antidepressant  
 ± anxiolytic

Response

No/partial response

Reevaluate medication (consider antipsychotics), psychotherapy, support, education

Response

No/partial response

### FOLLOW-UP

Follow-up and communication with primary oncology team, primary care physician, and family/caregivers

Evaluate for depression and other psychiatric comorbidity

[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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### TRAUMA AND STRESSOR-RELATED DISORDERS

### EVALUATION

### TREATMENT

### FOLLOW-UP

Signs and symptoms of trauma and stressor-related disorders in cancer:

- Post-traumatic stress disorder
- Adjustment disorder
- Acute stress disorder

- Evaluation, diagnostic studies, and modification of factors related to:
  - Cancer
  - Treatment
  - Medications
  - Medical causes
  - Pain
  - Poor concentration
  - Sleep disruption
  - Anxiety or panic attacks
  - Hypervigilance
  - Fears
  - Irritability
- Assess safety
- Assess decision-making capacity
- Evaluate family and home environment
- Assess past trauma and/or cancer-related post-traumatic stress

Psychotherapy (category 1) ± antidepressant ± anxiolytic

Response

No/partial response

Reevaluate medication (consider antipsychotics), psychotherapy, support, education

Response

No/partial response

Follow-up and communication with primary oncology team, primary care physician, and family/caregivers

Evaluate for depression and other psychiatric comorbidity

[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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# NCCN Guidelines Version 3.2019

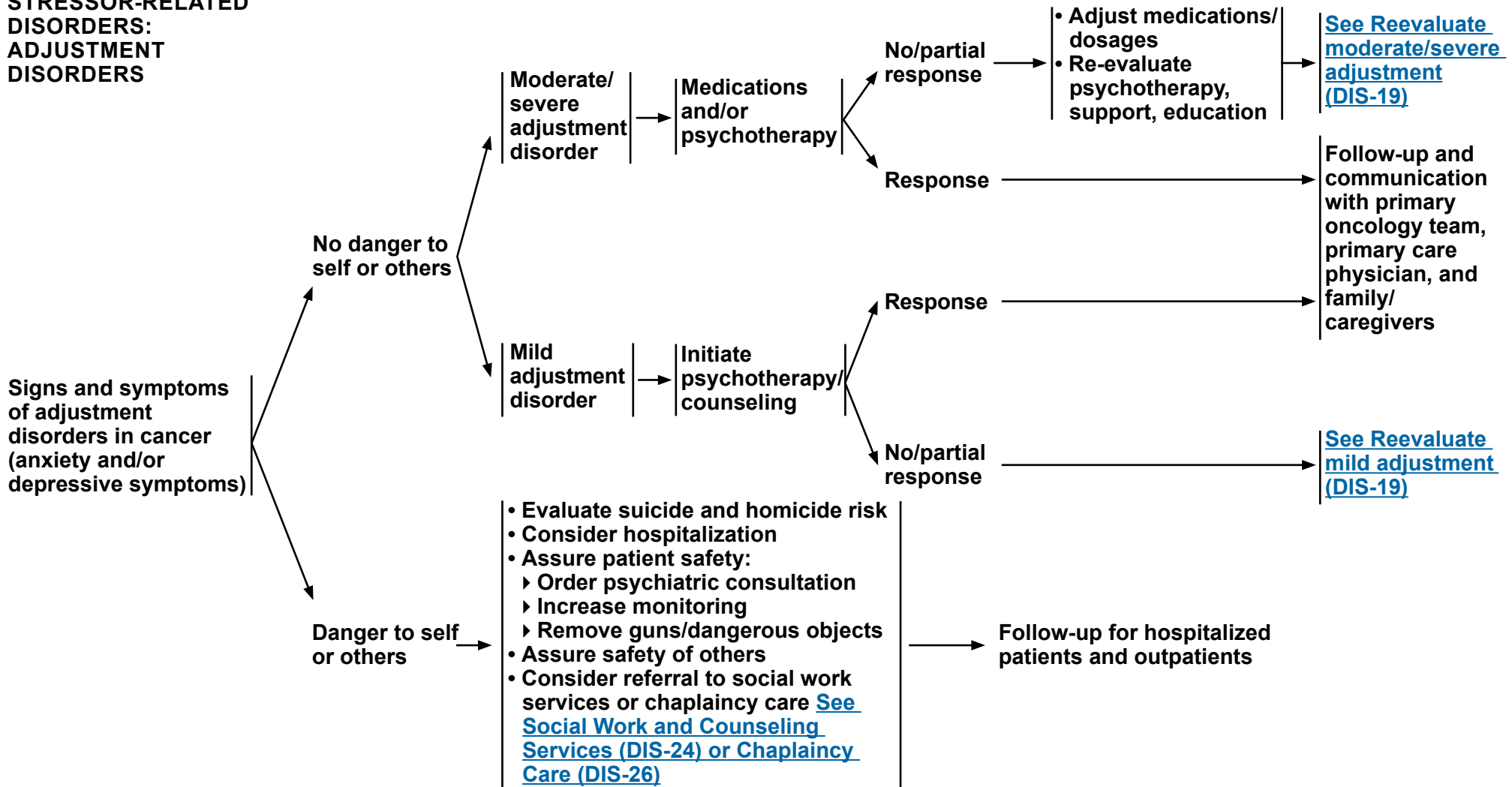
## Distress Management

### TRAUMA AND STRESSOR-RELATED DISORDERS: ADJUSTMENT DISORDERS

### EVALUATION

### TREATMENT

### FOLLOW-UP



[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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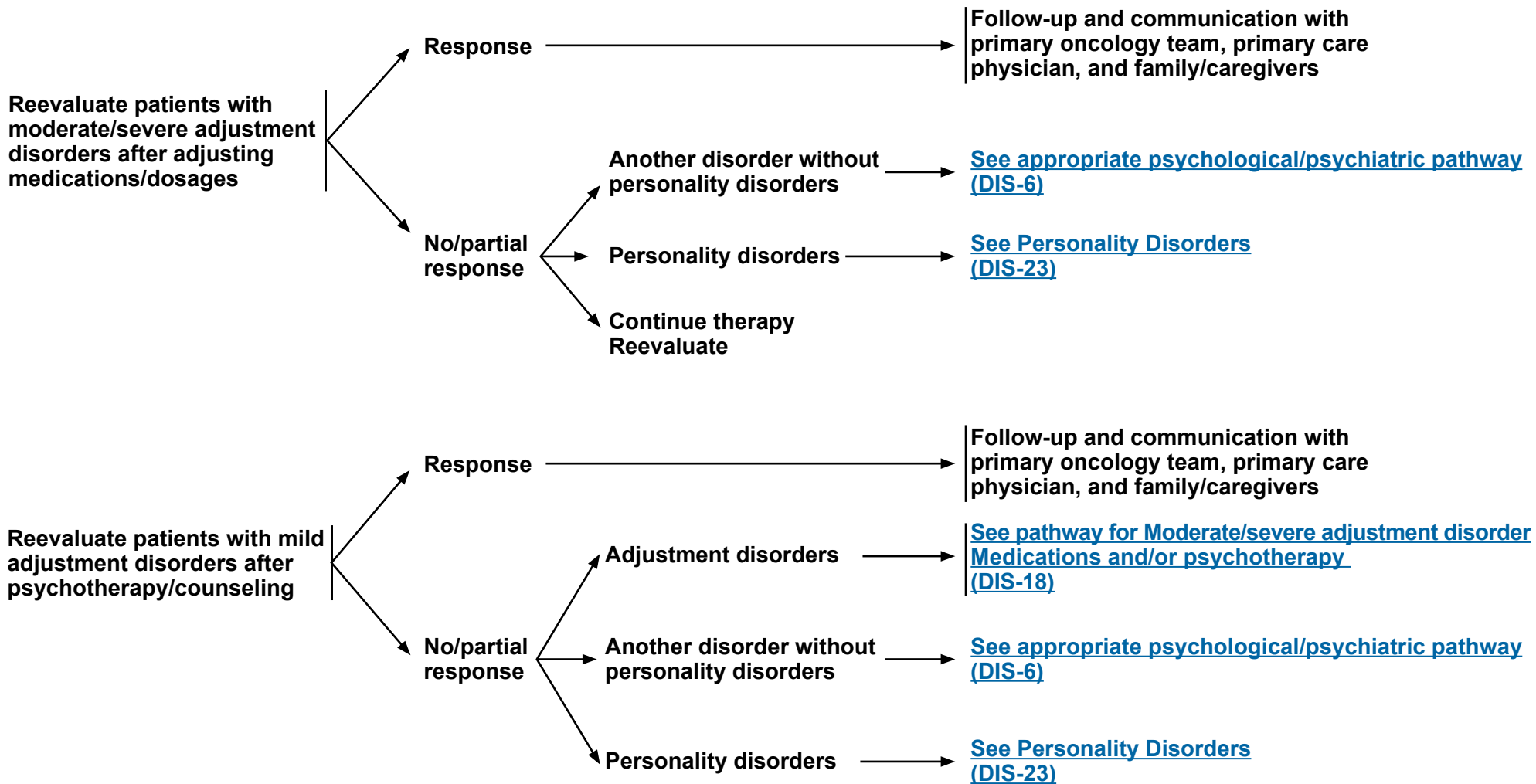


# NCCN Guidelines Version 3.2019

## Distress Management

### TRAUMA AND STRESSOR-RELATED DISORDERS: ADJUSTMENT DISORDERS (continued)

### FOLLOW-UP



[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

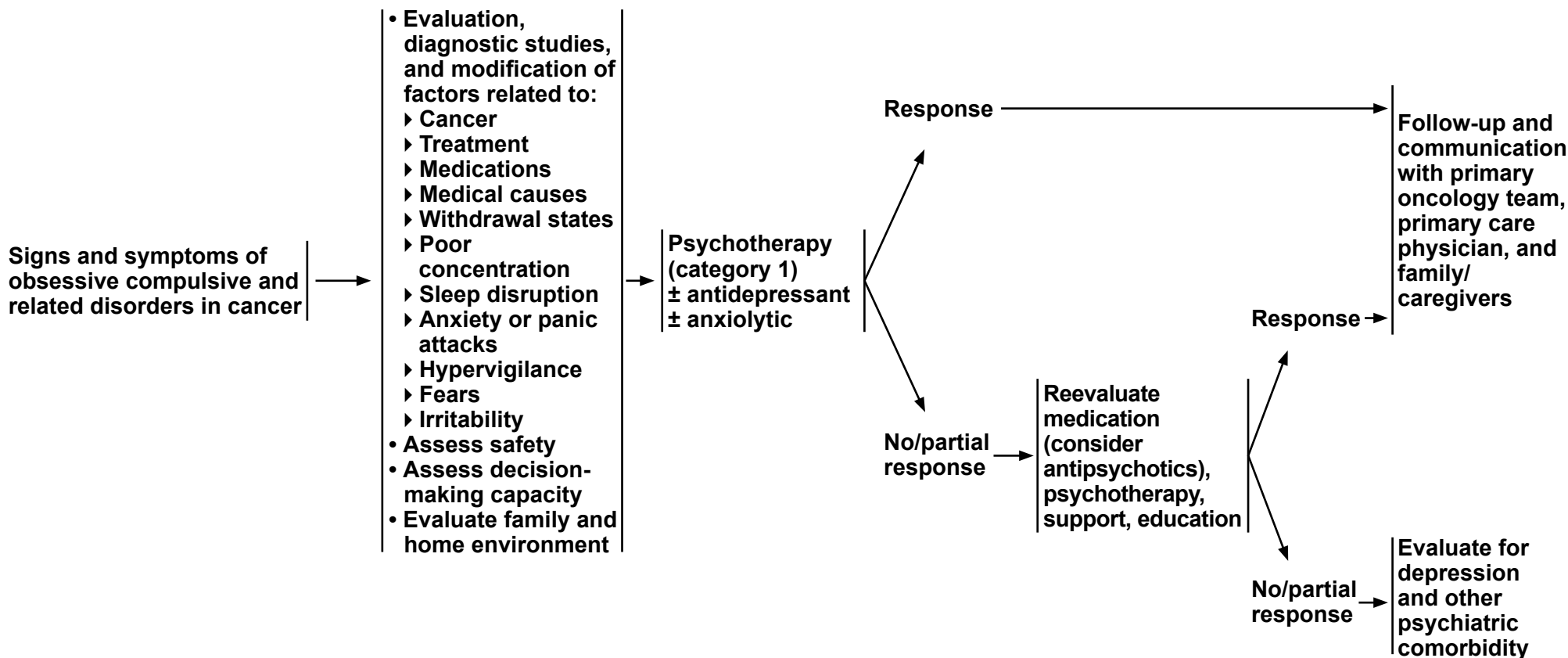
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### OBSESSIVE COMPULSIVE AND RELATED DISORDERS

### EVALUATION

### TREATMENT

### FOLLOW-UP



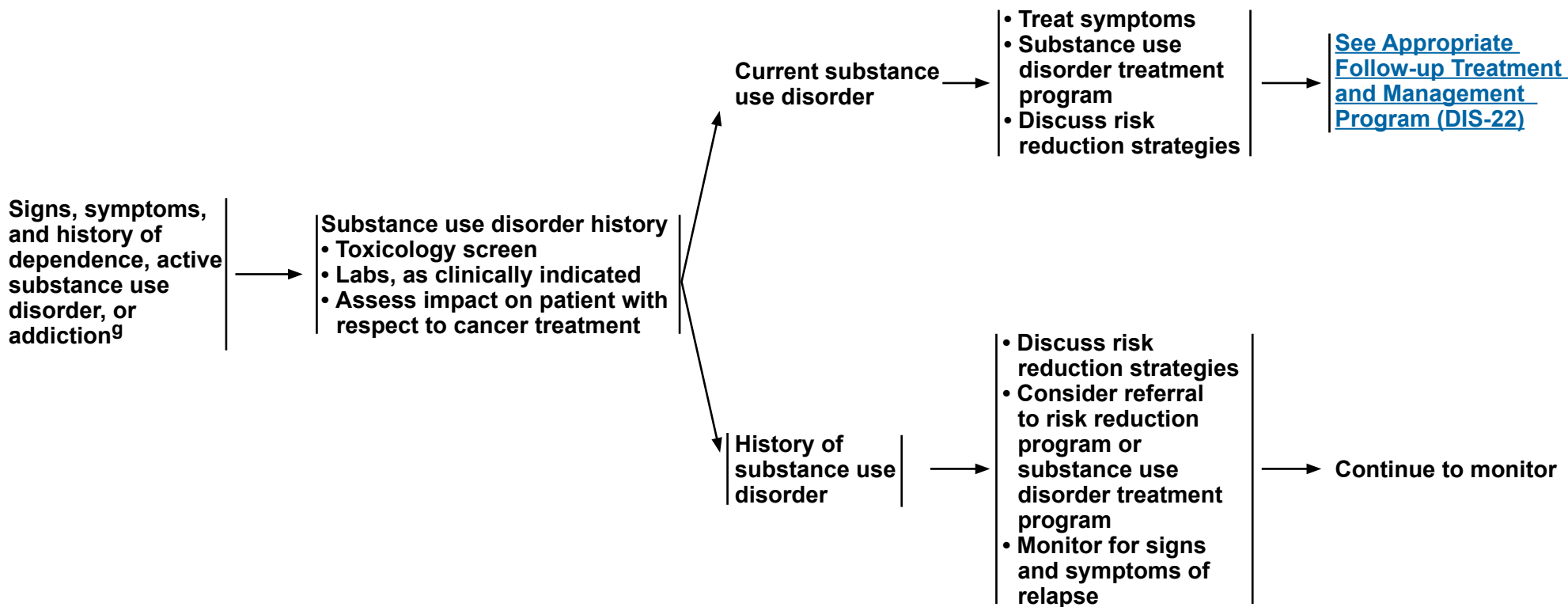
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### SUBSTANCE-RELATED EVALUATION AND ADDICTIVE DISORDERS

### TREATMENT



<sup>9</sup>Opioids, alcohol, tobacco, or other. For opioids, also see Opioid Principles, Prescribing, Titration, Maintenance, and Safety in the [NCCN Guidelines for Adult Cancer Pain \(PAIN-E\)](#). For tobacco use see the [NCCN Guidelines for Smoking Cessation](#).

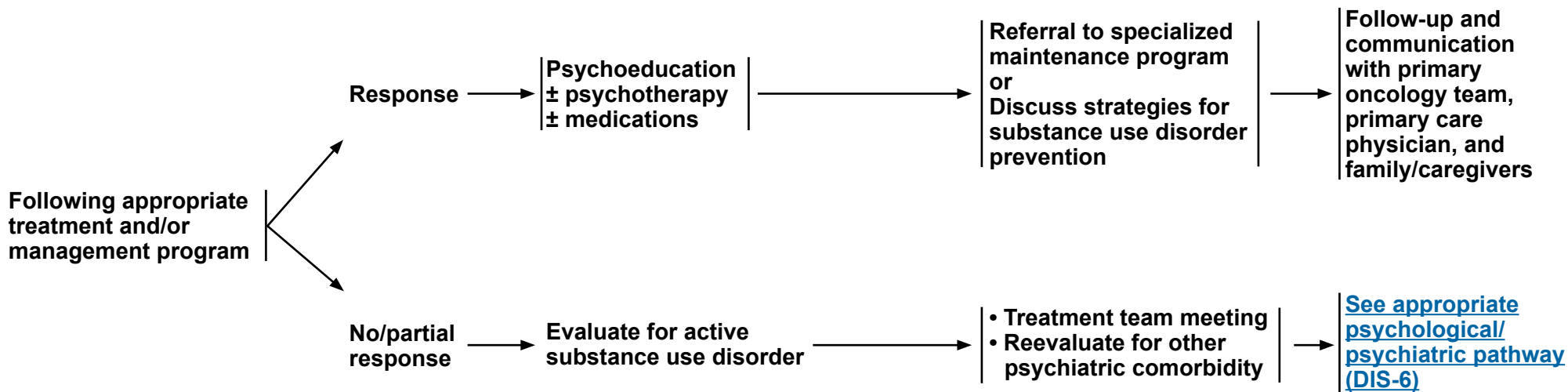
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### SUBSTANCE-RELATED AND ADDICTIVE DISORDERS (continued)

### FOLLOW-UP



[Return to Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

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# NCCN Guidelines Version 3.2019

## Distress Management

### PERSONALITY DISORDERS

### EVALUATION

### TREATMENT

### FOLLOW-UP

Signs and symptoms of personality disorders<sup>h</sup> in cancer:

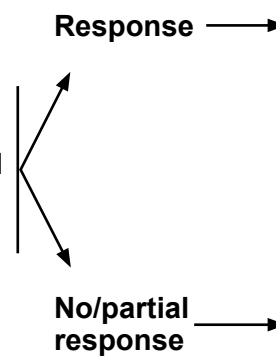
- Personality change related to medical or treatment factors
- Borderline
- Histrionic
- Schizoid
- Obsessive-compulsive
- Paranoid
- Antisocial
- Narcissistic
- Dependent
- Schizotypal



- Evaluation, diagnostic studies, and modification of factors related to:
  - Cancer
  - Treatment
  - Medications
  - Medical causes
  - Withdrawal states
  - Pain
  - Manipulative behavior
  - Anger
  - Threatening behavior
  - Histrionic behavior
  - Demanding behavior
  - Fear
- Assess safety
- Assess decision-making capacity
- Assess home situation



- Develop coordinated behavioral, psychological, and medical treatment plan with health care team (behavioral management ± medications)
- Staff education for management



<sup>h</sup>For a complete list of personality disorders, see the American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

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[Return to Psychological/ Psychiatric Treatment Guidelines \(DIS-6\)](#)



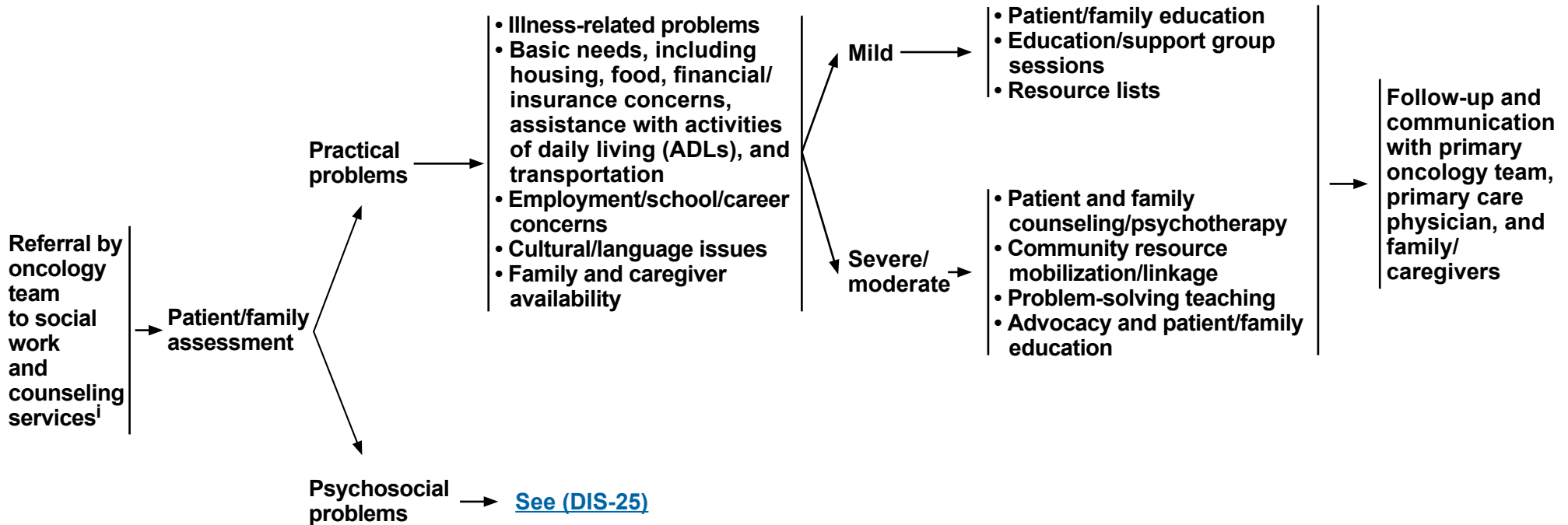
# NCCN Guidelines Version 3.2019

## Distress Management

### SOCIAL WORK AND COUNSELING SERVICES<sup>i</sup>

### CATEGORY TYPE OF PROBLEM

### SOCIAL WORK AND COUNSELING<sup>i</sup> INTERVENTIONS



<sup>i</sup>Social work and counseling services include mental health care as described in the psychological/psychiatric treatment guidelines ([See DIS-6](#)).

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**Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.**



CATEGORY	TYPE OF PROBLEM	SOCIAL WORK AND COUNSELING <sup>i</sup> INTERVENTIONS
Psychosocial problems	<ul style="list-style-type: none"> <li>• Adjustment to illness</li> <li>• Family and social conflict/isolation</li> <li>• Treatment decisions, quality-of-life issues, and transitions in care</li> <li>• Absent or unclear advance directive</li> <li>• Abuse and neglect</li> <li>• Coping/communication</li> <li>• Changes regarding body image and sexual health</li> <li>• Grief, bereavement, and coping with loss</li> <li>• Cultural concerns</li> <li>• Caregiver issues (mobilizing support for caregivers)</li> <li>• Depressive symptoms</li> <li>• Suicidal ideation</li> <li>• Anxiety (ie, fears, nervousness, worry)</li> </ul>	<div style="display: flex; flex-direction: column; align-items: center;"> <div style="display: flex; align-items: center; margin-bottom: 20px;"> <div style="margin-right: 10px;">Mild</div> <div style="margin-right: 10px;">→</div> <div style="border-left: 1px solid black; padding-left: 10px;"> <ul style="list-style-type: none"> <li>• Patient/family education</li> <li>• Education/support group sessions</li> <li>• Resource lists</li> <li>• Sexual health counseling</li> <li>• Grief counseling</li> <li>• Strengthen coping strategies</li> </ul> </div> </div> <div style="display: flex; align-items: center; margin-bottom: 20px;"> <div style="margin-right: 10px;">Severe/ moderate</div> <div style="margin-right: 10px;">→</div> <div style="border-left: 1px solid black; padding-left: 10px;"> <ul style="list-style-type: none"> <li>• Patient and family counseling/ psychotherapy, sexual health counseling, or grief counseling</li> <li>• Community resource mobilization</li> <li>• Problem-solving teaching</li> <li>• Advocacy and family/patient education</li> <li>• Education/support group sessions</li> <li>• Protective services</li> <li>• Consider referral for psychological/psychiatric treatment</li> <li>• Consider referral for chaplaincy care</li> </ul> </div> </div> <div style="border-left: 1px solid black; padding-left: 10px; width: 100%;"> <p>Follow-up and communication with primary oncology team, primary care physician, and family/caregivers</p> </div> </div>

<sup>i</sup>Social work and counseling services include mental health care as described in the psychological/psychiatric treatment guidelines ([See DIS-6](#)).

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### CHAPLAINCY CARE

#### CHAPLAINCY ASSESSMENT<sup>1,2</sup>

#### INTERVENTIONS BASED ON ASSESSMENT<sup>3</sup>

Referral by  
oncology team  
to chaplaincy  
care

- Interpersonal conflict regarding spiritual/religious beliefs and practices
- Concerns with lack of meaning/purpose
- Struggles with morality/values
  - ▶ Doubts about beliefs
  - ▶ Perception of being attacked by evil
  - ▶ Concerns about relationship with the sacred
  - ▶ Concerns about dying/death and/or afterlife
  - ▶ Grief/loss
  - ▶ Feelings of worthlessness or being a burden
  - ▶ Loneliness
  - ▶ Conflict between religious beliefs and recommended treatment
  - ▶ Ritual needs

- Spiritual/existential support/care
  - ▶ Spiritual/existential counseling
  - ▶ Spiritual/existential education (including resources)
  - ▶ Spiritual/existential ritual
- Meditation and/or prayer
- Referral to spiritual/existential community resources (eg, specific faith community, spiritual director, pastoral psychotherapist)
- Referral to other health care professional (eg, palliative care, mental health professional)

Follow-up and communication with primary oncology team, primary care physician, and family/caregivers

<sup>1</sup>Exline JJ, Pargament KI, Grubbs JB, Yali AM. The Religious and Spiritual Struggles Scale: Development and initial validation. *Psychology of Religion and Spirituality* 2014;6:208-222.

<sup>2</sup>Lo C, Panday T, Zeppieri J, et al. Preliminary psychometrics of the Existential Distress Scale in patients with advanced cancer. *Eur J Cancer Care (Engl)* 2017;26.

<sup>3</sup>Spiritual Health Victoria. Spiritual Care Minimum Data Set Framework. Abbotsford, Victoria, Australia; 2015. Available at: <http://www.spiritualhealthvictoria.org.au/standards-and-frameworks>.

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**PRINCIPLES FOR IMPLEMENTATION OF STANDARDS AND DISTRESS MANAGEMENT GUIDELINES<sup>1-8</sup>**

The Commission on Cancer's accreditation standards include screening all patients with cancer for psychosocial distress and referral for psychosocial care as needed.<sup>9</sup>

- **Recommend creation of a work group/cancer committee, which should be composed of multiple disciplines' representatives, including but not limited to physician champions, nurses, psychologists, information technology experts, administrative leadership, social workers, and chaplaincy.**
- **Explicit support and backing of the institutional leadership is essential. The committee should identify and organize advocates and institutional stakeholders who will support the implementation of the program. A small-scale pilot program may be a preferable way to test the screening process before a larger scale implementation is put in place.**
- **The following should be considered:**
  - ▶ **Already existing resources (eg, screening tools or programs already in place)**
  - ▶ **Current workflows, processes, and available technologies**
- **Various distress screening tools have been developed, including the NCCN Distress Thermometer and Problem List ([DIS-A](#)). The cancer committee should select the most appropriate screening tool to be administered in its setting.**
  - ▶ **Standardized, validated instruments, or tools with established clinical cutoffs, are recommended.**
  - ▶ **Determine the cutoff score or specific problems that will be used to identify distressed patients.**
  - ▶ **Determine the frequency of screening.**
  - ▶ **Develop a response algorithm (ie, who is alerted to screening results, how information is processed, triggering of appropriate referrals).**
  - ▶ **Develop a process in which distress screening results are made known to critical members of the care team, including such strategies as incorporating the results into the patient's medical record.**
  - ▶ **Develop results thresholds for generating respective referrals. These may vary based on types of services available and their capacity.**
  - ▶ **Consider incorporating distress screening into the institutions' quality improvement and assessment process (eg, distress screening becomes a measurable quality metric).**
  - ▶ **Distress screening and response to results data should be tracked and can be used for further improvements, as well as expansion of needed services.**

<sup>1</sup>Ehlers SL, Davis K, Bluethmann SM, et al. Screening for psychosocial distress among patients with cancer: implications for clinical practice, healthcare policy, and dissemination to enhance cancer survivorship. *Transl Behav Med* 2018.

<sup>2</sup>Smith SK, Loscalzo M, Mayer C, Rosenstein DL. Best practices in oncology distress management: Beyond the screen. *Am Soc Clin Oncol Educ Book* 2018;813-821.

<sup>3</sup>Ercolano E, Hoffman E, Tan H, et al. Managing psychosocial distress: Lessons learned in optimizing screening program implementation. *Oncology (Williston Park)* 2018;32:488-490, 492-493.

<sup>4</sup>Rodin G. From evidence to implementation: The global challenge for psychosocial oncology. *Psychooncology* 2018;27:2310-2316.

<sup>5</sup>Knies AK, Jutagir DR, Ercolano E, et al. Barriers and facilitators to implementing the commission on cancer's distress screening program standard. *Palliat Support Care* 2018;1-9.

<sup>6</sup>Fitch MI, Ashbury F, Nicoll I. Reflections on the implementation of screening for distress (sixth vital sign) in Canada: key lessons learned. *Support Care Cancer* 2018;26:4011-4020.

<sup>7</sup>McCarter K, Britton B, Baker AL, et al. Interventions to improve screening and appropriate referral of patients with cancer for psychosocial distress: systematic review. *BMJ Open* 2018;8:e017959.

<sup>8</sup>Grassi L, Spiegel D, Riba M. Advancing psychosocial care in cancer patients. *F1000Res* 2017;6:2083.

<sup>9</sup>American College of Surgeons Commission on Cancer. *Cancer Program Standards: Ensuring Patient-Centered Care*; 2016. Available at: <https://www.facs.org/quality-programs/cancer/coc/standards>.

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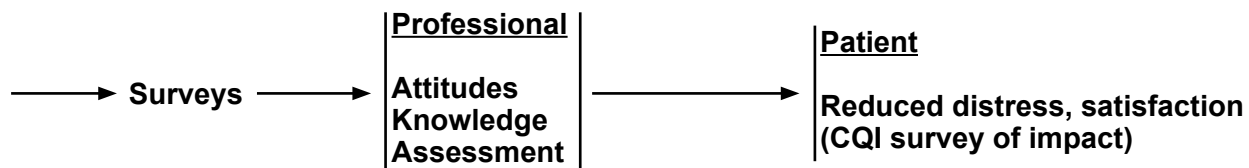
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### INSTITUTIONAL EVALUATION OF STANDARDS OF CARE<sup>1</sup>

#### INTERVENTIONS

- Interdisciplinary committee tailors standards to institutional setting
- Distress Thermometer (0–10) and Problem List screening tool in clinics and inpatient setting
- Problem list
- Education of primary oncology teams via rounds and liaison with nurses and social workers
- Clarification of available resources
- CQI studies

#### OUTCOMES



<sup>1</sup>Based on implementation/evaluation of pain management guidelines.

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# NCCN Guidelines Version 3.2019 Distress Management

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## Discussion

### NCCN Categories of Evidence and Consensus

**Category 1:** Based upon high-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

**Category 2A:** Based upon lower-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

**Category 2B:** Based upon lower-level evidence, there is NCCN consensus that the intervention is appropriate.

**Category 3:** Based upon any level of evidence, there is major NCCN disagreement that the intervention is appropriate.

**All recommendations are category 2A unless otherwise indicated.**

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# NCCN Guidelines Version 3.2019

## Distress Management

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### Overview

In the United States, it is estimated that a total of 1,762,450 new cancer cases and 606,880 deaths from cancer will occur in 2019.<sup>1</sup> All patients experience some level of distress associated with the cancer diagnosis and the effects of the disease and its treatment regardless of the stage of disease. Distress can result from the reaction to the cancer diagnosis and to the various transitions throughout the trajectory of the disease, including during survivorship. Clinically significant levels of distress occur in a subset of patients, and identification and treatment of distress are of utmost importance.

These NCCN Guidelines for Distress Management discuss the identification and treatment of psychosocial problems in patients with cancer. They are intended to assist oncology teams to identify patients who require referral to psychosocial resources and to give oncology teams guidance on interventions for patients with mild distress. These guidelines also provide guidance for social workers, certified chaplains, and mental health professionals by describing treatments and interventions for various psychosocial problems as they relate to patients with cancer.

### Literature Search Criteria and Guidelines Update Methodology

Prior to the update of this version of the NCCN Guidelines for Distress Management, an electronic search of the PubMed database was performed to obtain key literature, using the following search terms: (cancer distress) or (cancer depression) or (cancer anxiety) or (cancer dementia) or (cancer delirium) or (cancer depressive) or (cancer bipolar) (cancer post-traumatic stress) or (cancer acute stress) or (cancer adjustment disorder) or (cancer obsessive-compulsive disorder) or (cancer panic disorder) or (cancer schizophrenia) or (cancer psychotic disorder) or (cancer substance abuse) or (cancer substance dependence) or (cancer

substance addiction) (cancer personality disorder) or (cancer social work) or (cancer spiritual) or (cancer chaplain). The PubMed database was chosen because it remains the most widely used resource for medical literature and indexes peer-reviewed biomedical literature.<sup>2</sup>

The search results were narrowed by selecting studies in humans published in English. Results were confined to the following article types: Clinical Trial, Phase II; Clinical Trial, Phase III; Clinical Trial, Phase IV; Guideline; Practice Guidelines; Randomized Controlled Trials; Meta-Analysis; Systematic Reviews; and Validation Studies.

The data from key PubMed articles and articles from additional sources deemed as relevant to these guidelines and discussed by the panel have been included in this version of the Discussion section (eg, e-publications ahead of print, meeting abstracts). Recommendations for which high-level evidence is lacking are based on the panel's review of lower-level evidence and expert opinion.

The complete details of the Development and Update of the NCCN Guidelines are available on the NCCN website (available at [www.NCCN.org](http://www.NCCN.org)).

### Psychosocial Problems in Patients with Cancer

In recent decades, dramatic advances in early detection and treatment options have increased the overall survival rates in patients of all ages with cancer. At the same time, these improved treatment options are also associated with substantial long-term side effects that interfere with patients' ability to perform daily activities, such as fatigue, pain, anxiety, and depression. In addition, the physiologic effects of cancer itself and certain anti-cancer drugs can also be non-psychological contributors to distress symptoms.<sup>3-6</sup> Furthermore, patients with cancer may have pre-existing psychological or psychiatric conditions that impact their ability to cope with cancer. Survivors of cancer are about twice as likely to report

medication use for anxiety and depression as adults who don't have a personal history of cancer.<sup>7</sup>

Overall, surveys have found that 20% to 52% of patients show a significant level of distress.<sup>8-10</sup> A meta-analysis reported that 30% to 40% of patients with various types of cancer have some combination of mood disorders.<sup>11</sup> The prevalence of psychological distress in individuals varies by the type and stage of cancer as well as by patient age, gender, and race.<sup>12</sup> Further, the prevalence of distress, depression, and psychiatric disorders has been studied in many sites and stages of cancer.<sup>13-20</sup> A review of studies that assessed the prevalence of depression in patients with cancer showed that the highest prevalence was in patients with oropharyngeal cancer (22%–57%) and pancreatic cancer (33%–50%).<sup>18</sup> In a study of 4496 patients with cancer, Zabora and colleagues reported that the highest prevalence rates of distress were found in patients with cancers of the lung (43.4%) and brain (42.7%).<sup>21</sup>

Patients at increased risk for moderate or severe distress are those with a history of psychiatric disorder, depression, or substance use disorder and those with cognitive impairment, severe comorbid illnesses, uncontrolled symptoms, communication barriers, or social issues. Social issues/risk factors include younger age, living alone, having young children, and prior trauma and/or abuse (physical, sexual, emotional, and/or verbal). Learning about genetic/familial risk of cancer is also associated with distress.<sup>22,23</sup>

Distress is a risk factor for non-adherence to treatment, especially with oral medications. In women with primary breast cancer, Partridge and colleagues observed that the overall adherence to tamoxifen decreased to 50% in the fourth year of therapy and nearly one fourth of patients may be at risk of inadequate clinical response due to poor adherence.<sup>24</sup> In a meta-analysis, DiMatteo and colleagues found that noncompliance was 3 times greater in depressed patients compared to non-depressed patients.<sup>25</sup> In addition to decreased adherence to treatment, failure to

recognize and treat distress may lead to several problems: patients may have trouble making decisions about treatment and may make extra visits to the physician's office and emergency room, which takes more time and causes greater stress to the oncology team.<sup>26,27</sup> An analysis of 1036 patients with advanced cancer showed that distress is associated with longer hospital stays ( $P = .04$ ).<sup>28</sup> Distress in patients with cancer also leads to poorer quality of life and may even negatively impact survival.<sup>18,29-32</sup> Furthermore, survivors with untreated distress have poorer compliance with surveillance screenings and are less likely to exercise and quit smoking.<sup>33</sup>

Early evaluation and screening for distress leads to early and timely management of psychological distress, which in turn improves medical management.<sup>34,35</sup> A randomized study showed that routine screening for distress, with referral to psychosocial resources as needed, led to lower levels of distress at 3 months than did screening without personalized triage for referrals.<sup>36</sup> Those with the highest level of initial distress benefitted the most. In addition, there is evidence from randomized trials that psychologically effective interventions may lead to a survival advantage in patients with cancer.<sup>37-39</sup> Overall, early detection and treatment of distress lead to:

- better adherence to treatment,
- better communication,
- fewer calls and visits to the oncologist's office, and
- avoidance of patients' anger and development of severe anxiety or depression.

### Barriers to Distress Management in Cancer

Less than half of distressed patients with cancer are actually identified and referred for psychosocial help.<sup>40,41</sup> Many patients with cancer who are in need of psychosocial care are not able to get the help they need because of the under-recognition of patients' psychological needs by the primary



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oncology team and lack of knowledge of community resources.<sup>42</sup> The need is particularly acute in community oncologists' practices where there are few to no psychosocial resources.

An additional barrier to patients receiving the psychosocial care they require is the stigma associated with psychological problems. For many centuries, patients were not told their diagnosis of cancer due to the stigma attached to the disease. Since the 1970s, this situation has changed and patients are well aware of their diagnosis and treatment options.<sup>43</sup> However, patients are reluctant to reveal emotional problems to the oncologist. The words "psychological," "psychiatric," and "emotional" are as stigmatizing as the word "cancer." The word "distress" is less stigmatizing and more acceptable to patients and oncologists than these terms, but psychological issues remain stigmatized even in the context of coping with cancer. Consequently, patients often do not tell their physicians about their distress and physicians do not inquire about the psychological concerns of their patients. The recognition of patients' distress has become more difficult as cancer care has shifted to the ambulatory setting, where visits are often short and rushed. These barriers prevent distress from receiving the attention it deserves, despite the fact that distress management is a critical component of the total care of the person with cancer.

### NCCN Guidelines<sup>®</sup> for Distress Management

A major milestone in the improvement of psychosocial care in oncology was made by NCCN when it established a panel to develop clinical practice guidelines, using the NCCN format. The panel began to meet in 1997 as an interdisciplinary group. The clinical disciplines involved were: oncology, nursing, social work and counseling, psychiatry, psychology, and clergy. A patient advocate was also on the panel. Traditionally, clergy have not been included on NCCN Guidelines panels, but NCCN

recognized that many distressed patients prefer to speak with a certified chaplain.<sup>44</sup>

The first step was to understand why this area has been so difficult to develop. The panel members decided that words like "psychiatric" or "psychological" are stigmatizing; patients and oncologists were reluctant to label any symptoms or patients as such. The way around this barrier was developed by using a term that would feel "normal" and non-stigmatizing. This led to the first published guidelines in 1999 for the management of *distress* in patients with cancer. This accomplishment provided a benchmark, which has been used as a framework in the handbook for oncology clinicians published by the IPOS (International Psycho-Oncology Society) Press.<sup>45</sup>

The panel defines distress as a multifactorial, unpleasant experience of a psychological (ie, cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

Recommendations in the guidelines are based on evidence and on consensus among panel members. In addition to the guidelines for oncologists, the panel established guidelines for social workers, certified chaplains, and mental health professionals (psychologists, psychiatrists, psychiatric social workers, and psychiatric nurses).

### The New Standard of Care for Distress Management in Cancer

Psychosocial care had not been considered as an aspect of quality cancer care until the publication of a 2007 National Academy of Medicine

(formerly the Institute of Medicine) report, *Cancer Care for the Whole Patient*,<sup>46</sup> which is based on the pioneering work of the NCCN Panel. Psychosocial care is part of the standard for quality cancer care and should be integrated into routine care.<sup>46-48</sup> The National Academy of Medicine (NAM) report supported the work of the NCCN Guidelines for Distress Management by proposing a model for the effective delivery of psychosocial health services that could be implemented in any community oncology practice:

- Screening for distress and psychosocial needs;
- Making and implementing a treatment plan to address these needs;
- Referring to services as needed for psychosocial care; and
- Reevaluating, with plan adjustment as appropriate.

In August 2012, the Commission on Cancer (CoC) of the American College of Surgeons (ACS) released new accreditation standards for hospital cancer programs. Their patient-centered focus now includes screening all patients with cancer for psychosocial distress. These standards are required for accreditation, were enacted in 2015, and were updated in 2016 (<https://www.facs.org/quality-programs/cancer/coc/standards>). According to the updated accreditation standards, institutions are expected to document and monitor their distress screening process.

The standards of care for managing distress proposed by the NCCN Distress Management Panel are broad in nature and should be tailored to the particular needs of each institution and group of patients. The overriding goal of these standards is to ensure that no patient with distress goes unrecognized and untreated. The panel based these standards of care on quality improvement guidelines for the treatment of pain.<sup>49</sup> The standards of care developed by the NCCN Distress Management Panel, which can also be found in the guidelines, are:

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.
- Screening should identify the level and nature of the distress.
- Ideally, patients should be screened for distress at every medical visit as a hallmark of patient-centered care. At a minimum, patients should be screened to ascertain their level of distress at the initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status (eg, remission, recurrence, or progression; treatment-related complications).
- Distress should be assessed and managed according to clinical practice guidelines.
- Interdisciplinary institutional committees should be formed to implement standards for distress management.
- Educational and training programs should be developed to ensure that health care professionals and certified chaplains have knowledge and skills in the assessment and management of distress.
- Licensed mental health professionals and certified chaplains experienced in the psychosocial aspects of cancer should be readily available as staff members or by referral.
- Medical care contracts should include adequate reimbursement for services provided by mental health professionals.
- Clinical health outcomes measurements should include assessment of the psychosocial domain (eg, quality of life; patient and family satisfaction).
- Patients, families, and treatment teams should be informed that distress management is an integral part of total medical care and includes appropriate information about psychosocial services in the treatment center and in the community.
- Finally, the quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.





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Patients and families should be made aware that this new standard exists and that they should expect it in their oncologist's practice. The website for the Alliance for Quality Psychosocial Cancer Care, a coalition of professional and advocacy organizations whose goal is to advance the recommendations from the NAM report, has hundreds of psychosocial resources for health care professionals, patients, and caregivers, searchable by state (<http://www.wholecancerpatient.org/>). NCCN Guidelines for Patients® for managing distress have also been developed, based on the NCCN Clinical Practice Guidelines (available at [www.NCCN.org](http://www.NCCN.org)).

### Recommendations for Implementation of Standards and Guidelines

Jacobsen and colleagues conducted a study in 2005 evaluating the implementation of NCCN Guidelines for Distress Management by 15 NCCN Member Institutions.<sup>50</sup> Eight institutions (53%) conducted routine distress screening of some patient populations, and an additional 4 institutions (27%) also performed pilot testing of screening strategies. However, concordance to NCCN Guidelines (defined as screening all outpatients) was observed in only 20% of the NCCN Member Institutions at that time. A follow-up survey was conducted 7 years later that found increased levels of screening.<sup>51</sup> As of 2012, 14 of 20 responding NCCN Member Institutions (70%) performed routine screening for distress in at least some patient populations. Half of responding centers reported having screened all outpatients for distress. Another survey of 233 APOS members and APOS meeting attendees, representing 146 U.S. institutions, found that routine distress screening was not performed at a majority of cancer centers.<sup>52</sup> In this survey, 51% of cancer care organizations performed routine screening for distress in newly diagnosed patients with cancer. A 2013–2014 survey of applicants for a distress screening cancer education program, spanning 70 institutions, showed that fewer than half of these institutions had not yet begun distress

screening.<sup>53</sup> A 2014 survey of 55 cancer centers in the United States and Canada showed that adherence to an institution's distress screening protocol (ie, screening with appropriate documentation) occurred 63% of the time.<sup>54</sup>

Surveys of clinical staff have identified barriers to adoption of distress screening and found that time, staff uncertainties, competing demands, and ambiguous accountability are some of the biggest barriers.<sup>55,56</sup> A survey of oncology nurses also found that nurses who were familiar with these NCCN Guidelines for Distress Management were more comfortable discussing distress.<sup>55</sup>

The MD Anderson Cancer Center published a 2010 report on its efforts to implement the integration of psychosocial care into clinical cancer care.<sup>57</sup> The authors outline strategies they used to accomplish the required cultural shift and describe the results of their efforts. Other groups have also described their efforts toward implementing psychosocial screening in various outpatient settings.<sup>58-66</sup> Wagner and colleagues, for example, described efforts at oncology locations in the Chicago area to implement an electronic system that was tested between 2011 and 2012.<sup>65</sup> About one third of patients requested assistance with a psychosocial problem, including stress management and coping with a cancer diagnosis, and the authors deemed the system feasible.

Institutions should have a framework in place to address psychosocial care, in order to effectively manage distress in patients who need it. A 2012 survey completed by 20 NCCN Member Institutions showed most institutions do not formally keep track of the number of patients who utilize psychosocial care and/or services, which limits the ability to ensure that centers are adequately implementing standards of psychosocial care.<sup>67</sup> A 2014 survey of 2134 members of the AOSW who were also employees of a CoC-accredited cancer program showed that most programs now have procedures in place to address psychosocial care and are successful in

identifying psychosocial needs in patients and appropriately addressing these needs.<sup>68</sup> However, programs tend to be less successful with follow-up of psychosocial care and training of providers regarding psychosocial care.

Some initiatives have been developed to assist institutions with implementation of standards for distress screening and psychosocial care. Quality indicators can be used to determine the quality of psychosocial care given by a clinic or office. For example, Jacobsen and colleagues have developed a patient chart audit that permits an oncologist's office or clinic to evaluate the quality of their psychosocial care.<sup>69</sup> The survey queries whether there is documentation that the patient's current emotional well-being has been assessed and if there is documentation that any action has been taken if the patient has been identified as having a problem.

The Quality Oncology Practice Initiative (QOPI) was started in 2002 by ASCO as a pilot project (<http://qopi.asco.org/program.html>).<sup>70</sup> This program became available to all ASCO member medical oncologists in 2006. Jacobsen's psychosocial quality indicators were added as part of the core measures in the QOPI quality measures in 2008.<sup>71</sup> A 2008 manuscript showed that practices participating in QOPI demonstrated improved performance, with initially low-performing practices showing the greatest improvement.<sup>72</sup> Blayney and colleagues from the University of Michigan Rogel Cancer Center reported that QOPI can be adapted for use in practice improvement at an academic medical center.<sup>73</sup> APOS has also adopted these quality indicators.<sup>74</sup>

Additional guidance for the implementation and dissemination of the new NAM standards has been published.<sup>66,75-81</sup> In Canada, routine psychosocial care is part of the standard of care for patients with cancer; emotional distress is considered the sixth vital sign that is checked routinely along with pulse, respiration, blood pressure, temperature, and

pain.<sup>26,82</sup> A national approach has been used to implement screening for distress in Canada. Its strategies have been described.<sup>83,84</sup> Groups in Italy, France, the Netherlands, and Japan have also described results of their preliminary efforts toward the implementation of psychosocial distress screening.<sup>85-88</sup>

The panel has identified some principles of implementation to guide institutions in development of a distress screening protocol and process for appropriate referral and follow-up. These principles include the following:

- Creation of an interdisciplinary work group/committee, which ideally would include physicians, nurses, psychologists, information technology experts, social workers, chaplains, and administrative leadership
- Mandatory support from institutional leadership
- Development and execution of a pilot program prior to any large-scale implementation
- Consideration of the institution's already existing resources and current workflow/processes

Distress screening should be considered a measurable quality metric. Therefore, distress screening can be incorporated into institutions' quality improvement and assessment processes. Some results have caused doubt for some regarding the efficacy of distress screening for improving patient outcomes. For instance, a systematic review failed to find evidence that screening improved distress levels over usual care in patients with cancer.<sup>89</sup> Criticisms of this review include the inappropriately narrow inclusion criteria and the focus on only distress as an outcome.<sup>90</sup> An unblinded, two-arm, parallel randomized controlled trial (RCT) that used

the Distress Thermometer (DT) and Problem List (see below) as a screening tool versus usual care found no differences in psychological distress at 12 months between the arms.<sup>91</sup> However, no specific triage algorithms were followed, and inadequate staff training may have prevented effective referral and treatment.<sup>92</sup> Another systematic review found that trials reporting a lack of benefit to distress screening in patients with cancer lacked appropriate follow-up care of distressed patients, while trials that linked screening with mandatory referral or intervention showed improvements in patient outcomes.<sup>93</sup> Overall, results of these studies show that screening, while a critical component of psychosocial care, is not sufficient to impact patient outcomes without adequate follow-up referrals and treatment. Indeed, an RCT examining the effects of screening on 568 patients with cancer receiving radiotherapy showed that screening alone does not significantly impact distress and quality of life, but earlier referral to mental health professionals was associated with better outcomes (ie, greater health-related quality of life, less anxiety).<sup>94</sup> For implementation of a distress screening protocol, an ideal frequency of screening should be identified, and institutions should develop a process for generating referrals and alerting the appropriate staff based on screening results. Whether or not screening is occurring, how often, and whether or not appropriate referrals are generated, should be tracked. This information can be used by institutions to implement improvements in the process and potentially expand needed services.

Identification of a patient's psychological needs is essential to develop a plan to manage those needs.<sup>48</sup> In routine clinical practice, time constraints and the stigma related to psychiatric and psychological needs often inhibit discussion of these needs. It is critical to have a fast and simple screening method that can be used to identify patients who require psychosocial care and/or referral to psychosocial resources. The NCCN Distress Management Panel developed such a rapid screening tool, as discussed below.

## Screening Tools for Distress and Meeting Psychosocial Needs

Screening tools have been found to be effective and feasible in reliably identifying distress and the psychosocial needs of patients.<sup>95-99</sup> Completion of a psychosocial screening instrument may lead to earlier referral to social work services.<sup>100</sup> Mitchell and colleagues reported that ultra-short screening methods (Patient Health Questionnaire-2 [PHQ-2] or the DT) were acceptable to about three quarters of clinicians.<sup>101,102</sup> Other screening tools have also been described.<sup>103</sup> Automated touch screen technologies, interactive voice response, and web-based assessments have also been used for psychosocial and symptom screening of patients with cancer.<sup>104-107</sup> An internet-based program that includes distress screening, reporting, referrals, and follow-up components was validated in a trial of 319 community-based cancer survivors and showed good psychometric properties.<sup>108</sup>

### The Distress Thermometer

The NCCN Distress Management Panel developed the DT, a now well-known tool for initial screening, which is similar to the successful rating scale used to measure pain: 0 (no distress) to 10 (extreme distress). The DT serves as a rough, initial, single-item question screen, which identifies distress coming from any source, even if unrelated to cancer. The DT can be administered in a variety of settings, such as through a patient portal or given by a receptionist or medical assistant.

The word “distress” was chosen as described above, because it is less stigmatizing and more acceptable to patients and oncologists than other terms such as psychiatric, psychosocial, or emotional. Using this non-stigmatizing word diminishes clinicians' concerns that the patient will be embarrassed or offended by these questions. Asking an objective question such as, “How is your pain today on a scale of 0 to 10?” makes it easier and more comfortable for caregivers to learn about patients' pain.

Similarly, asking patients, “How is your distress today on a scale of 0 to 10?” opens a dialogue with the oncologist or nurse for a discussion about emotions that is more acceptable.

The patient places a mark on the DT scale in response to the following question: “How distressed have you been during the past week on a scale of 0 to 10?” Scores of 4 or higher suggest a level of distress that has clinical significance. If the patient’s distress level is mild (score is <4 on the DT), the primary oncology team may choose to manage the concerns by usual clinical supportive care management. If the patient’s distress level is 4 or higher, a member of the oncology team looks at the Problem List (see below) to identify key issues of concern and asks further questions to determine the best resources (mental health, social work and counseling, or chaplaincy professionals) to address the patient’s concerns.

The DT has been validated by many studies in patients with different types of cancer, in different settings, and in different languages, cultures, and countries. The DT has shown good sensitivity and specificity. A meta-analysis of 42 studies with greater than 14,000 patients with cancer found the pooled sensitivity of the DT to be 81% (95% CI, 0.79–0.82) and the pooled specificity to be 72% (95% CI, 0.71–0.72) at a cut-off score of 4.<sup>109</sup> However, an analysis including 181 Dutch women who completed the DT within one month following breast cancer diagnosis showed that sensitivity was 95% and specificity was only 45% when the recommended cut-off score of 4 was used.<sup>110</sup> Study investigators suggested that a cut-off score of 7 was optimal, with sensitivity being 73% and specificity being 84%. Using a higher cut-off score would reduce the number of false positives.

The DT is also a useful tool for screening distress among bone marrow transplant recipients.<sup>111,112</sup> The DT had acceptable overall accuracy and greater sensitivity and specificity when compared to the Center for Epidemiologic Studies Depression Scale (CES-D) in the assessment of depression in patients undergoing bone marrow transplants.<sup>111</sup>

While the DT is not a screening tool for psychiatric disorders, it has demonstrated concordance with the Hospital Anxiety and Depression Scale (HADS)<sup>95,113-129</sup> and the Depression Anxiety and Stress Scale-21.<sup>130</sup> A recent trial including 463 patients with cancer showed that the DT does not accurately detect mood disorders (based on DSM-IV criteria; AUC = 0.59), compared to the PHQ-2 (AUC = 0.83 with a cut-off score of ≥3) and PHQ-9 (AUC = 0.85 with a cut-off score of >9), which are both validated for screening patients with depressive symptoms.<sup>131</sup>

The NCCN DT and Problem List (discussed below) are freely available for non-commercial use. In addition, the NCCN patient website includes a patient-friendly description of distress with a copy of the tool ([http://www.nccn.org/patients/resources/life\\_with\\_cancer/distress.aspx](http://www.nccn.org/patients/resources/life_with_cancer/distress.aspx)). NCCN also has verified translations of the DT and Problem List in various languages that are freely available online ([https://www.nccn.org/global/international\\_adaptations.aspx](https://www.nccn.org/global/international_adaptations.aspx)).

### The Problem List

The screening tool developed by the NCCN Distress Management Panel includes a 39-item Problem List, which is on the same page as the DT. The Problem List asks patients to identify their problems in 5 different categories: practical, family, emotional, spiritual/religious, and physical. The panel notes that the Problem List may be modified to fit the needs of the local population.

An analysis of the DT and Problem List including principal component analysis, logistic regression, and classification and regression tree analyses showed that endorsement of Problem List items associated with emotion (ie, sadness, worry, depression, fears, nervousness, sleep), physical function (ie, transportation, bathing/dressing, breathing, fatigue, getting around, memory/concentration, pain), and support (ie, spiritual/religious concerns, insurance/finances, dealing with partner) were

significantly associated with moderate or severe distress ( $P < .001$ ,  $P = .003$ , and  $P = .013$ , respectively).<sup>132</sup> Two studies validated a version of the DT with an expanded problems list.<sup>133,134</sup> Tuinman and colleagues validated the DT with the 46-item Problem List in a cross-sectional group of 227 patients with cancer.<sup>134</sup> Graves and colleagues validated the DT with an adapted problems list with two new problem categories (information concerns and cognitive problems) in patients with lung cancer.<sup>133</sup>

### **Cognitive Impairment**

“Memory/concentration problems” is one item on the Problem List.

Cognitive impairment is common in patients with primary central nervous system (CNS) cancers, due to the effects of brain tumors themselves and the effects of treatment targeted to the brain.<sup>135,136</sup> Evidence has shown that chemotherapy-related cognitive dysfunction is also prevalent in patients with non-CNS cancers and without brain metastases.<sup>137-141</sup> Chemotherapy can cause subtle cognitive changes, which have been studied primarily in patients with breast cancer or lymphoma. These changes can continue over years and at times, when more severe, can impact quality of life and function. One study, however, showed that patients with breast cancer who received systemic adjuvant therapy did not report significantly greater cognitive impairment 7 to 9 years after treatment, compared to patients with breast cancer who did not receive systemic adjuvant therapy ( $N = 1889$ ), when statistically controlling for menopausal status and sociodemographic and clinical covariates.<sup>142</sup> The underlying mechanisms for chemotherapy-induced cognitive changes are not known. Studies have reported elevated levels of cytokines or DNA damage as some of the possible mechanisms.<sup>143</sup> Furthermore, changes in brain activity have been observed in patients following chemotherapy, suggesting that direct damage to the brain may contribute to chemotherapy-induced cognitive decline.<sup>144</sup>

Evidence suggests that cancer itself and therapies other than chemotherapy, such as hormone therapy, can cause cognitive impairments in patients with cancer.<sup>145-148</sup> A meta-analysis including 14 studies with 417 prostate cancer patients showed that androgen deprivation therapy negatively impacts performance of visuospatial tasks.<sup>149</sup> A national cross-sectional study found that a history of cancer is independently associated with a 40% increase in the likelihood of self-reported memory problems.<sup>150</sup> A case-control study ( $N = 226$ ) showed that patients with breast cancer may experience some cognitive impairment prior to beginning treatment, and this impairment may be due to post-traumatic stress symptoms.<sup>151,152</sup> A better understanding of the mechanisms that cause cancer-related cognitive impairment is essential for the development of treatments to improve cognitive function and quality of life in patients with cancer.<sup>135,136,153</sup>

There is no standard treatment for the management of cognitive changes in patients with cancer, and intervention studies to date have been limited by methodologic flaws such as a small sample size, poor generalizability, and lack of a proper control group.<sup>139,154</sup> Cognitive behavioral therapy (CBT), cognitive rehabilitation programs, compensatory strategy training, and exercise may be effective interventions to improve cognitive function in patients with cancer.<sup>139,154-158</sup> In addition, some studies have shown that the use of psychostimulants such as methylphenidate and modafinil improved cognitive function in patients with cancer.<sup>159-164</sup> Donepezil, a reversible acetylcholinesterase inhibitor (approved to treat mild to moderate dementia in patients with Alzheimer’s disease) also improved cognitive function, mood, and health-related quality of life in patients with primary low-grade glioma.<sup>165</sup> Further placebo-controlled trials are needed to confirm these preliminary findings.<sup>139,160</sup>

In October 2006 the International Cognition and Cancer Task Force (ICCTF), comprised of a multidisciplinary group of health professionals

and health advocates, was formed. The mission of ICCTF is to advance understanding of the impact of treatment-related cognitive and behavioral functioning in patients with non-CNS cancers.<sup>166</sup> ICCTF also has a website ([www.icctf.com](http://www.icctf.com)) to provide up-to-date information to both physicians and patients seeking assistance in the management of cognitive symptoms associated with cancer treatment.

The NCCN Guidelines for Survivorship (available at [www.NCCN.org](http://www.NCCN.org)) contain more information on this topic, with recommendations for the management of cognitive dysfunction in survivors.

### **Fertility**

Another item on the Problem List is the “ability to have children.” Chemotherapy and radiation therapy have an impact on the fertility of patients, especially in those who are of child-bearing age.<sup>167</sup> Therefore, the panel has included “ability to have children” as one of the items listed under the family problems category. The Oncofertility Consortium is a useful patient education resource for those who are concerned about the possible effect of cancer treatment on their fertility ([www.MyOncofertility.org](http://www.MyOncofertility.org)). Additionally, the NCCN Guidelines for Adolescent and Young Adult (AYA) Oncology (available at [www.NCCN.org](http://www.NCCN.org)) have information on fertility preservation.

### **Substance Use Disorder**

For the 2013 version of these guidelines, the panel added “substance abuse” to the list of possible physical problems. For the 2018 version of the guidelines, the item “substance abuse” was revised to “substance use,” consistent with the more neutral terminology used in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM).<sup>168</sup> Substance use disorder in patients with cancer who do not have a history of abuse or addiction is rare and is usually caused by insufficient symptom control. Improving symptom control often alleviates the substance

dependence. This problem is discussed in more detail below in *Substance-Related and Addictive Disorders*.

### **Financial Worries**

“Insurance/financial” concerns is included as a practical problem in the Problem List. The impact of “financial toxicity” on cancer care has recently gained attention as an important issue that impacts patients.<sup>169-171</sup> The cost of cancer care and diagnostic workup, as well as reduction in productivity or income due to limited ability to work, contribute to patients’ concerns about financial hardship.<sup>169,171,172</sup> Financial worries in cancer survivors may be more common in patients who are younger, uninsured, have a lower income, and were treated recently.<sup>172</sup> It is important for the primary oncology team to be aware of potential financial worries facing patients undergoing distress screening.

### **Initial Evaluation and Treatment by Oncology Team**

The panel recommends that all patients be assessed prior to clinical visits using a simple screening tool. While there are several types of screening tools, the DT and the accompanying Problem List are recommended to assess the level of distress and to identify causes of distress. If the patient's distress is moderate or severe (thermometer score  $\geq 4$ ), the oncology team must recognize that score as a trigger to a second level of questions, including clinical interviews and/or validated scales/screeners for anxiety and depression. A positive screen should prompt referral to a mental health professional, social worker, or spiritual counselor, depending on the problems identified in the Problem List. Common symptoms that require further evaluation are: excessive worries and fears, excessive sadness, unclear thinking, despair and hopelessness, severe family problems, social problems, and spiritual or religious concerns. Any unrelieved physical symptoms should be treated based on NCCN’s disease-specific guidelines, and referral for palliative care management

may also be considered (see the NCCN Guidelines for Palliative Care, available at [www.NCCN.org](http://www.NCCN.org)).

Mild distress (DT score <4) is routinely managed by the primary oncology team and represents what the panel terms "expected distress" symptoms. The symptoms that the team manages are fear and worry about the future; concerns about the illness; sadness about loss of good health; anger and the feeling that life is out of control; poor sleep, poor appetite, and poor concentration; preoccupation with thoughts of illness, death, treatment, and side effects; concerns about social roles (eg, mother, father); and spiritual or existential concerns. Many patients experience these symptoms at the time of diagnosis and during arduous treatment cycles. They might persist long after the completion of treatment. For instance, minor physical symptoms are often misinterpreted by survivors as a sign of recurrence, which causes fear and anxiety until they are reassured.

The primary oncology team is the first to deal with these distressing problems. The oncologist, nurse, and social worker each have a critical role. First and foremost, a critical component is the quality of the physician's communication with the patient, which should occur in the context of a mutually respectful relationship so that the patient can learn the diagnosis and understand the treatment options and side effects.<sup>173,174</sup> Adequate time should be provided for the patient to ask questions and for the physician to put the patient at ease. When communication is done well at diagnosis, the stage is set for future positive trusting encounters. It is important to ensure that the patient understands what has been said. Information may be reinforced with drawings or by recording the session and giving the recording to the patient. Communication skills training programs that teach oncology professionals, for example, how to discuss prognosis and unanticipated adverse events and how to reach a shared treatment decision, may be very helpful. In fact, in an RCT, it was found that patients of oncologists who had communication skills training were

less depressed at follow-up than patients of oncologists from the control group ( $P = .027$ ).<sup>175</sup> Communication skills training was reviewed by Kissane et al.<sup>176</sup>

It is important for the oncology team to acknowledge and validate that this is a difficult experience for the patient and that distress is normal and expected. Being able to express distress to the staff helps provide relief to the patient and builds trust. The team needs to ensure that social supports are in place for the patient and that he or she knows about community resources such as support groups, teleconferences, and help lines. The NAM report contains a list of national organizations and their toll-free numbers.<sup>46</sup> Some selected organizations that provide free information services to patients with cancer are:

- American Cancer Society: [www.cancer.org](http://www.cancer.org)
- American Institute for Cancer Research: [www.aicr.org](http://www.aicr.org)
- American Psychosocial Oncology Society: <http://apos-society.org/>
- Cancer Support Community: <http://www.cancersupportcommunity.org> (Cancer Support Community provides the Cancer Support Helpline at 888.793.9355)
- CancerCare: [www.cancer.org](http://www.cancer.org)
- National Cancer Institute: [www.cancer.gov](http://www.cancer.gov)
- Cancer.net, sponsored by ASCO: [www.cancer.net](http://www.cancer.net)

Clinicians should be aware of the evidence-supported interventions available for the management of distress. In addition to these NCCN Guidelines for Distress Management, the following clinical practice guidelines will be useful to clinicians, including the oncology team:

- National Cancer Institute and several partners have developed a website that provides information about research-tested intervention programs (<http://rtips.cancer.gov/rtips/index.do>).

- Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation (<http://www.asco.org/>)

Follow-up at regular intervals or at transition points in illness is an essential part of the NCCN Guidelines for Distress Management and the NAM model for care of the whole patient. This reassessment is particularly important in elderly patients with cancer.<sup>177</sup>

## Psychological/Psychiatric Treatment by Mental Health Professionals

### Psychosocial Interventions

Psychosocial interventions have been effective in reducing distress and improving overall quality of life among patients with cancer.<sup>46,47</sup> The 2007 NAM report noted that a strong evidence base supports the value of psychosocial interventions in cancer care.<sup>46</sup> The review examined the range of interventions (psychological, social, and pharmacologic) and their impact on any aspect of quality of life, symptoms, or survival. The extensive review found randomized clinical trials, systematic reviews, and meta-analyses supporting the conclusion that psychosocial aspects must be integrated into routine cancer care in order to give quality cancer care. More recent meta-analyses have come to similar conclusions, although more research is clearly needed.<sup>178-181</sup> Systematic reviews examining psychosocial interventions for patients with prostate cancer showed that these interventions may yield at least short-term effects on quality of life.<sup>182,183</sup> A meta-analysis including 53 studies of psychosocial interventions for patients with cancer ( $N = 12,323$ ) showed that patients were more willing to participate in interventions delivered over the telephone versus in-person ( $P = .031$ ) and when intervention is offered shortly after diagnosis versus later ( $P = .018$ ).<sup>184</sup> CBT, supportive psychotherapy, and family and couples therapy are three key types of psychotherapies discussed in the NAM report.<sup>46</sup>

### Cognitive Behavioral Therapy

CBT involves practicing relaxation techniques, enhancing problem-solving skills, and identifying and correcting inaccurate thoughts associated with feelings. In randomized clinical trials, CBT and cognitive-behavioral stress management have been shown to effectively reduce psychological symptoms (anxiety and depression) as well as physical symptoms (pain and fatigue) in patients with cancer.<sup>185-191</sup> However, a mindfulness-based cognitive therapy intervention for men with prostate cancer ( $N = 189$ ) did not significantly impact distress, compared to minimally enhanced usual care.<sup>192</sup> A Cochrane systematic review including 28 RCTs ( $N = 3940$ ) showed that CBT interventions favorably impact anxiety, depression, and mood disturbance in patients with non-metastatic breast cancer.<sup>193</sup> The quality of the evidence was low for anxiety and depression and moderate for mood disturbance, however, indicating the need for studies to use higher quality intervention methods and validated instruments for measuring outcomes. Another meta-analysis including 14 articles on 10 RCTs on mindfulness-based stress reduction and cognitive therapy for 1,709 patients with breast cancer showed that these interventions have short-term effects on anxiety and depression, but effect sizes were small.<sup>194</sup> A small RCT including 60 patients with cancer showed that a web-based CBT intervention may improve health-related quality of life, cancer-related distress, and anxious preoccupation following diagnosis.<sup>195</sup>

Ferguson and colleagues have developed a brief CBT intervention (Memory and Attention Adaptation Training [MAAT]) aimed at helping breast cancer survivors manage cognitive dysfunction associated with adjuvant chemotherapy.<sup>196</sup> In a randomized study, the study investigators found that patients in the intervention arm had improved verbal memory performance and spiritual well-being.<sup>155</sup> A randomized trial in which MAAT delivered through video conference was compared to supportive therapy in 47 survivors of breast cancer showed that MAAT improved self-reported



perceived cognitive impairments ( $P = .02$ ) and neuropsychological processing speed ( $P = .03$ ), compared to supportive therapy.<sup>197</sup>

### **Supportive Psychotherapy**

Supportive psychotherapy, aimed at flexibly meeting patients' changing needs, is widely used. Different types of group psychotherapy have been evaluated in clinical trials among patients with cancer. Supportive-expressive group therapy has been shown to improve quality of life and psychological symptoms, especially improvements in mood and pain control in patients with metastatic breast cancer.<sup>198,199</sup> Hematopoietic stem cell transplant survivors ( $n = 264$ ) who were experiencing survivorship problems and were randomized to an expressive helping intervention reported less distress, compared to survivors randomized to receive peer helping and neutral writing interventions ( $P < .05$ ).<sup>200</sup> Cognitive-existential group therapy has been found to be useful in women with early-stage breast cancer receiving adjuvant chemotherapy.<sup>201</sup> Meaning-centered group psychotherapy, designed to help patients with advanced cancer sustain or enhance a sense of meaning, peace, and purpose in their lives (even as they approach the end of life), has also been shown to reduce psychological distress among patients with advanced cancer.<sup>202-205</sup> Dignity therapy has been assessed in an RCT of patients with a terminal diagnosis (not limited to cancer).<sup>206</sup> Although there was no significant improvement in levels of distress in patients receiving dignity therapy as measured by several scales, significant improvements in depression and self-reported aspects of quality of life were seen. An RCT for patients with renal cell carcinoma ( $N = 277$ ) showed that expressive writing reduces self-reported cancer-related symptoms (eg, pain, nausea, fatigue) and improves physical functioning.<sup>207</sup> Secondary analyses from this study showed that the patients who benefited the most from the expressive writing intervention had both greater depressive symptoms and greater social support, as measured at baseline.<sup>208</sup> An individually delivered intervention targeting patients with advanced cancer, including

components of manualized, supportive, expressive, cognitive, existential, and meaning-centered group psychotherapy approaches ( $N = 39$ ), showed reduced depressive symptoms and death-related anxiety, and improved spiritual well-being in a feasibility study.<sup>209</sup> A larger RCT is currently being conducted.

Interventions incorporating internet support groups have become popular,<sup>210</sup> with a recent Cochrane review including 6 studies with 492 women with breast cancer showing a small to moderate effect on depression, based on low-quality evidence.<sup>211</sup> None of the 6 studies included in the review assessed emotional distress specifically, and results from 2 studies showed no significant impact on anxiety when comparing the intervention and control groups. Results of an RCT that included an internet support group with a prosocial component showed that this intervention did not reduce depression and anxiety in women with nonmetastatic breast cancer ( $N = 184$ ).<sup>212</sup>

### **Psychoeducation**

Psychoeducational interventions are those that offer education to those with specific psychological disorders or physical conditions. Psychoeducational interventions for patients with cancer may be general, such as providing information regarding stress management and healthy living (eg, nutrition, exercise),<sup>213,214</sup> while other interventions may be more specific to the cancer type. For example, an intervention for patients with melanoma was developed by Fawzy and Fawzy that provided information regarding sun protection, as well as stress management and coping strategies.<sup>215</sup> An RCT in which the effects of this intervention were tested with 262 patients with melanoma showed improvements in fatigue, vigor, mood disturbance, and coping strategies, though improvements did not persist past 6 months.<sup>216</sup> In an RCT examining the effects of a group-based psychoeducational intervention for 312 women with early-stage breast cancer, improved adjustment was demonstrated up to 6 months

after the intervention.<sup>217</sup> A year-long nurse-led intervention for patients with head and neck cancer ( $N = 205$ ) included education regarding problems related to head and neck cancer and, if indicated, CBT and referral for further psychological treatment. This intervention positively impacted emotional and physical functioning, social contact, and depressive symptoms.<sup>218</sup> At 12-month follow-up (ie, one year after the end of the year-long intervention), effects persisted for emotional functioning only.

A meta-analysis examining 19 psychoeducational interventions with 3857 cancer patients showed small post-treatment effects overall for emotional distress, anxiety, depression, and quality of life.<sup>178</sup> The only significant effects at long-term follow-up were for quality of life. Psychoeducation interventions that offer education regarding symptom management may also be effective when delivered via the internet.<sup>219-221</sup>

### **Exercise**

Exercise during and after cancer treatment can improve cardiovascular fitness and strength and can have positive effects on balance, body composition, and quality of life.<sup>222-224</sup> Small RCTs have shown that exercise may also impact mental health outcomes in patients with cancer and cancer survivors.<sup>225-227</sup> A Cochrane systematic review including 9 RCTs ( $N = 818$ ) showed that aerobic exercise for patients with hematologic malignancies may reduce depression (standardized mean difference [SMD], 0.25; 95% CI, 0.00–0.50,  $P = .05$ ) but not anxiety ( $P = .45$ ).<sup>228</sup> However, the quality of the evidence in this area is low, as larger RCTs and longer follow-up periods are needed.

### **Family and Couples Therapy**

A cancer diagnosis causes distress in partners and family members as well as the patient. Psychosocial interventions aimed at patients and their families together might lessen distress more effectively than individual interventions. In a longitudinal study of couples coping with early-stage breast cancer, mutual constructive communication was associated with

less distress and more relationship satisfaction for both the patients and partners compared to demand/withdraw communication or mutual avoidance, suggesting that training in constructive communication would be an effective intervention.<sup>229</sup>

Family and couples therapy has not been widely studied in controlled trials. In an RCT in which 62 couples (patients with localized prostate cancer and their partners) were randomly assigned to receive cognitive existential couples therapy or usual care, adaptive and problem-focused coping was improved in couples receiving the therapy sessions, which in turn improved relationship cohesion, as well as relationship function in younger patients.<sup>230</sup> A small randomized trial was reported in which patients and their caregivers received 8 emotionally focused therapy sessions or standard care.<sup>231</sup> Significant improvements in marital functioning and patient experience of empathetic care by the caregiver were seen. These effects were maintained 3 months after the intervention. In a pilot study, a telephone-based dyadic intervention for patients with advanced lung cancer and their families ( $N = 39$ ) improved depression, anxiety, and caregiver burden.<sup>232</sup> In addition, an RCT showed that family-focused grief therapy can reduce the morbid effects of grief in families with terminally ill patients with cancer.<sup>233</sup>

Some systematic reviews have been carried out to assess the efficacy of therapy involving patients' close others. A meta-analysis including 12 RCTs showed that couple-based interventions for patients with cancer and their spouses improved depression, anxiety, and marital satisfaction, compared to control groups.<sup>234</sup> A systematic review of 23 studies that assessed the efficacy of psychosocial interventions for couples affected by cancer found evidence that couples therapy might be at least as effective as individual therapy.<sup>235</sup> Another systematic review examining the effects of 10 interventions for couples coping with breast cancer showed that,

though results are mixed, these interventions tend to yield at least some benefit.<sup>236</sup>

### Pharmacologic Interventions

Research suggests that antidepressants and anti-anxiety drugs are beneficial in the treatment of depression and anxiety in adult patients with cancer.<sup>237-243</sup> In RCTs, alprazolam<sup>244,245</sup> (a benzodiazepine) and fluoxetine<sup>246,247</sup> (a selective serotonin reuptake inhibitor [SSRI]) are effective in improving depressive symptoms in patients with cancer. SSRIs are widely used for depression and anxiety symptoms. A systemic review including 38 studies showed that antidepressants are prescribed to 15.6% (95% CI, 13.3–18.3) of cancer patients, with prescriptions being common in women (22.6%; 95% CI, 16.0–31.0) and in patients with breast cancer (22.6%; 95% CI, 16.0–30.9).<sup>248</sup>

The psychostimulants methylphenidate and the wakefulness-promoting non-amphetamine psychostimulant modafinil have been evaluated for their effect on cancer-related fatigue (CRF), with mixed results in patients undergoing cancer therapy.<sup>164,249-251</sup> A meta-analysis showed that methylphenidate reduces CRF, compared to a placebo (SMD, -0.28; 95% CI, -0.44 to -0.12), but modafinil did not significantly reduce CRF, compared to placebo treatment.<sup>252</sup> Analyzing 5 RCTs, Minton et al<sup>253</sup> attributed a significant benefit to methylphenidate in alleviating fatigue compared to placebo (Z-score [Z] = 2.83;  $P = .005$ ). Patients have reported minor side effects with methylphenidate, including headache and nausea. Due to the limited number of studies and the marginal improvement in CRF in response to modafinil, it is not a recommended treatment. See the NCCN Guidelines for Cancer-Related Fatigue (available at [www.NCCN.org](http://www.NCCN.org)).

Withdrawal from pharmacologic agents (eg, benzodiazepines, opioids, antidepressants, anti-anxiety drugs) should be managed with care and will vary based on the specific agent.

### Complementary and/or Integrative Therapies

Regarding complementary and/or integrative therapies for patients with cancer, a systematic review showed that meditation, yoga, relaxation with imagery, massage, and music therapy may be helpful for patients with depressive disorders who have breast cancer.<sup>254,255</sup> Music therapy, meditation, and yoga may be used to reduce anxiety in patients with breast cancer.<sup>254,255</sup> A systematic review including 52 randomized and quasi-randomized trials with 3731 patients showed that music therapy benefits patients with anxiety ( $P < .001$ ).<sup>256</sup> Findings from this review also indicated that music therapy may impact patients with depression, but the quality of the evidence was low.

A meta-analysis including 16 RCTs with 930 patients with breast cancer showed that yoga may reduce depression (SMD, -0.17; 95% CI, -0.32 to -0.01;  $P < .001$ ) and anxiety (SMD, -0.98; 95% CI, -1.38 to -0.57;  $P < .001$ ) in these patients.<sup>257</sup> However, the methodologic quality of the studies included in this review was generally low. A recent Cochrane review showed that, when compared to psychosocial or educational interventions, yoga may have at least short-term effects on depression (pooled SMD, -2.29; 95% CI, -3.97 to -0.61) and anxiety (pooled SMD, -2.21; 95% CI, -3.90 to -0.52).<sup>258</sup> A small RCT ( $N = 54$ ) found that patients randomized to receive a 10-week yoga intervention reported less anxiety 22 weeks after randomization ( $P = .043$ ) and less depression 10 weeks after randomization ( $P = .038$ ) than patients randomized to a wait-list control group.<sup>259</sup> However, attrition was high and intervention adherence poor in this study. The panel currently does not recommend yoga for patients with distress, and larger randomized studies are needed to investigate the potential impact of yoga on distress.



# NCCN Guidelines Version 3.2019

## Distress Management

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Based on the evidence described above, the panel recommends relaxation, mediation, and creative therapies such as art and music for patients experiencing distress.

### Psychological/Psychiatric Treatment Guidelines

Patients scoring 4 or higher on the DT during any visit to the oncologist are referred to the appropriate supportive service (mental health, social work and counseling, or chaplaincy professionals) based on the identified problem.

Mental health professionals are expected to conduct a psychological or psychiatric evaluation that includes an assessment of the nature of the distress, problematic behaviors, psychological/psychiatric history and symptoms, use of medications, substance use disorder, pain, fatigue, sleep disturbances, other physical symptoms, cognitive impairment, body image, sexual health, and capacity for decision-making and physical safety. Demoralization, which is characterized by helplessness and loss of meaning and purpose, should be evaluated and distinguished from the presence of a depressive disorder.<sup>260,261</sup> A psychiatrist, psychologist, nurse, advanced practice clinician, or social worker may perform the evaluation. All of these professionals are skilled in mental health assessment and treatment.

Patients with mental illness experience cancer disparities, such as increased cancer mortality rates, more advanced cancer at time of diagnosis, and more comorbidities.<sup>262,263</sup> The panel has developed evaluation and treatment guidelines for the most commonly encountered psychiatric disorders, consistent with the classification in the most recent edition of the DSM.<sup>168</sup> These disorders include neurocognitive disorders (dementia and delirium), depressive disorders, bipolar and related disorders, trauma- and stressor-related disorders (including adjustment disorders), anxiety disorders, substance-related and addictive disorders,

schizophrenia spectrum and other psychotic disorders, obsessive compulsive and related disorders, and personality disorders. Psychotropic drugs are recommended throughout the guidelines to treat psychiatric disorders. It is important to note that these drugs can sometimes interact with anticancer therapies and cause adverse effects. Howard et al<sup>264</sup> reviewed some of these interactions and discusses other challenges in treating cancer in patients with severe mental illness.

Patients considered to be a danger to themselves or others should receive a psychiatric consultation. Increased monitoring is also warranted, as well as the removal of guns and other dangerous objects. Hospitalization and suicide and homicide risk evaluation may sometimes be necessary. Mental health treatment/follow-up of these patients, family education regarding safety, and assuring the safety of others is warranted. Referral to social work services or chaplaincy care may also be considered.

Additional information regarding treatment of distress and psychiatric disorders in cancer can be found in the comprehensive handbook, *Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management*,<sup>265</sup> and the comprehensive textbook, *Psycho-Oncology*.<sup>266</sup> Additional resources targeting specific age groups include the comprehensive handbooks, *Geriatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management*,<sup>267</sup> and *Pediatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management*,<sup>268</sup> which target management of psychological, cognitive, and social difficulties in older adults and children/adolescents, respectively. The NCCN Guidelines for Supportive Care may also be referred to as needed (available at [www.NCCN.org](http://www.NCCN.org)).

### Neurocognitive Disorders

Neurocognitive disorders that may affect patients being treated with cancer include dementia and delirium. Dementia and delirium are cognitive impairments that can severely alter the patient's decision-making capacity. Dementia is a permanent cognitive impairment. It is not a common complication of cancer treatment, but is often present in elderly patients as a comorbid condition.<sup>269,270</sup> A systematic review including 9 studies showed that patients with dementia are diagnosed at a later stage of cancer, receive less treatment, experience more complications, and have poorer survival, compared to patients without dementia.<sup>271</sup> Dementia can be treated with cognitive rehabilitation, with or without medications, though treatment is largely behavior management.

Delirium is a short-term cognitive impairment and has been reported to occur in as many as 43% of patients with advanced cancer.<sup>272</sup> Delirium is usually reversible and occurs in cancer treatment that is associated with toxicity; it is often related to medication, particularly opioids.<sup>273</sup>

Benzodiazepines should be used with caution, as their use may contribute to delirium.<sup>274-276</sup> A prospective case-control cohort study (N = 245) showed a significant association between benzodiazepine use and development of postoperative delirium (odds ratio [OR], 3.0; 95% CI, 1.3–6.8), with stronger associations for long-acting agents (OR, 5.4; 95% CI, 1.0–29.2) and high-dose exposure (OR, 3.3; 95% CI, 1.0–11.0).<sup>274</sup>

A prospective observational study of 243 patients with advanced cancer who presented to an emergency department at an NCCN Member Institution showed that delirium was present in 9% of all patients, but physicians correctly diagnosed delirium in only 59% of patients experiencing delirium.<sup>277</sup> Additional analyses from this study showed that patients with delirium had worse overall survival and were more likely to be hospitalized, compared to patients without delirium.<sup>278</sup> A retrospective chart review of 771 palliative care consultations showed that symptoms of

delirium were misinterpreted by the primary oncology team 61% of the time.<sup>279</sup> Delirium is managed by attention to safety, modification of opioids or other medications, antipsychotics, behavior management, and family support and education.<sup>280</sup>

The United Kingdom's National Institute for Health and Care Excellence (NICE) issued detailed guidelines for the diagnosis, prevention, and management of delirium.<sup>281</sup> In addition, a comprehensive review in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer by Breitbart and Alici<sup>282</sup> describes the evidence base for recommended pharmacologic and non-pharmacologic treatments for delirium in patients with cancer.

### Depressive and Bipolar-Related Disorders

Depressive and bipolar-related disorders are common in patients with cancer and can be debilitating.<sup>283-287</sup> A cross-sectional analysis of 2141 patients with cancer showed a 4-week prevalence rate of 6.5% (95% CI, 5.5–7.5) for a depressive or bipolar-related disorder.<sup>288</sup> Depressive symptoms during cancer diagnosis and treatment may persist for as long as 2 years following diagnosis.<sup>289</sup> Depressive and bipolar-related disorders are associated with poorer cancer survival.<sup>290-292</sup>

Patients with uncontrolled depressive and bipolar-related disorders can develop suicidal tendencies. A study of over 5,000 patients at one center found that 6% of patients with cancer experienced suicidal ideation.<sup>293</sup> The incidence of suicide among patients with cancer in the United States is twice that of the general population.<sup>294-296</sup> Older patients, patients who undergo high-morbidity surgeries, and men with head and neck cancer or myeloma seem to have a higher risk of suicide.<sup>297,298</sup> Among patients with breast cancer, suicide mortality is associated with younger age, being male, non-White non-Black race, being unmarried, having undergone surgery, having progesterone-receptor-positive disease, and shorter time

elapsed since diagnosis.<sup>299</sup> Violence may also be associated with depressive disorders, particularly when there is comorbid substance use.<sup>300</sup> Therefore, both suicide and homicide risk should be evaluated in patients believed to be a danger to themselves and others.

Depressive and bipolar-related disorders are usually managed with psychotherapy or psychotropic medication (category 1). The evidence for these treatments has been described.<sup>301-312</sup> In particular, a review by Li et al<sup>313</sup> in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer comprehensively describes the evidence for recommended pharmacologic and psychosocial interventions for treating depression in patients with cancer. Referral to social work counseling and chaplaincy services may also be considered. If these patients have no or only a partial response to treatment, then the chosen psychotherapeutic intervention should be re-evaluated. The following options should also be considered: 1) augmenting or changing medication; 2) electroconvulsive therapy (ECT); 3) higher level care with an intensive outpatient program; and 4) obtaining a second opinion. In ECT, electrical currents are passed through the brain in a controlled fashion, inducing a brief seizure. ECT appears to be an effective treatment of psychotic depression, mania, catatonia, and other psychiatric disorders.<sup>314-318</sup> Although the use of ECT in cancer has not been well-studied, several case studies suggest that it can be safe and effective.<sup>319-323</sup>

ASCO has released a clinical oncology guideline adaptation of a pan-Canadian practice guideline for the screening, assessment, and treatment of anxiety and depression in patients with cancer.<sup>324</sup> The panel recommends that PHQ-2 or PHQ-9 be used to screen for depressive disorders, since these brief tools are superior to the DT for this purpose (see *Screening Tools for Distress and Meeting Psychosocial Needs: Distress Thermometer*, above).

### Schizophrenia Spectrum and Other Psychotic Disorders

Psychotic disorders include hallucinations, delusions, and/or thought disorders; patients with recurrent psychotic episodes are considered to have a schizophrenia spectrum disorder. Schizophrenia spectrum and other psychotic disorders can exist as comorbidities in patients with cancer and can also be caused or exacerbated by cancer and its associated stress and treatment. In particular, corticosteroids or corticosteroid withdrawal can induce psychosis, which may be relieved by modifying dose or changing corticosteroid choice.<sup>325,326</sup> When a patient in a long-term psychiatric facility develops cancer, there is a need for coordination of care between the psychiatric facility and the inpatient cancer facility. Special attention should be paid to the transition of a psychiatric patient who needs inpatient oncology care. The issues around continuation of psychotropic medications, when they must be stopped for surgery or chemotherapy and when they should be restarted, are important issues in total care. Evaluation for any active signs of psychosis should be considered when someone with a history of schizophrenia or a psychotic disorder is diagnosed with cancer.

When a psychotic episode occurs in a patient with cancer, differential diagnoses must be ruled out. Delirium is often confused with psychotic disorder and is much more common; dementia, depressive and bipolar-related disorders, and substance-related and addictive disorders should also be considered. When psychotic disorder or schizophrenia spectrum disorder is diagnosed, several interventions can be considered: 1) anti-psychotic medication; 2) medication for mood; 3) transfer to a psychiatric unit/hospital; or 4) ECT for psychotic depression/mania or catatonia. Anti-psychotics may need to be urgently administered if there is risk to self, others, or the environment.

### Anxiety Disorders and Obsessive Compulsive and Related Disorders

Anxiety occurs at times in most patients with cancer.<sup>283,327</sup> A cross-sectional analysis of 2141 patients with cancer showed a 4-week prevalence rate of 11.5% (95% CI, 10.2–12.9) for any anxiety disorder.<sup>288</sup> The diagnosis of cancer and the effects of the disease and its treatment are obvious sources of unease; however, anxiety may also be related to physiologic aspects of the medical condition (eg, hormone-secreting tumors; effects of certain types of medications [bronchodilators]; withdrawal from alcohol or narcotics; pain or some other distressing physical symptom). Anxiety may not be severe or problematic, but needs to be addressed when it becomes disruptive. After ruling out medical causes, the clinician should assess symptoms to determine the particular nature of the anxiety disorder(s). Generalized anxiety disorder is usually pre-existing and may be exacerbated by illness. Panic disorder may recur during illness in a person with previous panic symptoms. Patients with cancer may also be at increased risk of agoraphobia.<sup>328</sup> Obsessive-compulsive disorder is a pre-existing disorder that results in difficulty in making decisions, ruminative thoughts about illness, and fearfulness to take medication. Some patients develop phobias of needles, hospitals, and blood or conditioned nausea/vomiting related to chemotherapy. Chemotherapy-induced nausea and vomiting should be managed according to the NCCN Guidelines for Antiemesis (available at [www.NCCN.org](http://www.NCCN.org)). Patients with anxiety associated with religious or spiritual concerns should be referred to chaplaincy care.

The NCCN Distress Management Panel recommends psychotherapy as a category 1 recommendation for the treatment of anxiety disorders, including obsessive compulsive disorder, after eliminating medical causes. Treatment with an antidepressant or an anxiolytic is also recommended. If there is a response to initial treatment, follow-up should occur with the primary oncology team, primary care physician, and family/caregivers. If

no response or a partial response is noted, the patient should be re-evaluated and treated with different medications (an antipsychotic should be considered) with continued psychotherapy, support, and education. If there is still not a complete response, then the patient should be evaluated for depression and other psychiatric comorbidity.

The evidence for the effectiveness of these treatments has been reviewed.<sup>46,47</sup> In a review in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer, Traeger et al<sup>329</sup> give a comprehensive description of the evidence for recommended pharmacologic and non-pharmacologic treatments for anxiety in patients with cancer.

### Trauma- and Stressor-Related Disorders

Trauma and stressor-related disorders that may affect patients with cancer include post-traumatic stress disorder (PTSD), acute stress disorder, and adjustment disorder. PTSD may develop after arduous cancer treatments, during a cancer treatment that triggers a traumatic memory of a past frightening event, or just from the stress of a cancer diagnosis. As many as 12% of patients with stage I–III breast cancer have been found to have persistent PTSD. Survivors of cancer may continue to experience PTSD symptoms.<sup>330,331</sup> A meta-analysis including 25 studies with 4,189 cancer survivors (mostly survivors of breast cancer) showed that self-reported PTSD symptoms occur in 7.3% of survivors, while rates based on structured clinical interviews are 12.6% for lifetime PTSD and 6.4% for current PTSD.<sup>332</sup> A PTSD diagnosis prior to cancer diagnosis or previous trauma is a risk factor for cancer-related PTSD.<sup>333</sup> Acute stress disorder is diagnosed in the first month following a traumatic event, and the criteria contain a greater emphasis on dissociative symptoms. Twenty-three percent to 28% of patients diagnosed with cancer meet criteria for acute stress disorder.<sup>334-336</sup> Adjustment disorder refers to a cluster of symptoms such as stress, depressive symptoms, and physical symptoms following a



stressful life event such as cancer diagnosis and treatment. It may be diagnosed when a patient who experienced a stressful life event does not meet criteria for PTSD or acute stress disorder. Adjustment disorder occurs in 15.4% of patients in palliative care settings and in 11% to 19% of patients in oncologic and hematologic settings.<sup>11,288</sup>

Treatment of trauma- and stressor-related disorders in patients with cancer includes psychotherapy (category 1) with or without an antidepressant and/or an anxiolytic. If this treatment yields no response or a partial response, then psychotherapy, support, and education should be reevaluated. Choice of medication should also be reconsidered, with a consideration of antipsychotics. The National Cancer Institute's Physician Data Query (PDQ®) provides information on cancer-related posttraumatic stress education resources that may be useful for patients (<https://www.cancer.gov/about-cancer/coping/survivorship/new-normal/ptsd-pdq>) and health care professionals (<https://www.cancer.gov/about-cancer/coping/survivorship/new-normal/ptsd-hp-pdq>).

For patients diagnosed with adjustment disorder specifically, patients with moderate/severe disorder should receive medication and/or psychotherapy, while patients with mild disorder should receive psychotherapy only. For patients who receive medication, type of medication and the dosage should be adjusted as needed. Patients diagnosed with adjustment disorder that does not respond to treatment should have their treatment plan, support, and education re-evaluated and should also be evaluated for personality disorders.

### Substance-Related and Addictive Disorders

Substance dependence, abuse, and addiction are rare among patients with cancer who do not have a history of active dependence, abuse, or addiction to opioids, alcohol, or tobacco. Substance use disorder

developing during the course of the treatment may be due to insufficient symptom control and can be treated by improving symptom control. Alcohol and recreational drug use should be evaluated in patients with signs and symptoms of depressive disorders, bipolar and related disorders, and anxiety disorders, as substance use may exacerbate symptoms of these disorders. The NCCN Guidelines for Adult Cancer Pain (available at [www.NCCN.org](http://www.NCCN.org)) provide information on prescription, titration, maintenance, and safety of opioids. For patients who use tobacco, see the NCCN Guidelines for Smoking Cessation (available at [www.NCCN.org](http://www.NCCN.org)).

In patients with a history of substance use disorder, its impact on cancer treatment should be assessed. Patients with a history of substance use disorder should also be monitored for signs and symptoms of relapse. Referral should be considered for risk reduction, substance use disorder management, or specialized treatment programs as needed. For patients with current substance dependence issues, symptoms should be treated and they should enter an appropriate substance use disorder treatment program. Risk reduction strategies should be discussed with all patients who have either a current substance use disorder or a history of a substance use disorder.

Following the appropriate treatment/management program, patients should be provided with psychoeducation with or without psychotherapy and with or without medication. CBT may be effective for substance use disorder, though a meta-analysis of 53 studies showed only a small effect (Hedges'  $g = 0.15$ ,  $P < .005$ ).<sup>337</sup> Studies evaluating the efficacy of CBT for substance use disorder in patients with cancer are lacking. Referral can also be made to specialized maintenance programs, and strategies to prevent future abuse can be discussed.



### Personality Disorders

Patients with cancer may have a pre-existing personality disorder, which can be exacerbated by the stress of cancer and its treatment.<sup>338</sup> When a personality disorder is suspected, the patient should be evaluated by a mental health professional, and safety, home situation, and decision-making capacity should be assessed. If possible, any medication or other factors that could be aggravating the condition should be modified. A coordinated behavioral, psychological, and medical treatment plan, with or without medication, should be developed with the health care team.

### Social Work and Counseling Services

Social work and counseling services are recommended when a patient has a psychosocial or practical problem. Practical problems are illness-related concerns; basic needs (eg, housing, food, financial/insurance concerns, help with activities of daily living, transportation); employment, school, or career concerns; cultural or language issues; and family/caregiver availability. The guidelines outline interventions that vary according to the severity of the problem.

Common psychosocial problems are adjustment to illness; family conflicts and social isolation; difficulties in treatment decision-making; quality-of-life issues; difficulties with transitions in care; absent or unclear advance directive or other concerns about advance directives; domestic abuse and neglect; poor coping or communication skills; concerns about functional changes (eg, body image, sexual health); depressive symptoms and/or suicidal ideation; fears, nervousness, and worry; and issues pertaining to end of life and bereavement (including cultural and caregiver concerns).

Social workers intervene in mild psychosocial problems by using patient and family education, support groups, and/or sexual health or grief counseling and by suggesting available local resources. Social workers can also help foster healthy coping strategies, such as problem solving,

cognitive restructuring, and emotion regulation.<sup>339</sup> For moderate to severe psychosocial problems, counseling and psychotherapy are used (including sexual health and grief counseling); community resources are mobilized; problem solving is taught; and advocacy, education, and protective services are made available.

### Spiritual and Chaplaincy Care

Religiousness and spirituality are positively associated with mental health in patients with cancer,<sup>340</sup> and attendance at religious services is associated with lower cancer-related mortality.<sup>341</sup> Many patients use their religious and spiritual resources to cope with illness,<sup>342</sup> and many cite prayer as a major help. In addition, the diagnosis of cancer can cause an existential crisis, making spiritual support of critical importance. Balboni et al<sup>343</sup> surveyed 230 patients with advanced cancer treated at multiple institutions who had failed to respond to first-line chemotherapy. The majority of patients (88%) considered religion as somewhat or very important. Nearly half of the patients (47%) reported receiving very minimal or no support at all from their religious community, and 72% reported receiving little or no support from their medical system.<sup>343</sup>

Importantly, patients receiving spiritual support reported a higher quality of life. Religiousness and spiritual support have also been associated with improved satisfaction with medical care. Astrow et al<sup>344</sup> found that 73% of patients with cancer had spiritual needs, and that patients whose spiritual needs were not met reported lower quality of care and lower satisfaction with their care. A multi-institution study of 75 patients with cancer and 339 oncologists and nurses (the Religion and Spirituality in Cancer Care Study) found that spiritual care had a positive effect on patient-provider relationships and the emotional well-being of patients.<sup>345</sup> However, a survey conducted in 2006 through 2009 found that most patients with advanced cancer never receive spiritual care from their oncology team.<sup>346</sup> Spiritual needs may include searching for the meaning and purpose of life; searching for the meaning in experiencing a disease like cancer; being

connected to others, a deity, and nature; maintaining access to religious/spiritual practices; spiritual well-being; talking about death and dying; making the most of one's own life; and being independent and treated like a "normal person."<sup>347</sup>

A meta-analysis including 12 studies with 1878 patients showed that spiritual interventions improve quality of life ( $d = 0.50$ ; 95% CI, 0.20–0.79), but the effect was small at 3- to 6-month follow-up ( $d = 0.14$ ; 95% CI, -0.08–0.35).<sup>348</sup> Another meta-analysis including 24 studies showed that existential interventions positively impacted existential well-being, quality of life, hope, and self-efficacy, though results were moderated by intervention characteristics (eg, therapist's professional background, intervention setting).<sup>349</sup>

The panel has included chaplaincy care as part of psychosocial services. All patients should be referred to a chaplaincy professional when their problems are spiritual or religious in nature or when they request it. Guided by the Religious and Spiritual Struggles Scale<sup>350</sup> and the Existential Distress Scale,<sup>351</sup> the panel identified three main issues that should be included as part of evaluation by a chaplain: interpersonal conflict regarding spiritual/religious beliefs and practices; concerns with lack of meaning and purpose; and struggles with morality and values (including doubts about beliefs; perceptions of being attacked by evil; concerns about one's relationship with the sacred; concerns about death, dying, and the afterlife; grief and loss; feeling worthless or like a burden; loneliness; conflict between religious beliefs and treatment options; and ritual needs).

The panel has identified interventions that may be carried out based on this assessment. These interventions, which are based on recommendations by Spiritual Health Victoria ([www.spiritualhealthvictoria.org.au/standards-and-frameworks](http://www.spiritualhealthvictoria.org.au/standards-and-frameworks)), include spiritual/existential counseling, education, and rituals; meditation and/or

prayer; referral to appropriate spiritual/existential community resources; and referral to other health care professionals (eg, palliative care, mental health professional) as needed.

A consensus conference on improving the quality of spiritual care as a dimension of palliative care was held in February 2009. The report from this conference provides recommendations for health care professionals on the integration of spiritual care into the patient's overall treatment plan.<sup>352</sup> The inclusion of a certified chaplain on the interdisciplinary team is critical for the implementation of spiritual care into routine clinical practice.

The following guidelines on religion and spirituality in cancer care may be useful for clinicians and patients:

- National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Third Edition, 2013. These guidelines provide a framework to acknowledge the patient's religious and spiritual needs in a clinical setting. Spiritual, religious, and existential aspects of care are included as 1 of the 8 clinical practice domains.
- The National Cancer Institute's comprehensive cancer information database (PDQ®) has information on "Spirituality in Cancer Care" for patients (<http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/Patient>) and for health care professionals (<http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional>).

### Oncologist Burnout

The stress and demands of treating patients with cancer and making life and death decisions daily often cause psychologic distress for oncologists. This distress can in turn cause depression, anxiety, and fatigue. It can also cause moral distress, compassion fatigue, and/or burnout. Burnout, characterized by a lack of enthusiasm for work, feelings of cynicism, and a



low sense of personal accomplishment with work, occurs in as many as 28% to 45% of oncologists.<sup>353-356</sup> Burnout can affect patient care, physician-patient relationships, and personal relationships and can lead to substance use disorder and even suicide. Strategies for avoiding and reducing burnout include training in self-care, personal wellness, mindful meditation, and behavioral change by medical schools, residency programs, hospitals, and private practices.<sup>353,357</sup> Organizational strategies can also create a culture that is less stressful and less conducive to oncologist burnout.

### **The *Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer**

In April 2012, the *Journal of Clinical Oncology* published a Special Series on psychosocial care (<https://ascopubs.org/doi/full/10.1200/JCO.2011.39.5046>), demonstrating the importance of this topic. The Special Series includes a review by Jacobsen and Wagner that describes how the new standard of psychosocial care, the development of clinical practice guidelines for psychosocial care such as these NCCN Guidelines, and the establishment of indicators to measure the quality of psychosocial care can help increase the number of patients with cancer receiving psychosocial care.<sup>358</sup> Central to the successful integration of psychosocial care into routine cancer care is a distress screening program. In the Special Series, Carlson et al<sup>75</sup> present their recommendations for implementing such a program, and Fann et al<sup>76</sup> discuss the organizational challenges of this new integrated care model, with a focus on the collaborative care service model.

Research on psychosocial care in cancer treatment has expanded greatly in recent years. This fact attests to the growing awareness of the importance of the topic, both by health care professionals and by the public.<sup>359</sup> The Special Series includes reviews of evidence-based

interventions for 3 common psychosocial problems in patients with cancer: depression, anxiety, and delirium.<sup>282,313,329</sup>

Worries and concerns about cancer do not necessarily end with the end of acute care. The Special Series thus also includes articles addressing the psychosocial needs of AYAs and adult cancer survivors.<sup>360,361</sup> An article on the psychosocial needs of caregivers is also included.<sup>362</sup>

In addition, an article was included on oncologist burnout.<sup>353</sup> The Special Series concludes with a review and meta-analysis of studies that provide evidence for the development of an appropriate curriculum for communication skills training of oncologists.<sup>176</sup> Patient benefit from such training (eg, better adherence to treatment) has yet to be demonstrated.

### **Summary**

Psychosocial care is an integral component of the clinical management of patients with cancer. The CoC's accreditation standards include distress screening for all patients and referral for psychosocial care as needed. Screening for and treating distress in cancer benefits patients, their families/caregivers, and staff and helps improve the efficiency of clinic operations. For patients with cancer, integration of mental health and medical services is critically important. Spirituality and religion also play an important role for many patients with cancer in coping with the diagnosis and the illness.

The NCCN Guidelines for Distress Management recommend that each new patient be rapidly assessed in the office or clinic waiting room for evidence of distress using the DT and Problem List as an initial global screen. A score of 4 or greater on the DT should trigger further evaluation by the oncologist or nurse and referral to an appropriate resource, if needed. The choice of which supportive care service is needed is dependent on the problem areas specified on the Problem List. Patients with practical and psychosocial problems should be referred to social



workers; those with emotional or psychological problems should be referred to mental health professionals including social workers; and spiritual concerns should be referred to certified chaplains. Physical concerns may be best managed by the medical team.

Education of patients and families is equally important to encourage them to recognize that control of distress is an integral part of their total cancer care. The patient version of the NCCN Guidelines for Distress Management is a useful tool to accomplish this (available at [www.NCCN.org](http://www.NCCN.org)).

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