



National  
Comprehensive  
Cancer  
Network®

**NCCN Clinical Practice Guidelines in Oncology™**

# **Distress Management**

V.1.2008

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 $\text{£}$  Supportive Care including Palliative, Pain management,  
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 $\xi$  Bone Marrow Transplantation  
 $\text{¥}$  Patient advocacy  
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 $\Psi$  Neurology/neuro-oncology  
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**Continue**

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**Clinical Trials:** The NCCN believes that the best management for any cancer patient 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/physician.html](#)

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

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

[Order the Patient Version of the Distress Management Guidelines](#)

## Summary of the Guidelines Updates

Summary of changes in the 1.2008 version of the Distress Management Guidelines from the 1.2007 version include:

**(DIS-B)**

- Under “Patients at increased risk for distress”: The panel added “Spiritual/religious concerns”.

**(DIS-10)**

- “Suicidal risk” pathway; Under “Assure patient safety”: The panel added “Increase monitoring, Consider removing sharp objects, Consider psychiatric consultation”.

**(DIS-20)**

- Spiritual evaluation, top pathway: The panel added “Spiritual counseling”.

## “DISTRESS”

### 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 \(DIS-2\)](#)

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

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## DEFINITION OF DISTRESS IN CANCER

**Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual 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.**

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

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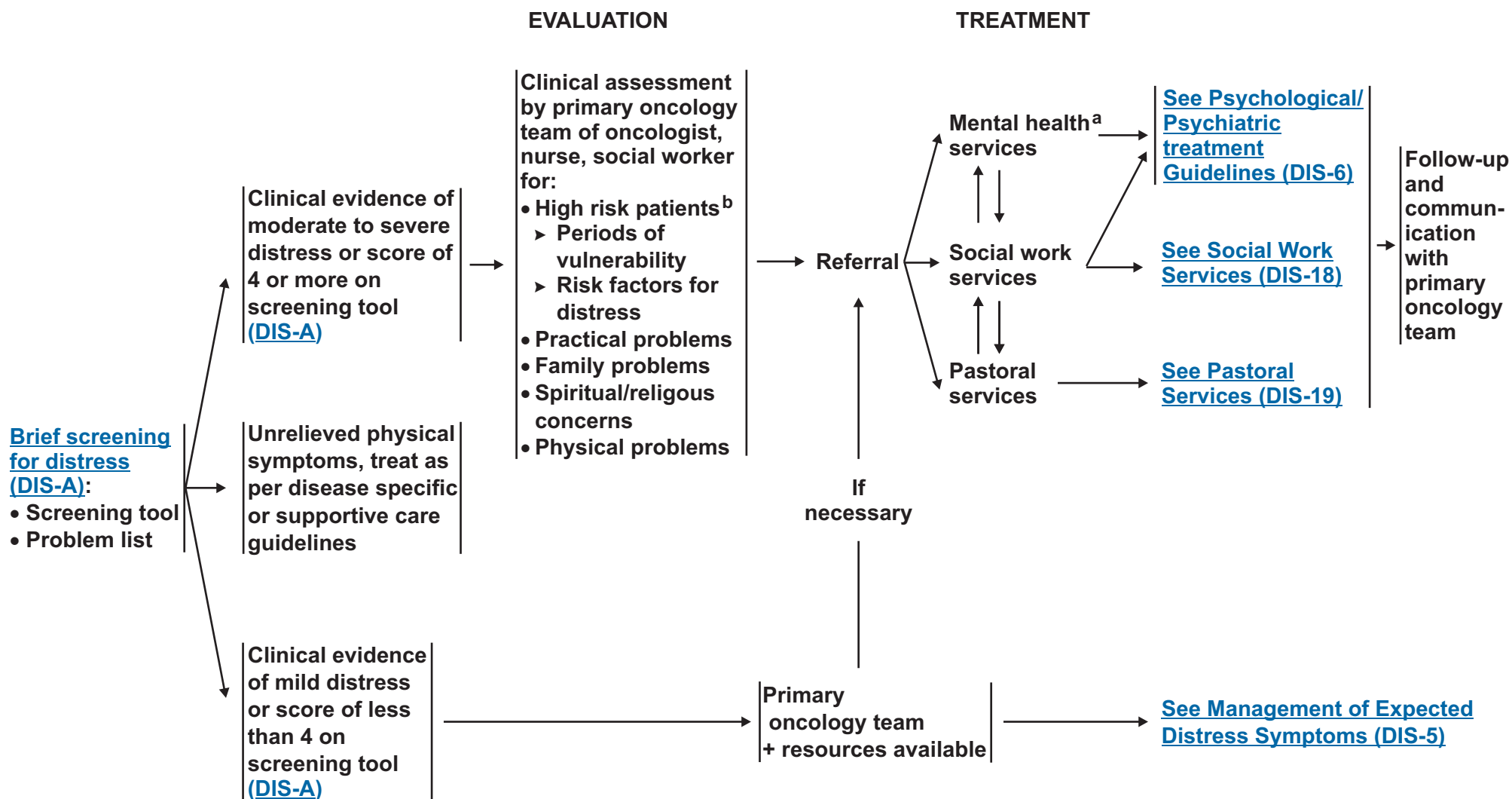
STANDARDS OF CARE FOR  
DISTRESS MANAGEMENT

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease.
- All 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).
- Screening should identify the level and nature of the distress.
- Distress should be assessed and managed according to clinical practice guidelines.
- Multidisciplinary 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 pastoral caregivers have knowledge and skills in the assessment and management of distress.
- Licensed mental health professionals and certified pastoral caregivers experienced in psychosocial aspects of cancer should be readily available as staff members or by referral.
- Medical care contracts should include 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 management of distress is an integral part of total medical care and provided with appropriate information about psychosocial services in the treatment center and the community.
- Quality of distress management should be included in institutional continuous quality improvement (CQI) projects.

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## OVERVIEW OF EVALUATION AND TREATMENT PROCESS



<sup>a</sup>Psychiatrist, psychologist, nurse, clinical nurse specialist, social worker and pastoral counselor.

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

[Refer to NCCN Guidelines Table of Contents for Supportive Care Guidelines.](#)

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## EXPECTED DISTRESS SYMPTOMS

## INTERVENTIONS

## RE-EVALUATION

- Patients at increased risk of vulnerability to distress<sup>b</sup>
- Signs and symptoms of normal fear and worry of the future and uncertainty
  - ▶ 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
  - ▶ Disease or treatment side effects



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



Monitor functional level and reevaluate at each visit



Stable or diminished distress



Continue monitoring and support

Increased or persistent distress



[See Distress Score ≥ 4 or moderate to severe distress \(DIS-4\)](#)

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

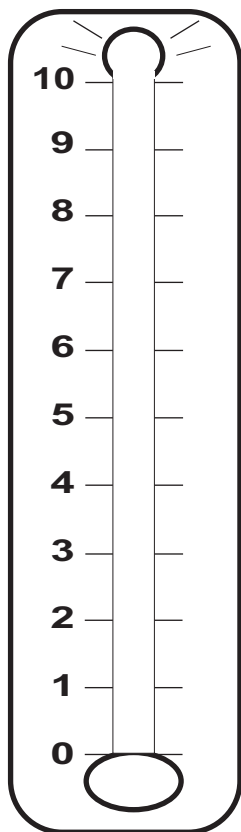
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## SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First 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

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

**YES NO Practical Problems**

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school

**Family Problems**

- Dealing with children
- Dealing with partner

**Emotional Problems**

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

- Spiritual/religious concerns**

**YES NO Physical Problems**

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Tingling in hands/feet

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

\_\_\_\_\_

**PSYCHOSOCIAL DISTRESS PATIENT CHARACTERISTICS<sup>c</sup>****PATIENTS AT INCREASED RISK FOR DISTRESS<sup>d</sup>**

- History of psychiatric disorder/substance abuse
- History of depression/suicide attempt
- Cognitive impairment
- Communication barriers<sup>e</sup>
- Severe comorbid illnesses
- Social problems
  - Family/caregiver conflicts
  - Inadequate social support
  - Living alone
  - Financial problems
  - Limited access to medical care
  - Young or dependent children
  - Younger age; woman
  - Other stressors
- Spiritual/religious concerns

**PERIODS OF INCREASED VULNERABILITY**

- Finding a suspicious symptom
- During workup
- Finding out the diagnosis
- Awaiting treatment
- Change in treatment modality
- End of treatment
- Discharge from hospital following treatment
- Stresses of survivorship
- Medical follow-up and surveillance
- Treatment failure
- Recurrence/progression
- Advanced cancer
- End of life

<sup>c</sup>For site-specific symptoms with major psychosocial consequences, see Holland, JC, Greenberg, DB, Hughes, MD, et al. Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management. (Based on NCCN Distress Management Guidelines). IPOS Press, 2006. Available at [www.apos-society.org](http://www.apos-society.org).

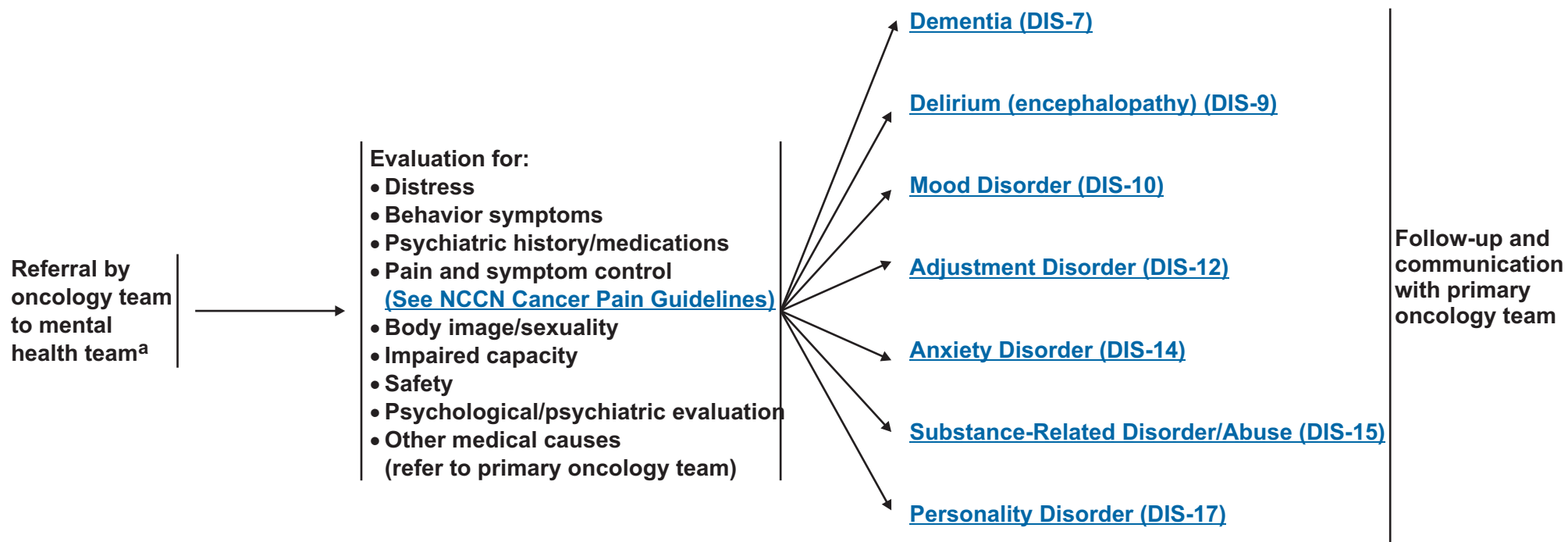
<sup>d</sup>From the NCCN Palliative Care Clinical Practice Guidelines in Oncology. Available at [www.nccn.org](http://www.nccn.org).

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

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

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

## PSYCHOLOGICAL/PSYCHIATRIC TREATMENT GUIDELINES



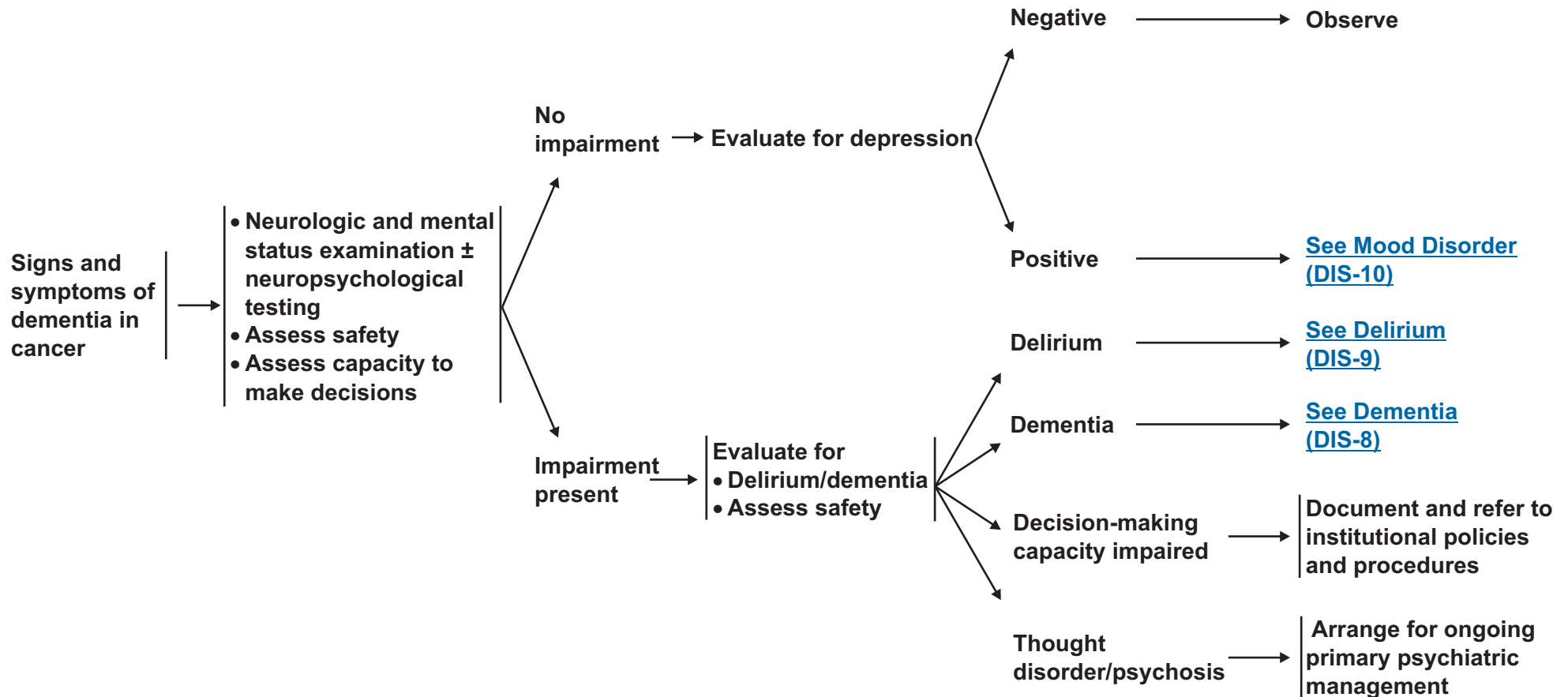
<sup>a</sup>Psychiatrist, psychologist, nurse, clinical nurse specialist, social worker and pastoral counselor.

[For End of Life Issues, See NCCN Palliative Care Guidelines](#)

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**DEMENTIA**  
(ICD-10 codes: F00-F03)

**EVALUATION**

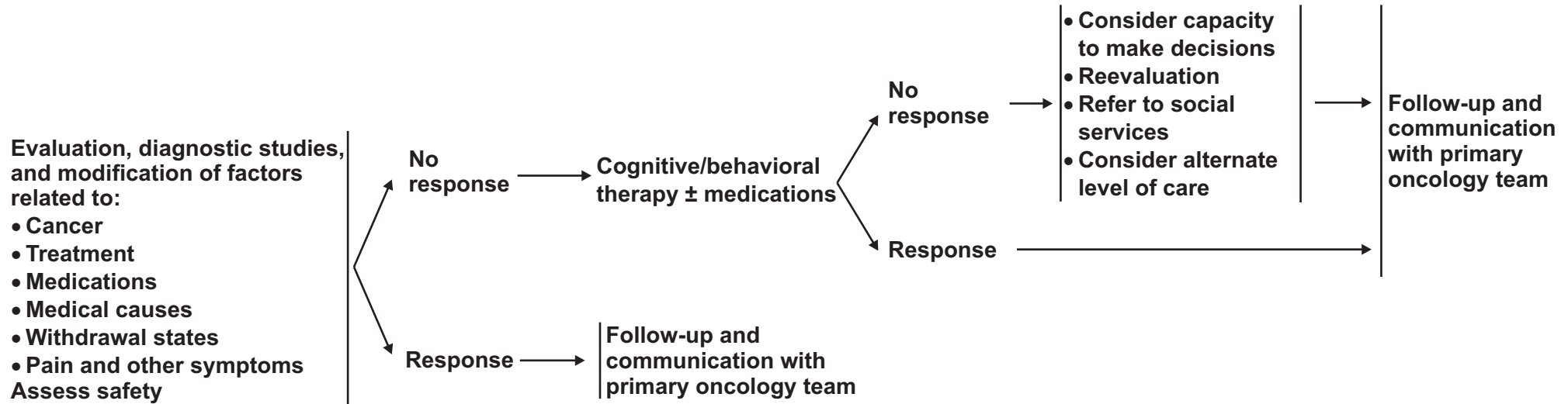


[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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DEMENTIA (continued)  
(ICD-10 codes: F00-F03)

TREATMENT/FOLLOW-UP

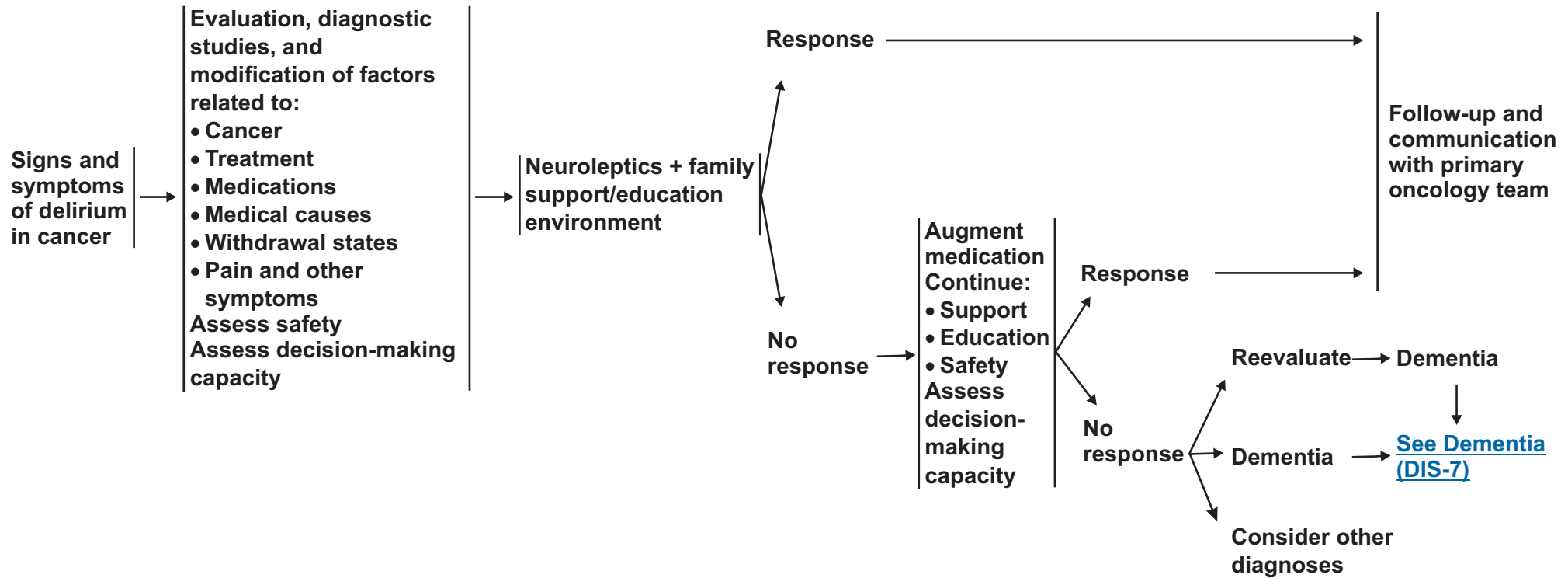


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Guidelines \(DIS-6\)](#)

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**DELIRIUM**  
(Encephalopathy)  
(ICD-10 code: F05)

EVALUATION/TREATMENT/FOLLOW-UP

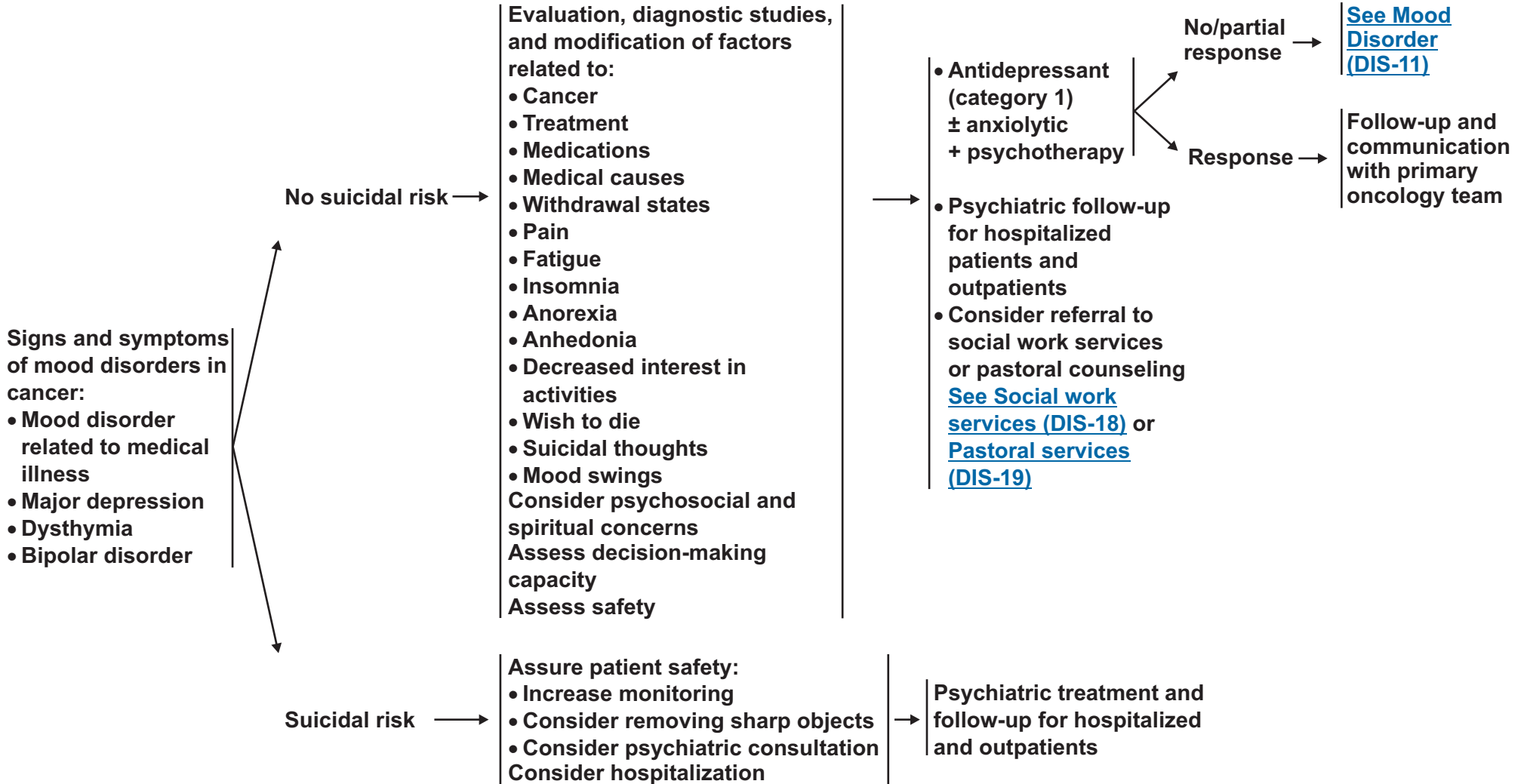


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**MOOD DISORDER**  
(ICD-10 codes: F34, F38, F39)

**EVALUATION/TREATMENT/FOLLOW-UP**



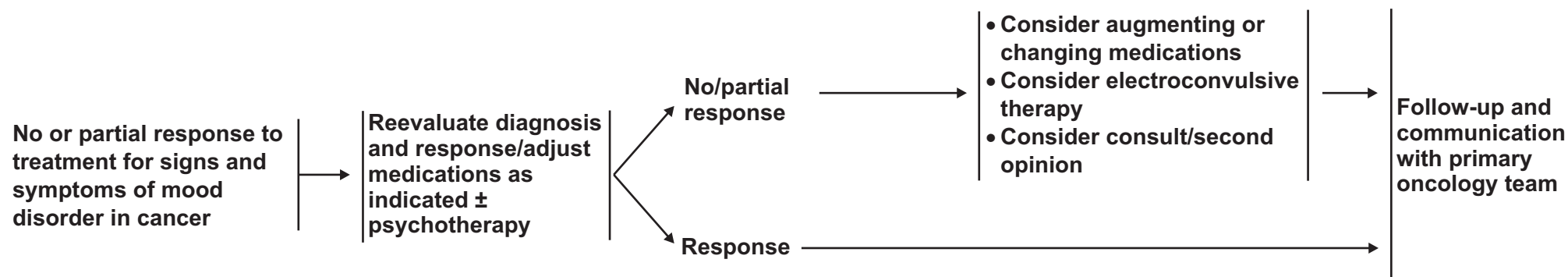
[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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**MOOD DISORDER (continued)**  
(ICD-10 codes: F34, F38, F39)

**EVALUATION/TREATMENT/FOLLOW-UP**

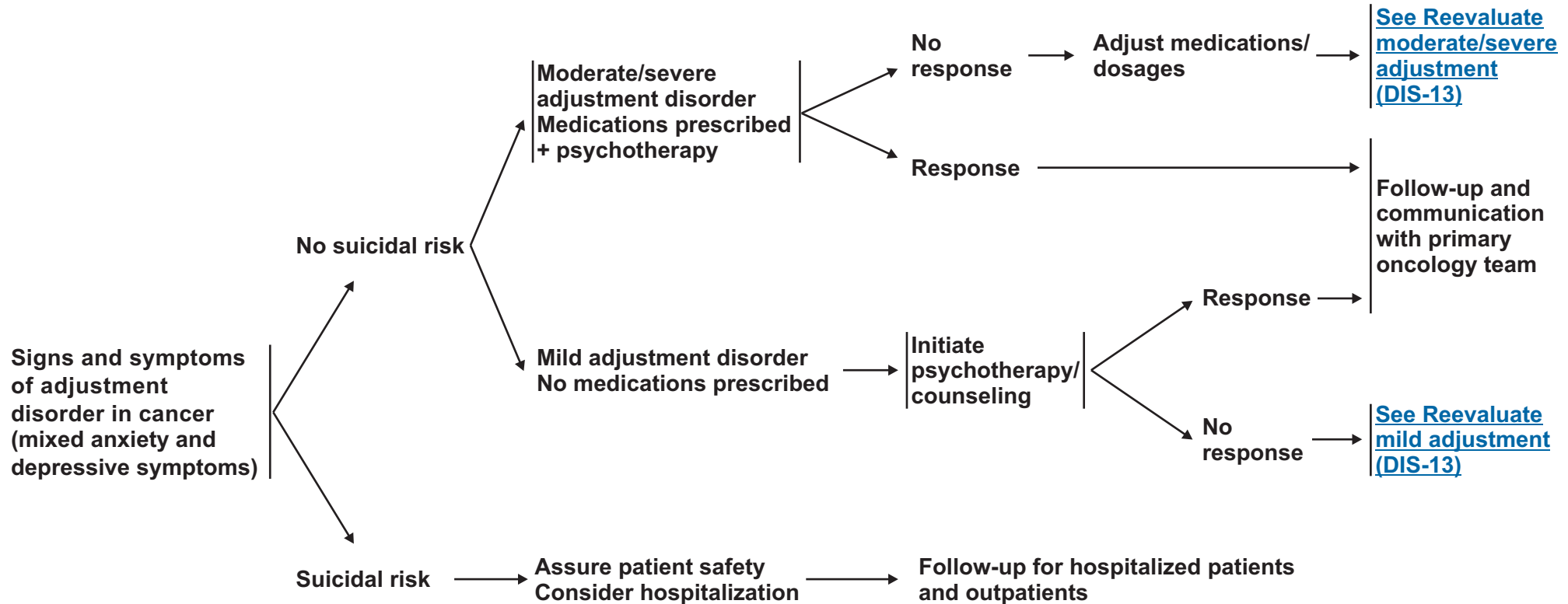


[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

**Note:** All recommendations are category 2A unless otherwise indicated.  
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**ADJUSTMENT DISORDER**  
(ICD-10 code: F43.2)

**EVALUATION/TREATMENT/FOLLOW-UP**

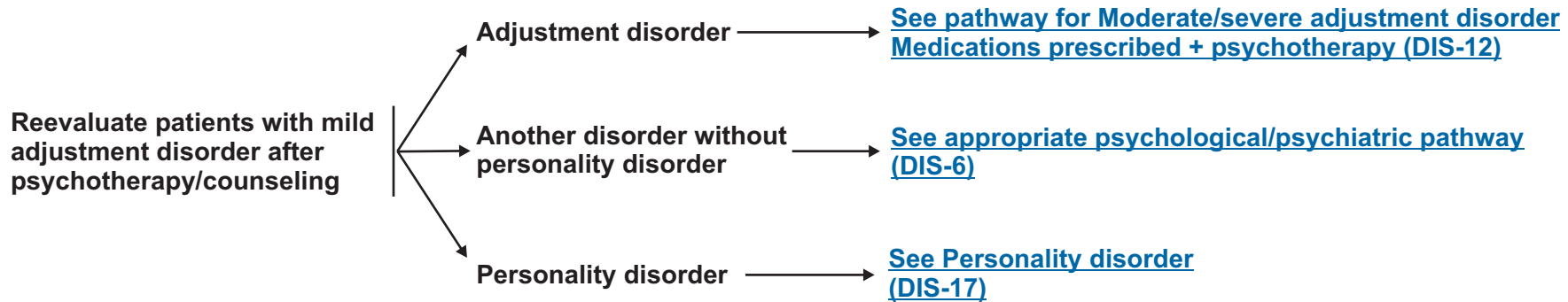
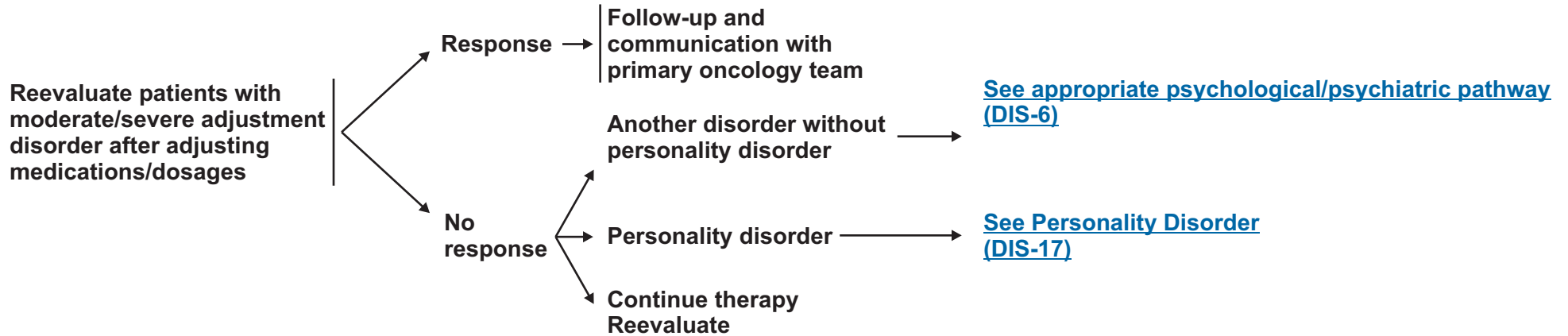


[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

**Note:** All recommendations are category 2A unless otherwise indicated.  
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**ADJUSTMENT DISORDER (continued)**  
(ICD-10 code: F43.2)

**EVALUATION/TREATMENT/FOLLOW-UP**

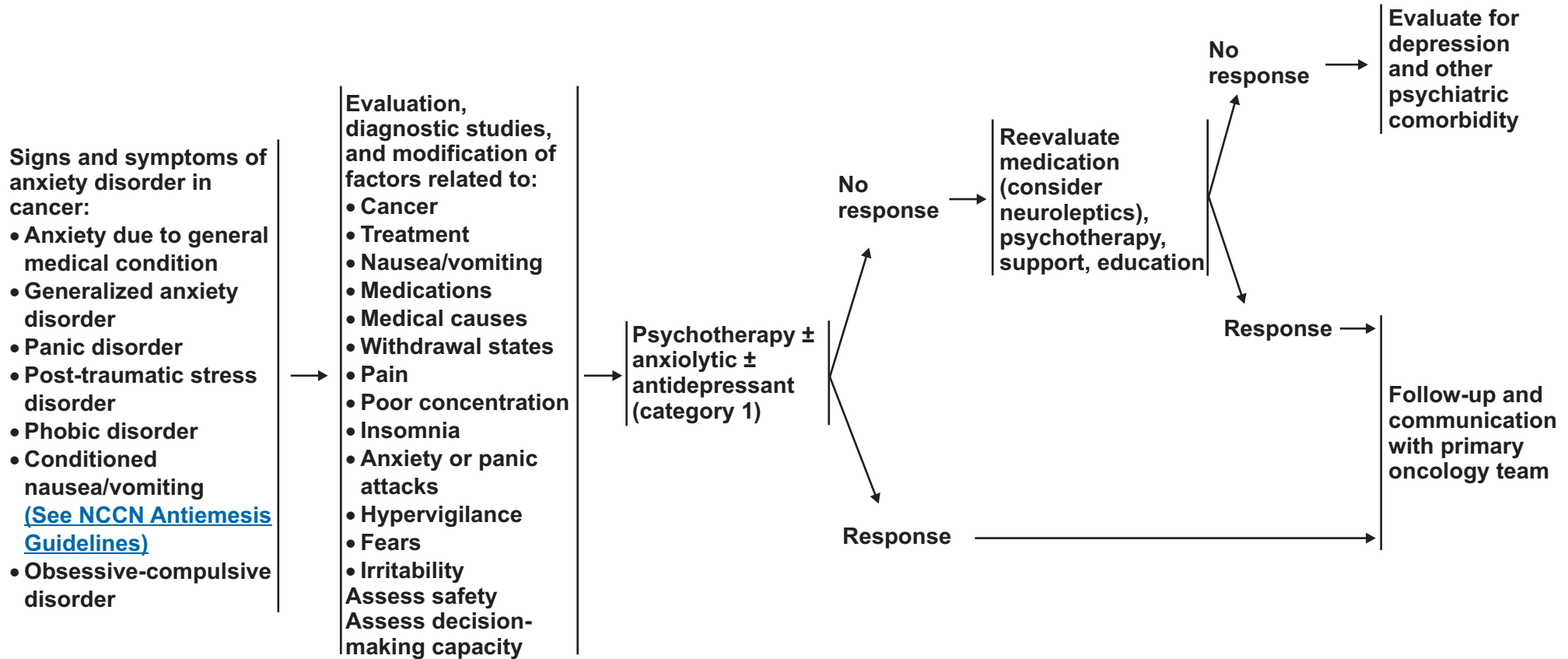


[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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**ANXIETY DISORDER**  
(ICD-10 codes: F40, F41)

**EVALUATION/TREATMENT/FOLLOW-UP**

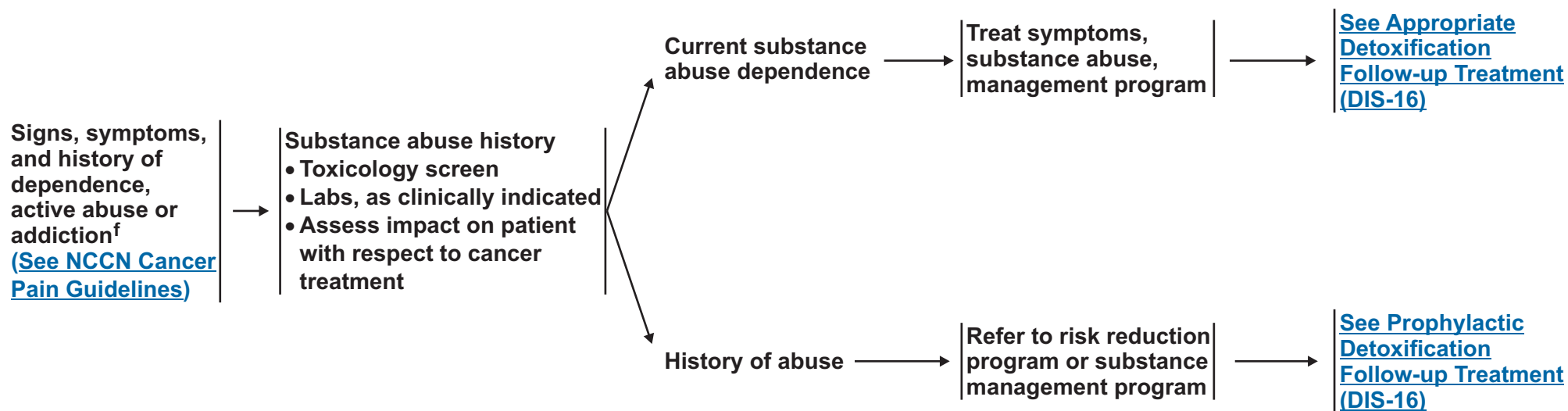


[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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**SUBSTANCE-RELATED DISORDER/ABUSE**  
(ICD-10 codes: F09-F19)

**EVALUATION/TREATMENT**



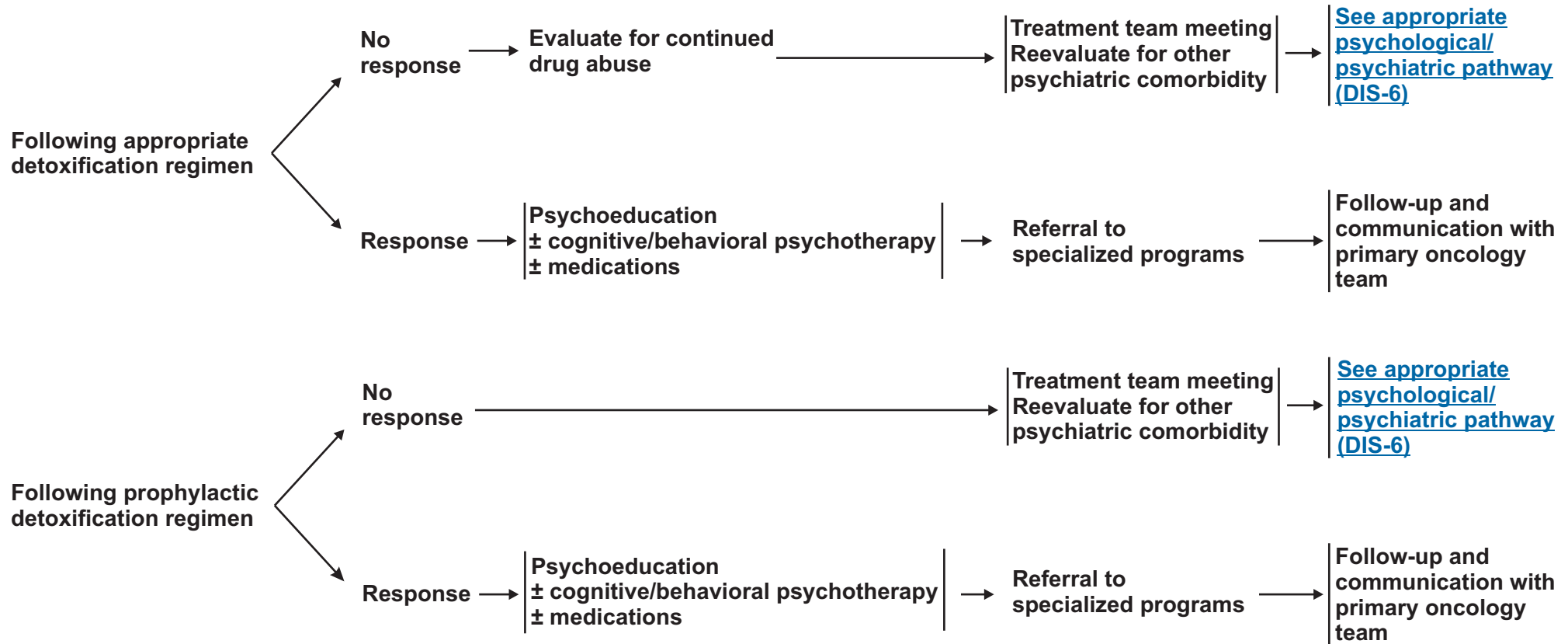
[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

<sup>f</sup>Opioids, alcohol, tobacco, or other.

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**SUBSTANCE-RELATED DISORDER/ABUSE(continued)**  
(ICD-10 codes: F09-F19)

**FOLLOW-UP**

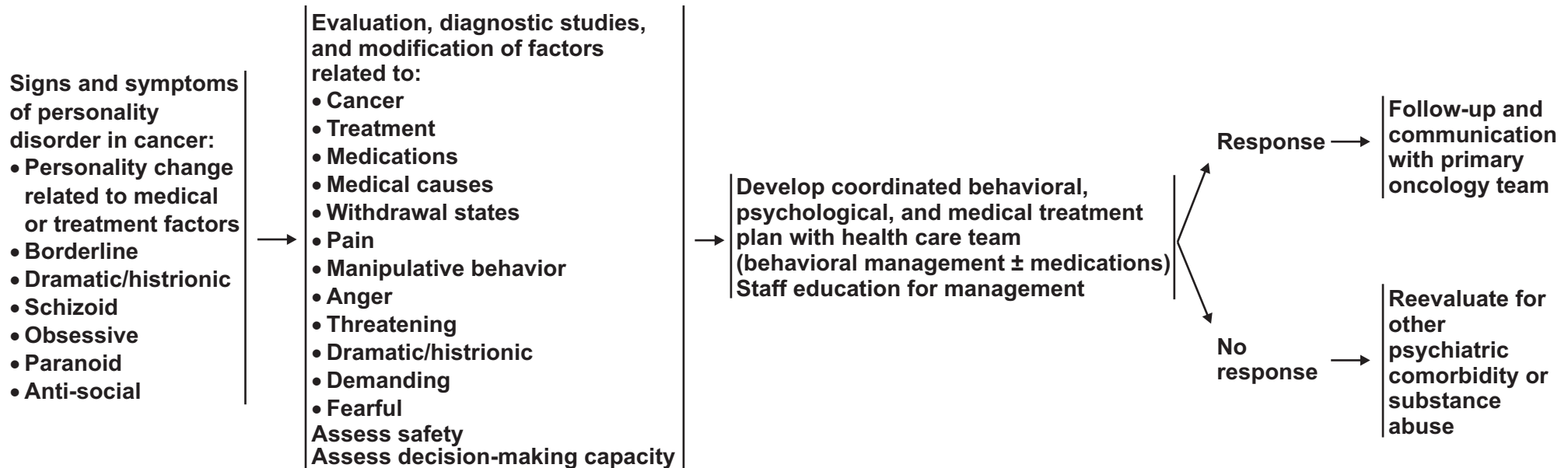


[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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**PERSONALITY  
DISORDER**  
(ICD-10 code: F60)

**EVALUATION/TREATMENT/FOLLOW-UP**



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

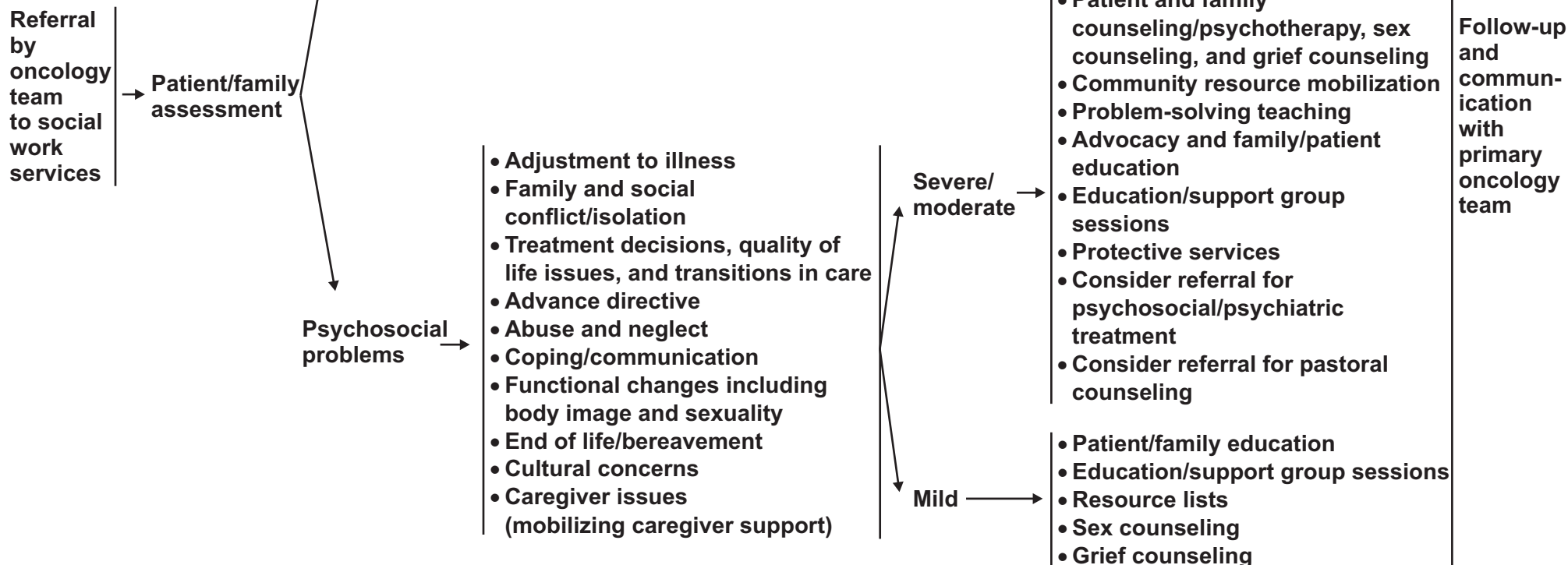
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**SOCIAL WORK SERVICES<sup>9</sup>**

**CATEGORY**

**TYPE OF PROBLEM**

**SOCIAL WORK INTERVENTIONS**



<sup>9</sup>Social work services include mental health services using psychological/psychiatric treatment guidelines.

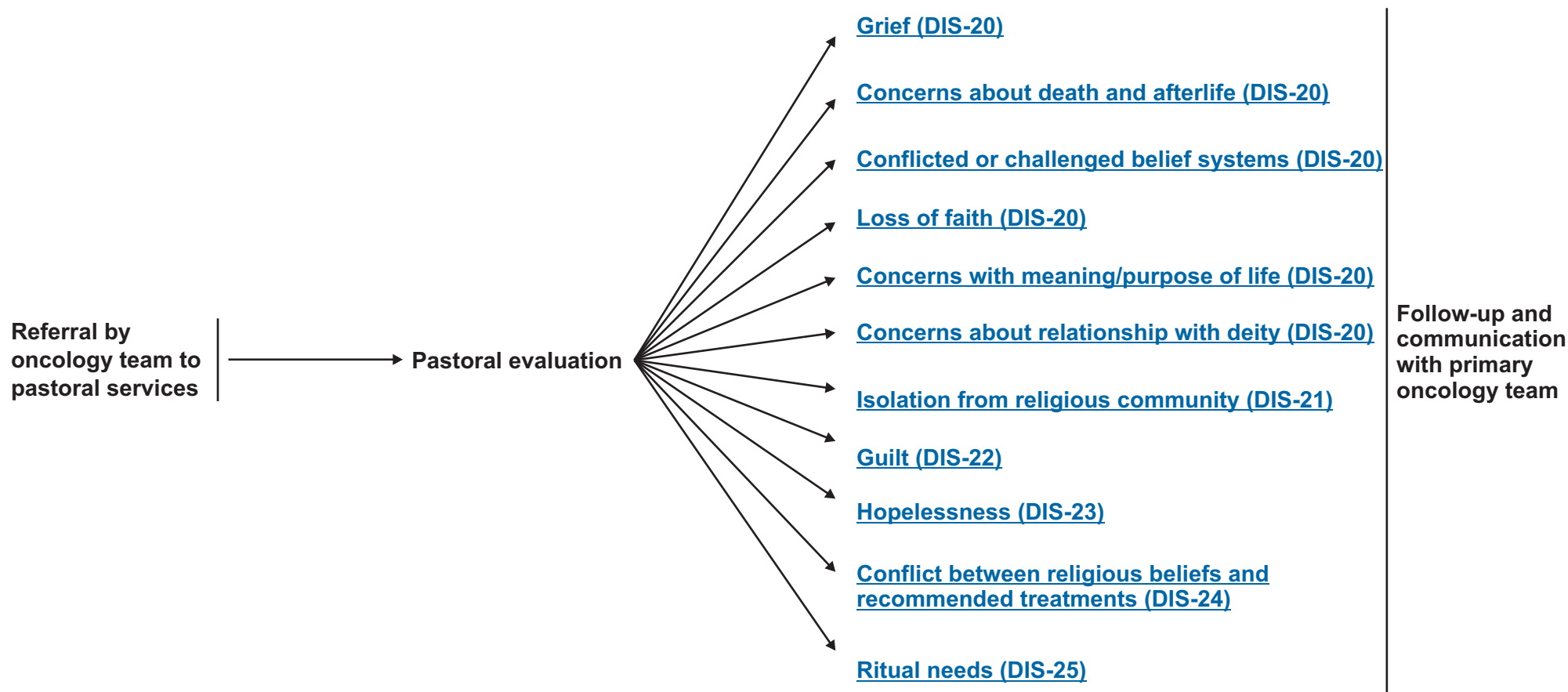
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[See NCCN Palliative Care Guidelines](#)



## PASTORAL SERVICES

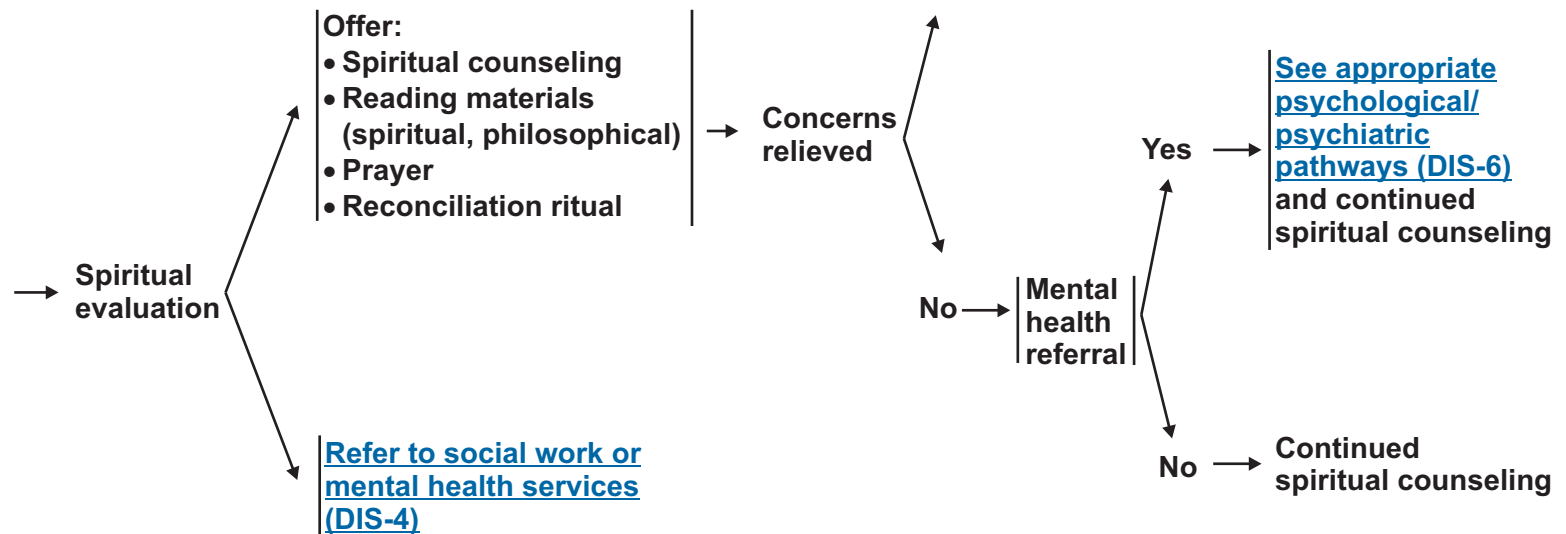


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PASTORAL SERVICES

Evidence of:

- Grief
- Concerns about death and afterlife
- Conflicted or challenged belief systems
- Loss of faith
- Concerns with meaning/purpose of life
- Concerns about relationship with deity

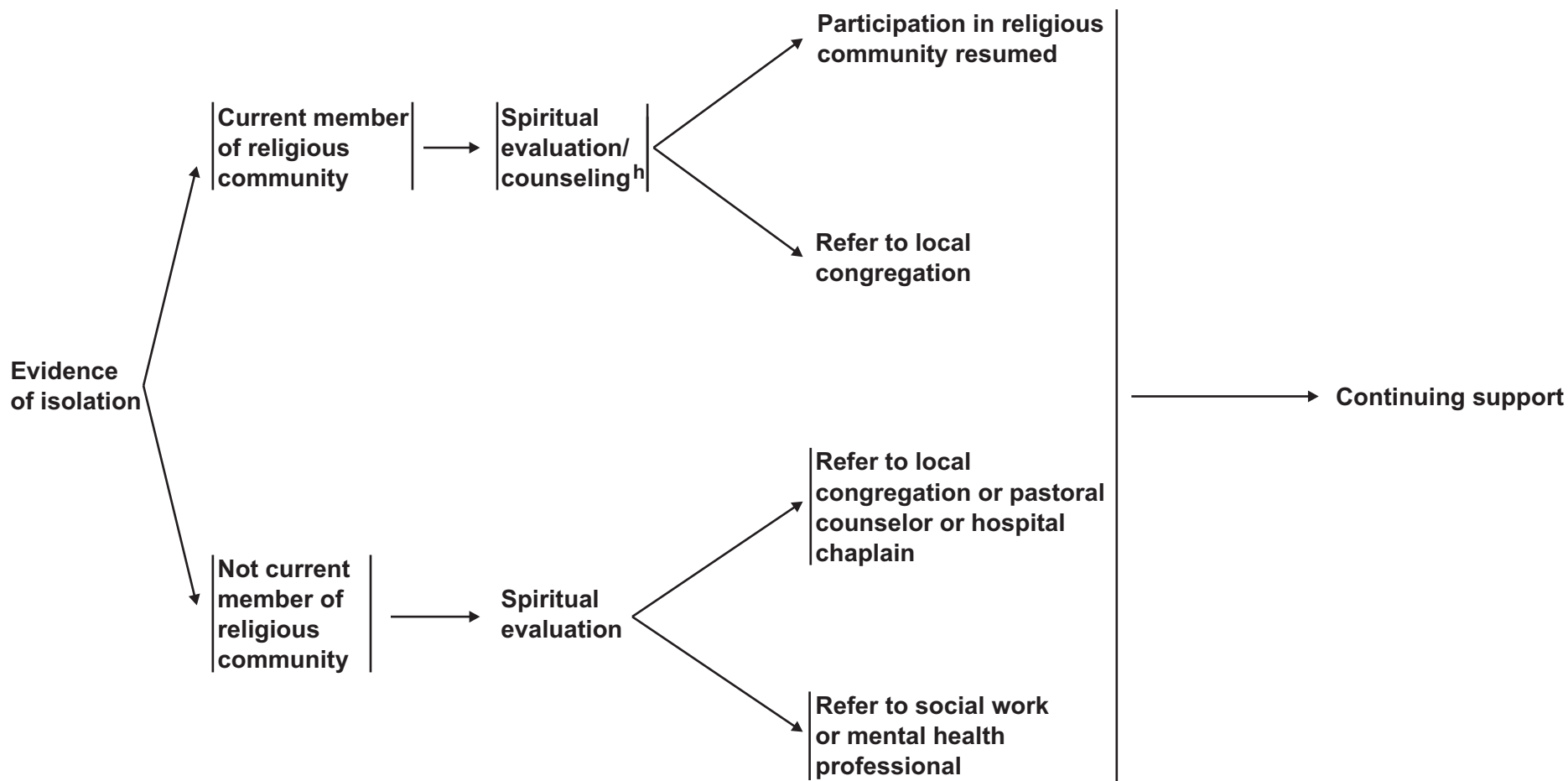


[Return to Pastoral Services \(DIS-19\)](#)

[See NCCN Palliative Care Guidelines](#)

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PASTORAL SERVICES: ISOLATION FROM RELIGIOUS COMMUNITY

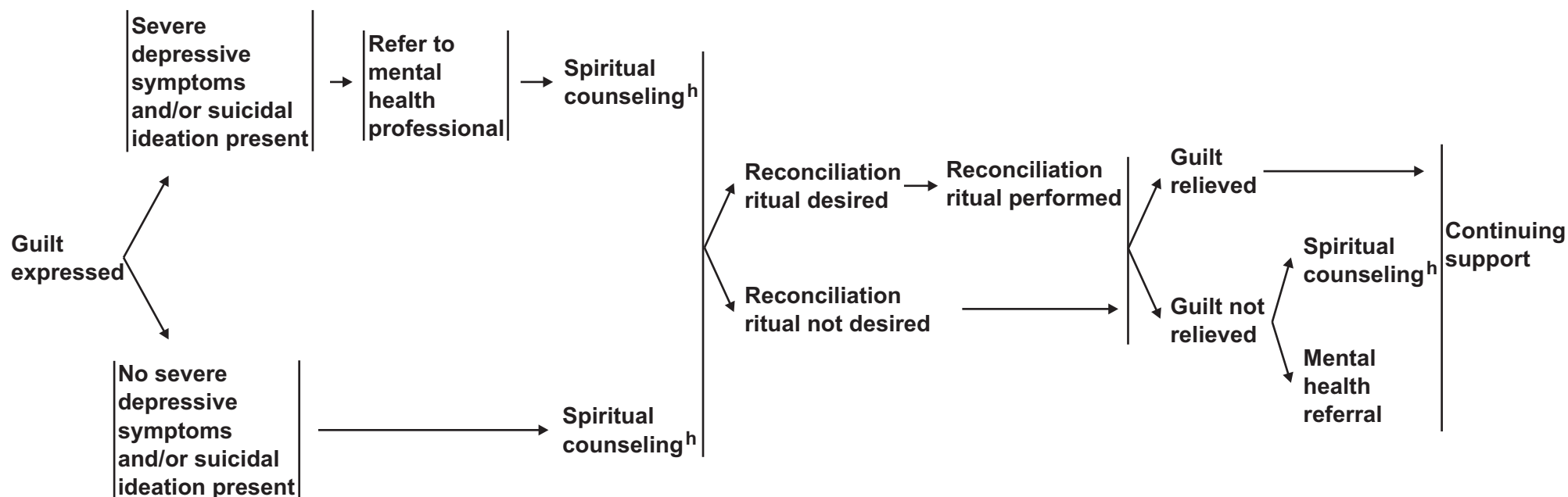


<sup>h</sup>Referral to clergy of person's faith.

[Return to Pastoral Services \(DIS-19\)](#)

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PASTORAL SERVICES: GUILT

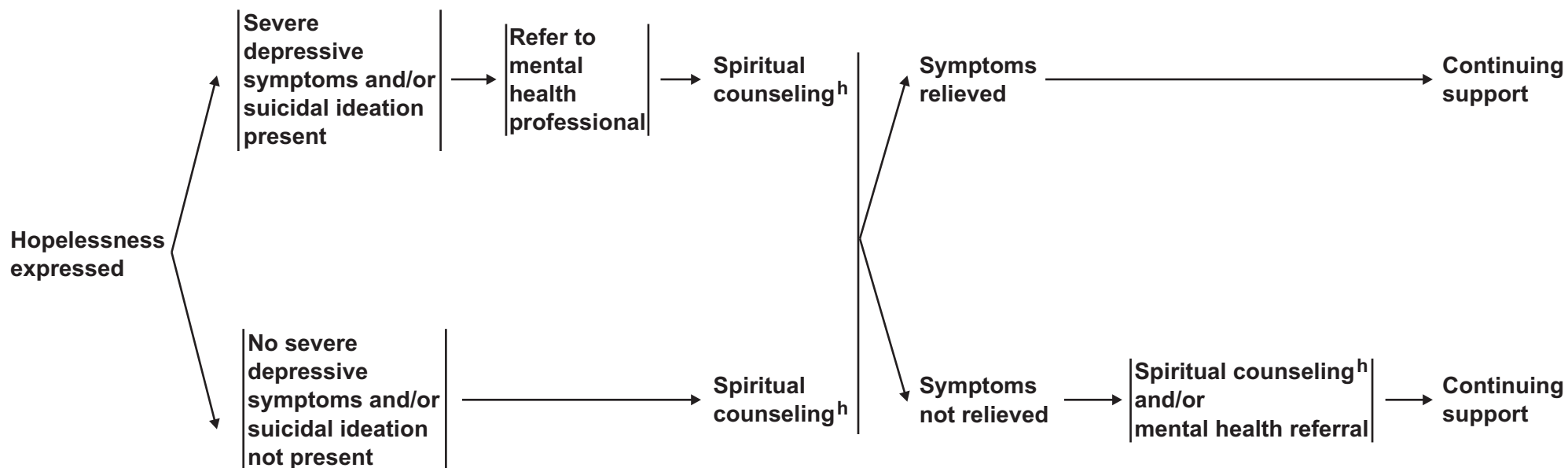


<sup>h</sup>Referral to clergy of person's faith.

[Return to Pastoral Services \(DIS-19\)](#)

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PASTORAL SERVICES: HOPELESSNESS

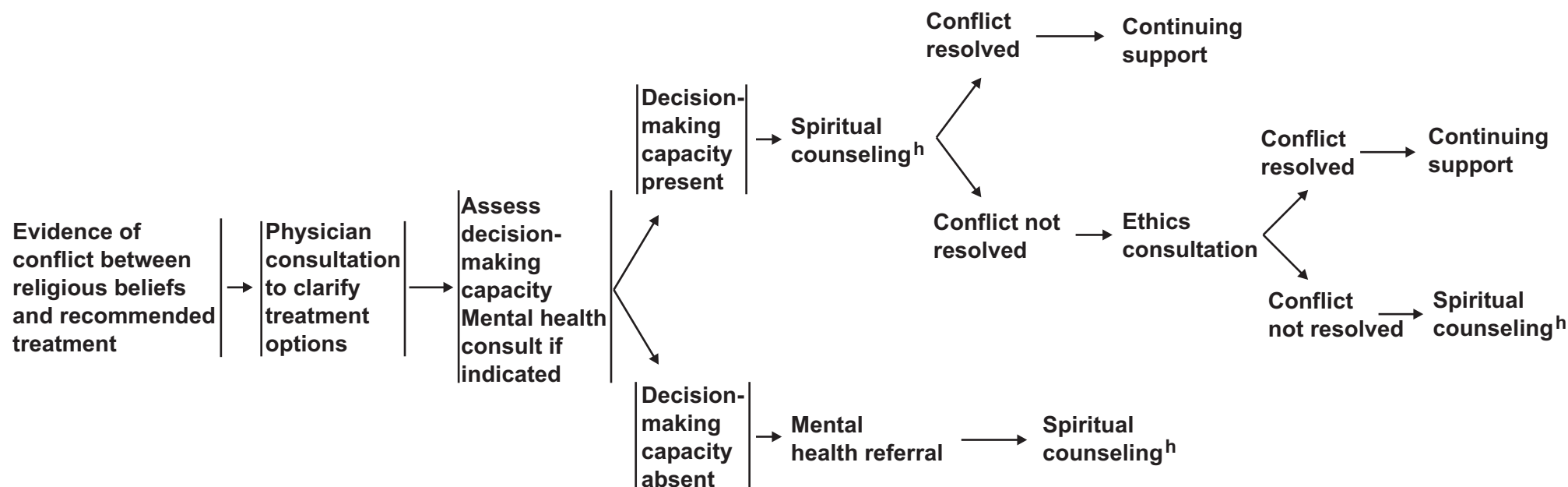


<sup>h</sup>Referral to clergy of person's faith.

[Return to Pastoral Services \(DIS-19\)](#)

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PASTORAL SERVICES: CONFLICT BETWEEN RELIGIOUS BELIEFS  
AND RECOMMENDED TREATMENTS



<sup>h</sup>Referral to clergy of person’s faith.

[Return to Pastoral Services \(DIS-19\)](#)

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## PASTORAL SERVICES: RITUAL NEEDS



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RECOMMENDATIONS FOR IMPLEMENTATION  
OF STANDARDS AND GUIDELINES

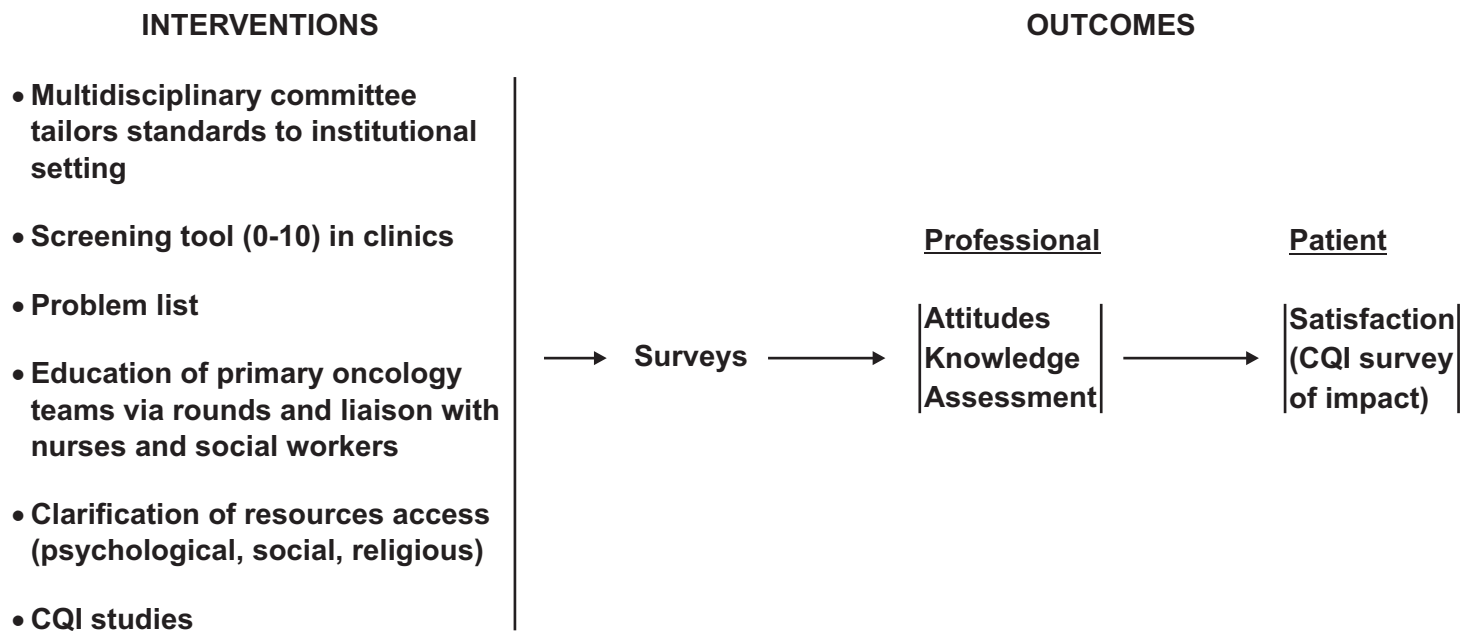
- Encourage establishment of institutional multidisciplinary committees for implementation of standards and guidelines
- Conduct multicenter trials that explore brief screening instruments and pilot treatment guidelines
- Encourage institutional CQI (continuous quality improvement) projects in quality of distress management
- Develop educational approaches to distress management for staff, patients, and family

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



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

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## Manuscript

### NCCN Categories of Evidence and Consensus

**Category 1:** There is uniform NCCN consensus, based on high-level evidence, that the recommendation is appropriate.

**Category 2A:** There is uniform NCCN consensus, based on lower-level evidence including clinical experience, that the recommendation is appropriate.

**Category 2B:** There is nonuniform NCCN consensus (but no major disagreement), based on lower-level evidence including clinical experience, that the recommendation is appropriate.

**Category 3:** There is major NCCN disagreement that the recommendation is appropriate.

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

### Overview

In the United States, an estimated 1,444,920 new cancer cases will be diagnosed and 559,650 individuals are expected to die of cancer in 2007.<sup>1</sup> All patients experience some level of distress associated with diagnosis and treatment of cancer at various stages of the disease. The ability of physicians to recognize patients' distress has become more difficult as cancer care has shifted to the ambulatory setting, where visits are often short and rushed. Development of clinical practice guidelines for the management of psychosocial distress in cancer patients is therefore very important.<sup>2</sup>

Surveys have found that 20-40% of patients show a significant level of distress.<sup>3,4</sup> However, less than 10% of patients are actually identified and referred for psychosocial help.<sup>5</sup> Patients were not told about their diagnosis of cancer for many centuries due to the stigma attached to

the disease. As a result, the physicians were not able to communicate with the patients freely about the disease. In the last three decades this situation has changed and patients are well aware of their diagnosis and treatment options. In spite of the increased awareness, patients are reluctant to report distress. The words "psychological," "psychiatric," and "emotional" can be as stigmatizing as the word "cancer." Consequently, they often do not want to tell their physicians about their distress. Physicians are often rushed during brief clinic visits and do not inquire about the psychological concerns of their patients. These barriers prevent distress from receiving the attention it deserves, yet this is a critical component of the total care of the person with cancer. Psychooncology is now an important and integral part of cancer care especially related to improvement of quality of life, symptom management and control.<sup>6,7</sup> Patients and families should be made aware that this aspect of care is equally important.<sup>8</sup>

Psychosocial morbidity leads to severe distress in cancer patients. Failure to recognize and treat distress leads to several problems. Patients in distress may make extra visits to the physician's office and the hospital emergency department. Distressed patients have trouble making decisions about treatment and adhering to treatment; they may also become dissatisfied with their physicians and medical care. Management of the extremely distressed patient (who is anxious, depressed, and angry) adds to the time demands as well as the stress on the busy oncologist. Systematic screening may prove to be essential for the early evaluation and effective management of psychological distress in cancer patients.<sup>9,10</sup> Psychosocial interventions have been shown to be effective in reducing distress and improving overall quality of life among cancer patients).

The Patients' Bill of Rights does not address psychosocial concerns within total health care. Regulatory bodies (such as the Joint Commission on Accreditation of Healthcare Organizations; the Health

Plan Employer Data and Information Set) are establishing standards regarding patient decision-making and the ethical aspects of care. However, psychosocial care remains an area for which minimum standards do not exist.

The NCCN Distress Management Guidelines panel is composed of representatives from all the disciplines involved in the delivery of ambulatory cancer care: oncology, nursing, social work, psychiatry, psychology, and clergy. A patient advocate is also on the panel. Traditionally, clergy have not been included in medical teams. However, chaplains were invited to participate, because a diagnosis of cancer provokes an existential crisis. Many patients seek supportive help from the clergy when dealing with a life-threatening illness, such as cancer. In one survey, more than 85% of patients state they draw on spiritual and religious beliefs when coping with cancer.<sup>11</sup>

## Defining Distress

The word “distress” was chosen to characterize the psychosocial aspects of patient care, because it is less stigmatizing and more acceptable than other terms. Also, distress is considered a natural response when an individual or family member is diagnosed with cancer. Distress exists along a continuum ranging from “normal” reactions to the stress of coping with cancer and its treatment (eg, sadness about the loss of good health, fear about the future) to symptoms so intense they meet the criteria for a psychiatric disorder (ie, major depression, generalized anxiety disorder), a severe social or family problem, or significant spiritual crisis. The word “distress” is also easier for medical professionals to use when inquiring about patients' emotions. 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 of distress.<sup>12</sup> The panel also recommends asking patients this question (about distress) in the waiting room using a single page that also provides a Problem List for the patient to indicate the reasons (causes) of patient's distress ([DIS-A](#)).

As it applies to patients with cancer, distress is defined as a multifactorial, unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer, its physical symptoms, and its treatment. Distress extends along a continuum ranging from normal feelings of vulnerability, sadness, and fear to disabling conditions, such as clinical depression, anxiety, panic, isolation, and existential or spiritual crisis.

## Standards of Care for Distress Management

The NCCN panel developed a set of standards of care for the management of distress ([DIS-3](#)) using quality improvement guidelines for the treatment of pain as a model.<sup>13</sup> The standards of care for managing distress proposed by the panel are broad in nature and should be tailored to particular needs of each institution and patient. The overriding goal of these standards is to ensure that no patient with distress goes unrecognized and untreated. Therefore, the first principle is that distress, like pain, should be recognized, monitored, documented, and promptly treated at all stages.<sup>14</sup>

The NCCN standards for managing distress suggest that all patients should be screened to ascertain their levels of distress at the initial visit, at appropriate intervals, and as clinically indicated, especially when changes occur in disease status (remission, recurrence or progression). During screening, the overall nature of distress, as well as the sources of distress, should be identified.

Patients need to understand the importance of reporting their distress and the distress of family members to the oncology team. The panel recognizes that the primary oncology team (oncologist, nurse and social worker) plays a central role in evaluating and triaging patients with distress in the ambulatory setting. Understanding the level and the cause of patients' distress will allow the primary oncology team to send patients to the appropriate psychosocial resource for evaluation and treatment. The nurses on the team are key figures because of their constant presence at all patient visits, their concern for the total patient, and their opportunity to ask additional questions and to refer patients to a counseling service. When the oncology team refers a patient to the psychosocial staff, distress should be managed according to the NCCN Distress Management Guidelines.

The NCCN panel established these first supportive care guidelines for the management of distress in cancer patients for social workers, pastoral counselors, and mental health professionals (psychologists, psychiatrists, psychiatric social workers, and psychiatric nurses). The panel recommends that each cancer center establish a multidisciplinary committee that will assume responsibility for implementing the standards of care and for overseeing distress management efforts ([DIS-4](#)). Educational and training programs should be developed through the multidisciplinary committee to ensure that the oncology team, mental health professionals, and pastoral counselors have the appropriate knowledge and skills to manage distress. Mental health professionals and clergy experienced in addressing psychosocial issues related to cancer should be available either as staff members within the cancer center or by referral. The institutional multidisciplinary committees need to develop educational programs for patients and their families to ensure that patients understand that management of distress is an integral part of their total medical care.

Medical care contracts should include reimbursement for services to patients for evaluating and treating distress. Presently, medical insurance contracts usually do not include psychological or social services. Behavioral health plans cover these services and often overlook the need for integrated medical and psychological care in medically ill patients.

Clinical outcomes measurements should incorporate assessment of the psychosocial domain (ie, cost-effectiveness, quality of life, and patient and family satisfaction). Researchers evaluating treatment outcomes must consider patients' self-reported satisfaction and quality of life levels.

Finally, the quality of distress management should be included in institutional, multidisciplinary continuous quality improvement (CQI) projects. Improvement will occur only through the evaluation of patients' needs and the identification of system changes required to increase the recognition and treatment of distress. The NCCN panel believes the goal of improved treatment of patients' distress will be realized when these standards of care are adopted and an institutional multidisciplinary committee is given responsibility for their implementation.

### Screening Tools for Measuring Distress

Several ultra short methods have been developed to screen for distress in cancer patients. The most well known tool is the Distress thermometer, which is similar to the rating scale used to measure pain: 0 (no distress) to 10 (extreme distress).<sup>15-19</sup> This method has been validated by several studies. The needs assessment surveys performed in ambulatory clinics using these screens show 20-40% of patients have significant levels of distress. Functional Assessment of Cancer Therapy-General (FACT-G) quality-of-life scale and Brief Symptom Inventory (BSI) are two other methods used for screening distress.

Distress thermometer serves as a rough single-item question screen, which will identify distress coming from any source even if unrelated to cancer. The patient places a mark on the scale answering: “How distressed have you been during the past week on a scale of 0 to 10?” Scores of 4 or more indicate a significant level of distress that should be evaluated, based on comparisons of these scores with the validated Hospital and Anxiety Scale. The nurse, social worker, or oncologist then determines if the patient has significant distress. The nurse is also expected to ask some additional questions as a second-stage screen. The Problem List which is on the same page as the Distress Thermometer asks patients to identify their problems: physical, practical (eg, transportation, financial), psychological, social, or spiritual ([DIS-A](#)). The completed list is reviewed by the nurse, because he/she is present at all visits and is the likely person to look at the Distress Thermometer/Problem List and to ask clarifying questions. Social workers are often not immediately available in busy clinics. If the patient's distress level is mild, the primary oncology team may choose to handle the problem or recommend a support group.

FACT-G quality-of-life scale was developed by Cella and coworkers.<sup>20</sup> The patient's responses, which are recorded in a handheld computer, are downloaded into a personal computer and transcribed in real time so that they are noted on the patient's chart when the physician evaluates the patient. Thus, physicians can determine how patients are functioning physically, psychologically, and socially.

BSI is the method used at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, in which a volunteer asks all new patients to answer questions while they are waiting to be seen by a physician.<sup>21</sup> Responses are immediately scanned and scored. Patients with the highest scores are seen immediately by a social worker. Individuals with midlevel scores are called and given an appointment. Patients with

the lowest scores receive a letter informing them of available supportive services.

To ensure that distress in cancer patients is recognized, the panel recommends that all patients be assessed in the waiting room using a simple diagnostic tool comprising of the “Distress Thermometer” ([DIS-A](#)) to assess the level of distress and the accompanying “Problem List,” to identify the causes for distress. In Canada, emotional distress has become the sixth vital sign to be checked routinely along with pulse, respiration, blood pressure, temperature and pain.<sup>22</sup>

### Initial Evaluation, Triage and Treatment

Initial evaluation should include assessment of risk factors, practical, family and physical problems, spiritual or religious concerns. Patients at increased risk for distress include those with a history of psychiatric disorder or depression, substance abuse, cognitive impairment, severe comorbid illnesses, social problems and communication barriers ([DIS-B](#)). Risk factors for psychosocial distress include younger age, female gender, living alone, having young children, patients with cumulative stress and past psychiatric treatment, history of alcohol or substance abuse. Patients will be referred to appropriate supportive services (mental health, social work or pastoral services) based on the identified problem.

Patients with moderate to severe distress or score of 4 or more on the screening tool are evaluated by the primary oncology team. The panel also recognized that in many clinics, the only resource is the social worker, and the social worker takes care of all psychological, social, and spiritual problems. However, even in that circumstance, it is important to use the clinical practice guidelines for each of these areas in the treatment of the patient. The professional who receives the patient on referral may decide that another discipline is more appropriate for treating the patient's problem. In these cases, that

professional should arrange a referral within the system so that the patient experiences his or her care within a single delivery system, and not from a fragmented set of disconnected services. The supportive care professional who receives the referral for patients' distress management should evaluate the patient using the clinical practice guidelines developed for managing distress in cancer for that discipline: mental health, social work, or pastoral care.

Mild distress (a score of less than 4) is routinely managed by the primary oncology team and represents what the panel termed "expected distress" symptoms: part of the normal response to a cancer diagnosis and treatment. Patients with unrelieved physical symptoms are treated according to the disease specific or supportive care guidelines.

The medical staff must try to discern between normal stress levels and those that exceed normal, indicating that the patient should be referred for supportive services. The "normal" symptoms that the team manages are the fears, worry, and uncertainty about the future; concerns about the illness and treatment effects and side effects; sadness about loss of good health; anger and the feeling that life is out of control; poor sleep, poor appetite, and poor concentration; and preoccupation with thoughts of illness and death. These symptoms are often particularly troublesome during the times of greatest uncertainty: during a workup for a suspicious symptom; at a time of diagnosis; when awaiting treatment; during arduous treatment cycles; at the end of treatment when paradoxical anxiety and distress occur; before follow-up visits with the oncologist; with minor symptoms that could reflect recurrence; actual recurrence; progression of disease; treatment failure; transition to palliative or hospice care; and awareness of end of life.

The primary oncology team is the first to deal with these painful problems. The oncologist, nurse, and social worker each have a critical role, and the team manages these problems. First and foremost 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 as well as understand the treatment options and side effects. Enough time is needed for asking questions and for putting the patient at ease.<sup>23</sup> When communication is done well at diagnosis, the stage is set for future positive trusting encounters. It is important to ensure that the patient mentally grasps what has been said, and this may be reinforced with drawings or taping the session and giving the tape to the patient.

It is important for the oncology team to acknowledge that this is a difficult experience for the patient and that distress is normal and expected. Being able to express distress to the staff relieves it somewhat and builds trust. The team may need to ensure that social supports are in place for the patient and that the patient is informed about community resources, such as support groups, teleconferences, and help lines. Patients should be made aware of the various resources and educational materials that discuss the management of psychological distress. Some of the useful resources are listed below:

- ASCO (American Society of Clinical Oncology) web site for patients "People Living with Cancer" ([www.plwc.org](http://www.plwc.org)).
- American Cancer Society's NCCN patient guidelines ([www.nccn.org](http://www.nccn.org)), which were developed by NCCN in partnership with the American Cancer Society.

In addition to the above resources the following guidelines will be useful for health care professionals in providing clinical care for patients:

- ACCC (Association of Community Cancer Centers) Cancer Program Guidelines ([www.accc-cancer.org](http://www.accc-cancer.org)).
- Clinical practice guidelines for the psychosocial care of adults with cancer have been developed by the National Breast Cancer Centre

and the National Cancer Control Initiative:

(<http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm>).

If distress is interfering with sleep or appetite, a bedtime hypnotic or a daytime anti-anxiety medication can be considered. Pain must be addressed, because distress cannot be controlled if pain is not controlled. Patients need to feel that the oncology team is the core of their treatment and will remain so, reinforcing their sense of continuity in their care. The team has to advise patients that they may experience greater than usual levels of distress at some points in the treatment and during the course of illness and, consequently, they should not be surprised if they sometimes experience greater distress. Patients should tell the team when that happens so the team can evaluate their distress and obtain the appropriate help for them, by referral to a supportive service. If the patient's distress is moderate or severe (thermometer score of 4 or more), the guidelines suggest the oncology team use that as a trigger to prompt referral to a mental health professional, social worker, or spiritual counselor, depending on the problems identified in the Problem List. During clinical assessment, the primary oncology team should be aware that these common symptoms require further evaluation: excessive worries and fears, excessive sadness, unclear thinking, despair and hopelessness, severe family problems, and spiritual crises.

### Mental Health Services

Mental health professionals are expected to conduct a psychological or psychiatric evaluation that includes an assessment of the nature of the distress, behavior, psychological symptoms, psychiatric history, use of medications, control of pain and other physical symptoms, body image and sexuality, and capacity for decision-making and physical safety. The evaluation may be performed by a psychiatrist, psychologist, nurse, clinical nurse specialist and social worker. All of these

professionals are skilled in mental health assessment and treatment. The Diagnostic and Statistical Manual of Mental Disorders, 4th edition text revision (DSM-IV-TR) classification of mental disorders was used to identify the psychological and psychiatric disorders that commonly occur in patients with cancer. The panel has developed evaluation and treatment guidelines for the seven most commonly encountered disorders: dementia, delirium (encephalopathy), mood disorder, adjustment disorder, anxiety disorder, substance abuse-related disorder, and personality disorder ([DIS-6](#)).

Dementia and delirium are cognitive changes that can occur during the course of cancer treatment, and can severely impair the patient's decision making capacities.<sup>24,25</sup> Dementia occurs over a period of time, usually after the treatment. Mild dementia is sometimes referred to as chemo-brain. Dementia can be treated with cognitive behavioral therapy with or without medications ([DIS-8](#)). If there is no response, patients can be referred to social work services. Delirium may occur suddenly and is usually reversible. Delirium can be managed with neuroleptics along with family support and education ([DIS-9](#)).

Patients with mood and adjustment disorders can develop suicidal tendencies. In patients with no suicidal risk, mood disorder is usually managed with an antidepressant along with psychotherapy with or without anxiolytics. Referral to social work services and pastoral counseling can be considered ([DIS-10](#)). No medications are prescribed for those with mild adjustment disorder. Moderate to severe adjustment disorder is treated with medication and psychotherapy. Safety measures such as increased monitoring removal of sharp objects and psychiatric consultation should be considered for patients at suicidal risk. If necessary, these patients should be hospitalized and appropriate psychiatric treatment should be provided ([DIS-12](#)).

Anxiety disorder is common in most cancer patients.<sup>26</sup> The patient is evaluated first to determine if the anxiety is related to the general

medical condition [eg, hormone-secreting tumor, effects of certain types of medications (bronchodilators), withdrawal from alcohol or narcotics, pain, or some other distressing physical symptom]. The evaluation must also include assessment of the patient's capacity to make decisions about treatment and if impaired, ensure the patient's physical safety. After ruling out medical causes, the clinician should assess symptoms to determine the particular nature of the anxiety disorder(s) related to psychological causes: generalized anxiety disorder (usually pre-existing and exacerbated by illness), panic disorder (also may recur during illness in a person with previous panic symptoms), post-traumatic stress disorder (which may develop after arduous cancer treatments or may occur during cancer treatment that triggers a traumatic memory of a past frightening event), phobic disorder (phobias of needles, hospital, blood), conditioned nausea/vomiting and/or obsessive-compulsive disorder (pre-existing disorder that results in difficulty in making decisions, ruminative thoughts about illness, fearfulness to take medication). Chemotherapy induced nausea and vomiting can be managed as described in the [NCCN Antiemesis guidelines](#).

The treatment recommended for anxiety (after eliminating medical causes) is psychotherapy with or without an anxiolytic with or without an antidepressant (category 1). If the anxiety responds to initial treatment, follow-up should occur with the primary oncology team. If no response is noted, the patient should be reevaluated and treated with different medications (neuroleptic), with continued psychotherapy, support, and education. If there is still no response, then the patient should be evaluated for depression and other psychiatric comorbidity ([DIS-14](#)).

Substance abuse is rare among cancer patients who do not have a history of active abuse or addiction to opioids, alcohol or tobacco. Substance abuse or dependence developed during the course of the treatment may be due to insufficient symptom control and can be

treated by improving symptom control and management. In patients with a history of substance abuse, its impact on cancer treatment should be assessed and referral should be made to risk reduction or substance management program ([DIS-15](#) and [DIS-16](#)).

### Social Work Services

Social work services are recommended when a patient has a psychosocial or practical problem ([DIS-18](#)). Social worker evaluates the patient to determine whether the problem falls into the area of psychosocial or practical problems.

Practical problems are illness-related concerns; concrete needs (eg, housing, food, financial assistance, help with activities of daily living, transportation); employment, school, or career concerns; cultural or language issues; and caregiver availability. The guidelines outline interventions that vary according to the severity of the problem.

Psychosocial problems are adjustment to illness, family conflicts and social isolation, difficulties in decision-making, quality-of-life issues, advance directives, domestic abuse and neglect, coping or communication skills, functional changes (eg, body image, sexuality), 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 sex or grief counseling and by suggesting available local resources. For moderate-to-severe psychosocial problems, counseling and psychotherapy are used (including sex and grief counseling); community resources are mobilized; problem-solving is taught; and advocacy, education, and protective services are made available. Referral may be considered for psychosocial or psychiatric treatment.



### Pastoral Services

Many patients use their religious and spiritual resources to cope with illness, citing prayer as a major help. A study at Memorial Sloan-Kettering Cancer Center found that 65% of 300 randomly selected patients said they were either deeply or fairly religious. More than 50% of patients said religion and spirituality provided strength and comfort in coping with their illness. Another 30% said religion and spirituality were of some comfort to them. These facts suggest that a substantial number of people use religion and spirituality as a way of coping with illness.

The panel included pastoral counseling as part of psychosocial services, because the diagnosis of cancer is an existential crisis.<sup>27</sup> All patients should be referred for pastoral counseling, if their problems are spiritual or religious in nature. The panel identified 11 issues related to illness for which people often seek pastoral counseling ([DIS-19](#)) and treatment guideline is available for each of these issues: grief, concerns about death and the afterlife, conflicted or challenged belief systems, loss of faith, concerns with meaning and purpose of life, concerns about relationship with deity, isolation from the religious community, guilt, hopelessness, conflict between beliefs and recommended treatments.

The pastoral counselor evaluates the problem and may offer spiritual or philosophical reading materials, spiritual advice and guidance, prayer, and reconciliation rituals. Some patients may be referred for social work or mental health services if the problems indicate a need for more than spiritual counseling. Patients who do respond receive continued support. Patients whose concerns are not allayed may be referred for mental health evaluation while continuing to receive spiritual counseling if they wish. For patients who have significant family conflict, referral to social work may be advisable in addition to pastoral interventions. Patients who experience guilt or hopelessness may also have severe

depressive symptoms or suicidal ideation and should be evaluated by mental health professionals.

### Planning Need: Assessing the Quality of Distress Management

The panel encourages the establishment of institutional multidisciplinary committees in NCCN institutions to implement and monitor distress management ([DIS-26](#)). Multicenter trials to explore brief screening instruments, and pilot testing and comparison of instruments are needed. The clinical use of screening instruments has been reported.<sup>28-32</sup>

The panel encourages multidisciplinary CQI (continuous quality improvement) studies to assess the quality of distress management educational approaches for patients and staff to increase awareness of distress among cancer patients, and surveys of staff, patients, and families to evaluate the effect of distress-management programs as well as the efficacy of standards of care and these NCCN guidelines. The NCCN treatment guidelines are assessed annually, and evidence-based interventions are added. This process highlights the critical role of feedback for implementing, assessing, and improving standards of care and guidelines.

### Benefits of Distress Management

The panel believes that the early diagnosis and referral of patients with distress will provide several benefits: patients will experience enhanced quality of care and satisfaction; doctor-patient communication will be improved; trust and respect will be increased; and patients' adherence to treatment recommendations will improve. A randomized study conducted by the Mayo Clinic cancer center, evaluated the effectiveness of multidisciplinary intervention on the overall quality of life (QOL) in patients undergoing radiation therapy for advanced stage cancer.<sup>33</sup> Patients who were assigned to an eight-session structured

multidisciplinary intervention maintained and improved their QOL during treatment. In patients assigned to standard care as control, there was a significant decrease in their QOL. Additionally, the early diagnosis and treatment of distressed patients will save staff time, because fewer telephone calls and follow-up visits will occur (which would otherwise be prompted by patients' undiagnosed anxieties).

## Summary

In the NCCN Distress Management Guideline, the evaluation and treatment model recommends that each new patient be rapidly assessed in the office or clinic waiting room for evidence of distress using a brief screening tool (Distress Thermometer and Problem List) ([DIS-A](#)).<sup>34</sup> A score of 4 or greater on the Distress Thermometer should trigger further evaluation and referral to a psychosocial service. The choice of which service should be determined by 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 (excessive sadness, worry, nervousness) should be referred to mental health professionals, and spiritual concerns should be referred to pastoral counselors.

The primary oncology team members (oncologist, nurse, and social worker) are central to making this model work. Team members look at the score on the Distress Thermometer and the items checked on the Problem List as the first stage of screening. The nurse will follow with further questions as a second stage of screening. It is critical for at least one team member to be familiar with the mental health, psychosocial, and pastoral counseling resources available in the institution and the community. A list of the names and phone numbers for these resources should be kept in all oncology clinics and updated frequently.

The panel has the following recommendations for the implementation of the guidelines.

- encourage the establishment of a multidisciplinary committee in each institution for implementing and monitoring the use of these guidelines.
- conduct multicenter trials that explore brief screening instruments and treatment guidelines.
- encourage institutional CQI studies to evaluate distress management programs.
- develop educational programs about distress management for medical staff, patients and family.

The standard of care should be revised and modified so that they are compatible with the clinical care offered at each institution. The medical staff should be made aware of the resources available to treat distress. It is important to have access to mental health professionals and clergy who are trained to deal with cancer-related distress. The benefits of treating distress in cancer accrue to the patients and their families, the treating staff, and improve efficiencies in clinic operations. Education of patients and families is equally important to encourage them to recognize that control of their distress is an integral part of cancer care.

Health care contracts often allow these services to “fall through the cracks” by failing to reimburse for them through either behavioral health or medical insurance. Reimbursement for services to treat psychosocial distress must be included in medical health care contracts to prevent fragmentation of services for the medically ill. For patients with cancer, integration (not separation) of mental health services and medical services is critically important. Outcomes research studies that include quality-of-life assessment and analysis of cost-effectiveness are also needed. Patients and families should be informed that management of distress is part of their total medical care. Spirituality and religion also play an important role for many patients with cancer in coping with the

diagnosis and the illness. Pastoral services should be an integral part of psychosocial services for such patients.

Finally, the multidisciplinary committee must be responsible for evaluation of standard care in distress management ([DIS-27](#)), with CQI studies. Presently, the quality of the psychological care that patients receive is not routinely monitored. Accrediting bodies have not directly examined the quality of psychosocial care nor have they established minimal performance standards for its delivery. The panel believes that psychosocial care should and will eventually be on our institution's report cards.

### **Disclosures for the NCCN Distress Management Guideline Panel**

At the beginning of each panel meeting to develop NCCN guidelines, panel members disclosed financial support they have received in the form of research support, advisory committee membership, or speakers' bureau participation. Members of the panel indicated that they have received support from the following: Abbott-Ross, Celgene, Eli Lilly, GlaxoSmithKline, Pfizer, PharmAdura and Purdue Pharma. Some panel members do not accept any support from industry. The panel did not regard any potential conflicts of interest as sufficient reason to disallow participation in panel deliberations by any member.

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