



Clinical Practice Guidelines in Oncology – v.2.2005

Palliative Care

Version 2.2005

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](http://nccn.org/clinical_trials/physician.html)

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

See [NCCN Categories of Consensus](#)

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PALLIATIVE CARE OVERVIEW

SCREENING^{a,b}

ASSESSMENT

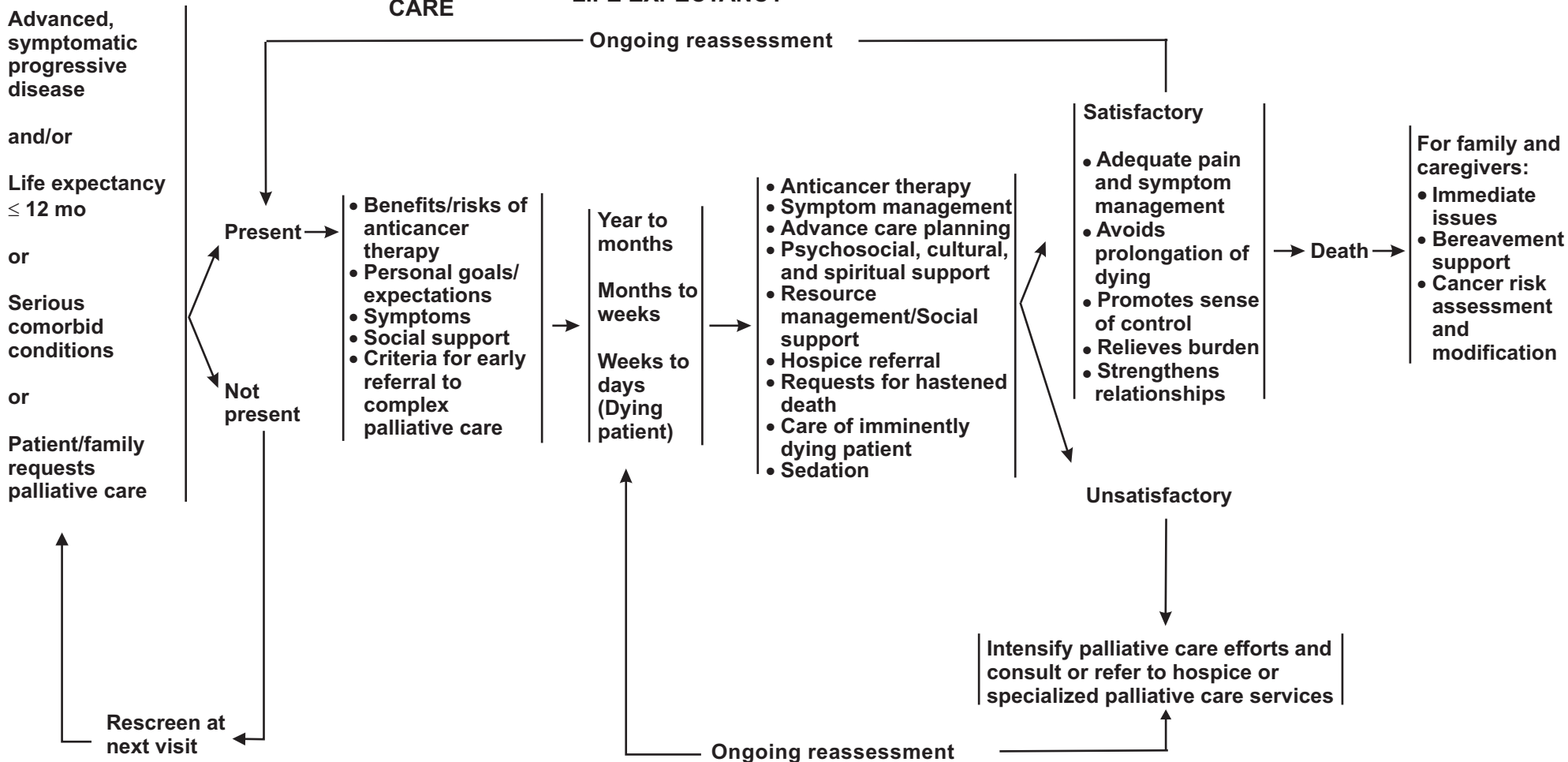
PALLIATIVE CARE INTERVENTIONS^b

REASSESSMENT

AFTER DEATH CARE

PALLIATIVE CARE

LIFE EXPECTANCY



^aManagement of any patient with positive screening requires a care plan developed by a multidisciplinary team of physicians, nurses, mental health professionals, and chaplains.

^bOncologists should integrate palliative care into general oncology care for patients who meet screening criteria.

Consultation/collaboration with a palliative care specialist/hospice team is recommended for patients with more complex issues.

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[Palliative Care Assessment \(PAL-2\)](#)

SCREENING^{a,b}

Advanced, symptomatic progressive Stage III or IV disease or any patient for whom best supportive care is recommended ([See NCCN disease specific guidelines](#))

and/or

Life expectancy ≤ 12 mo

Indicators include:

Performance status

ECOG ≥ 3 or KPS ≤ 50

▶ Poor prognostic signs

- * Hypercalcemia
- * Brain or cerebrospinal fluid metastasis
- * Superior vena cava syndrome
- * Spinal cord compression
- * Cachexia
- * Malignant effusions
- * Bilirubin ≥ 2.5
- * Creatinine ≥ 3

or

Serious comorbid conditions

or

Patient/family requests palliative care

Present →

Not present

Rescreen at next visit

ASSESSMENT

Perform full palliative care assessment:

- Benefits and risks of anticancer therapy
- Personal goals and expectations

→ [See PAL-3](#)

- Symptom management
- Advance care planning
- Resource management/Social support

→ [See PAL-4](#)

- Criteria for early referral to complex palliative care

→ [See PAL-5](#)

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PALLIATIVE CARE ASSESSMENT

Benefits and risks of anticancer therapy →

- Natural history of specific tumor
- Potential for response to further treatment
- Impairment of vital organs
- Performance status
- Serious comorbid conditions

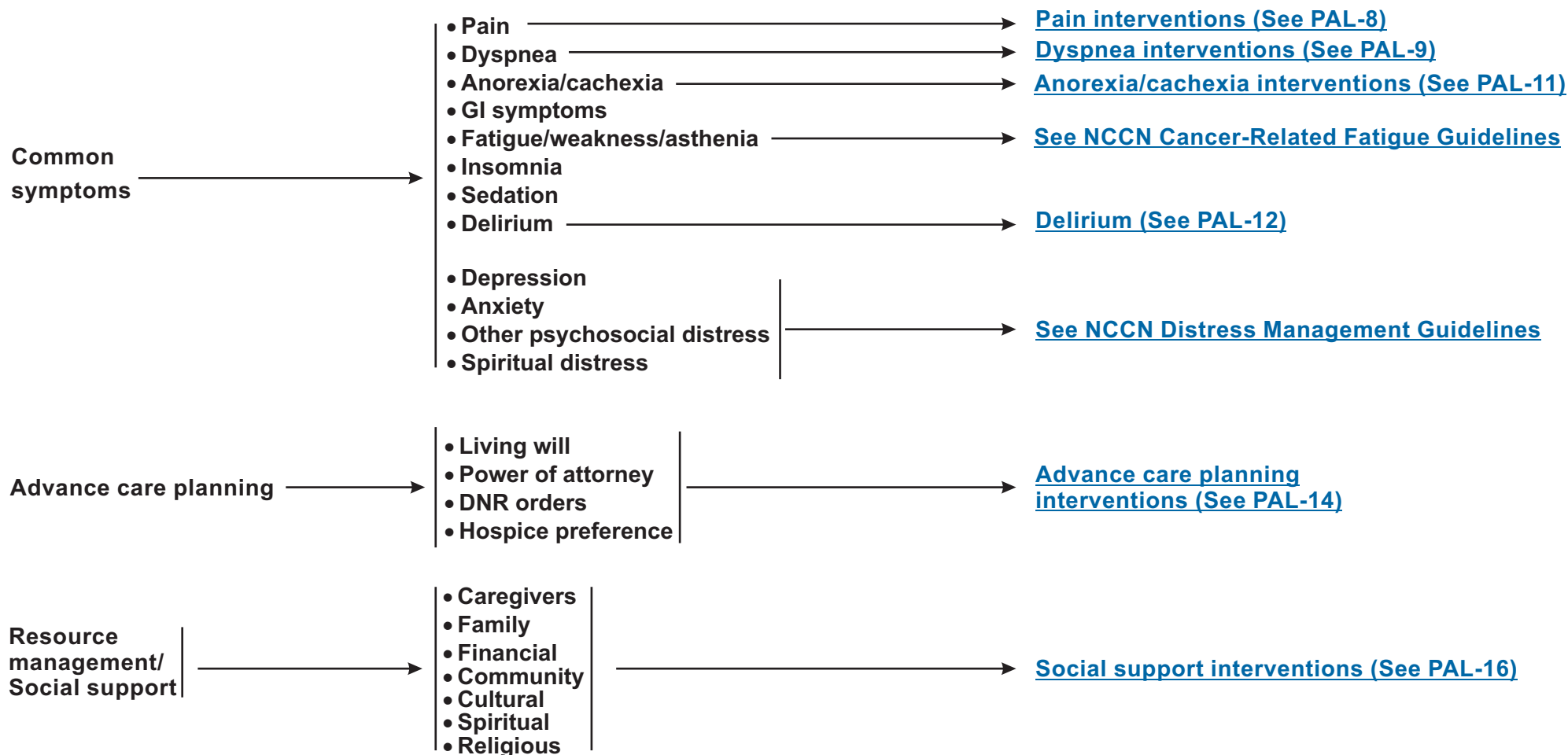
→ [Interventions \(See PAL-6\)](#)

Patient and family goals and expectations →

- Patient
- Family
- Priorities for palliative care
 - Goals of anticancer therapy
 - Quality of life
 - * Spiritual
 - * Religious
 - * Cultural
- Readiness to accept hospice

→ [Interventions \(See PAL-7\)](#)[Symptom management \(See PAL-4\)](#)[Advance care planning \(See PAL-4\)](#)[Resource management/Social support \(See PAL-4\)](#)[Early referral for complex palliative care \(See PAL-5\)](#)**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.

PALLIATIVE CARE ASSESSMENT



[Benefits and risks of anticancer therapy \(See PAL-3\)](#)

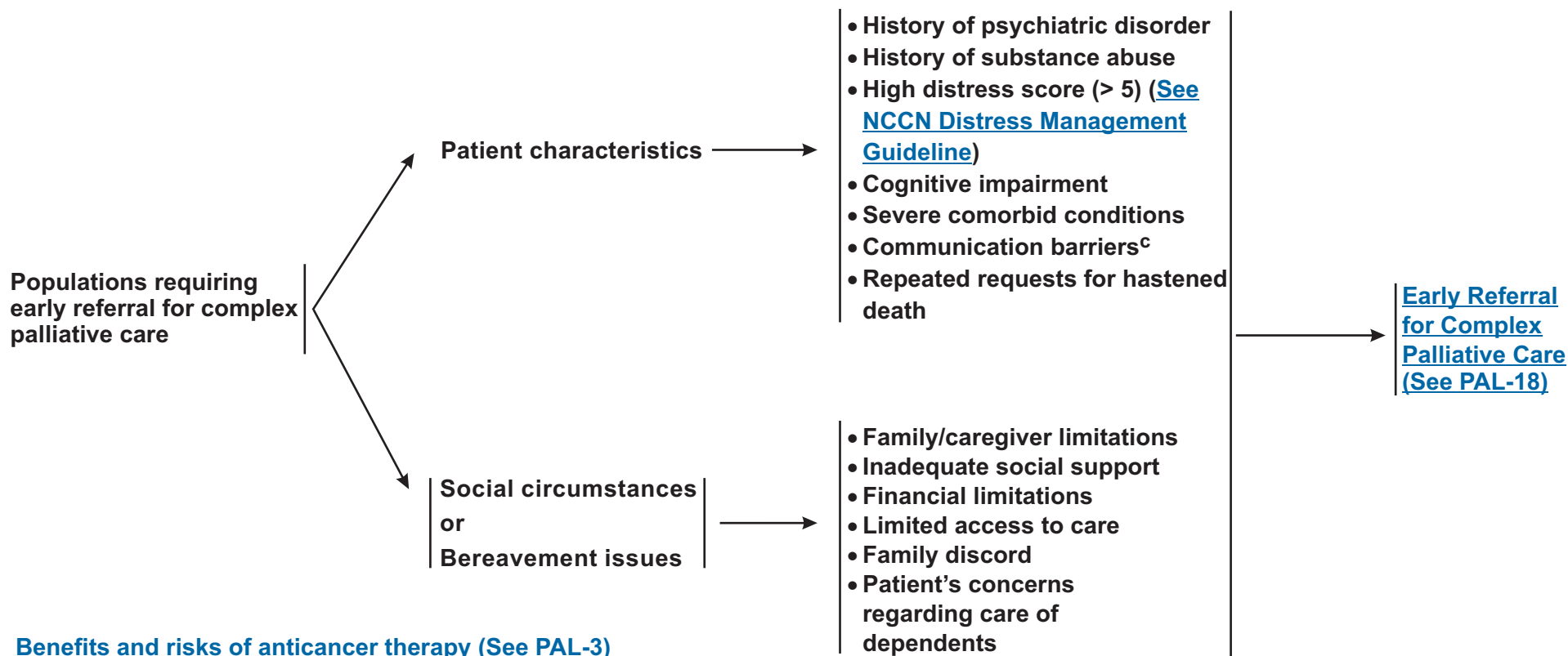
[Patient and family goals and expectations \(See PAL-3\)](#)

[Early referral for complex palliative care \(See PAL-5\)](#)

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PATIENT CARE ASSESSMENT



[Benefits and risks of anticancer therapy \(See PAL-3\)](#)

[Patient and family goals and expectations \(See PAL-3\)](#)

[Symptom management \(See PAL-4\)](#)

[Advance care planning \(See PAL-4\)](#)

[Social support \(See PAL-4\)](#)

^cCommunication barriers include language, literacy, and physical barriers.

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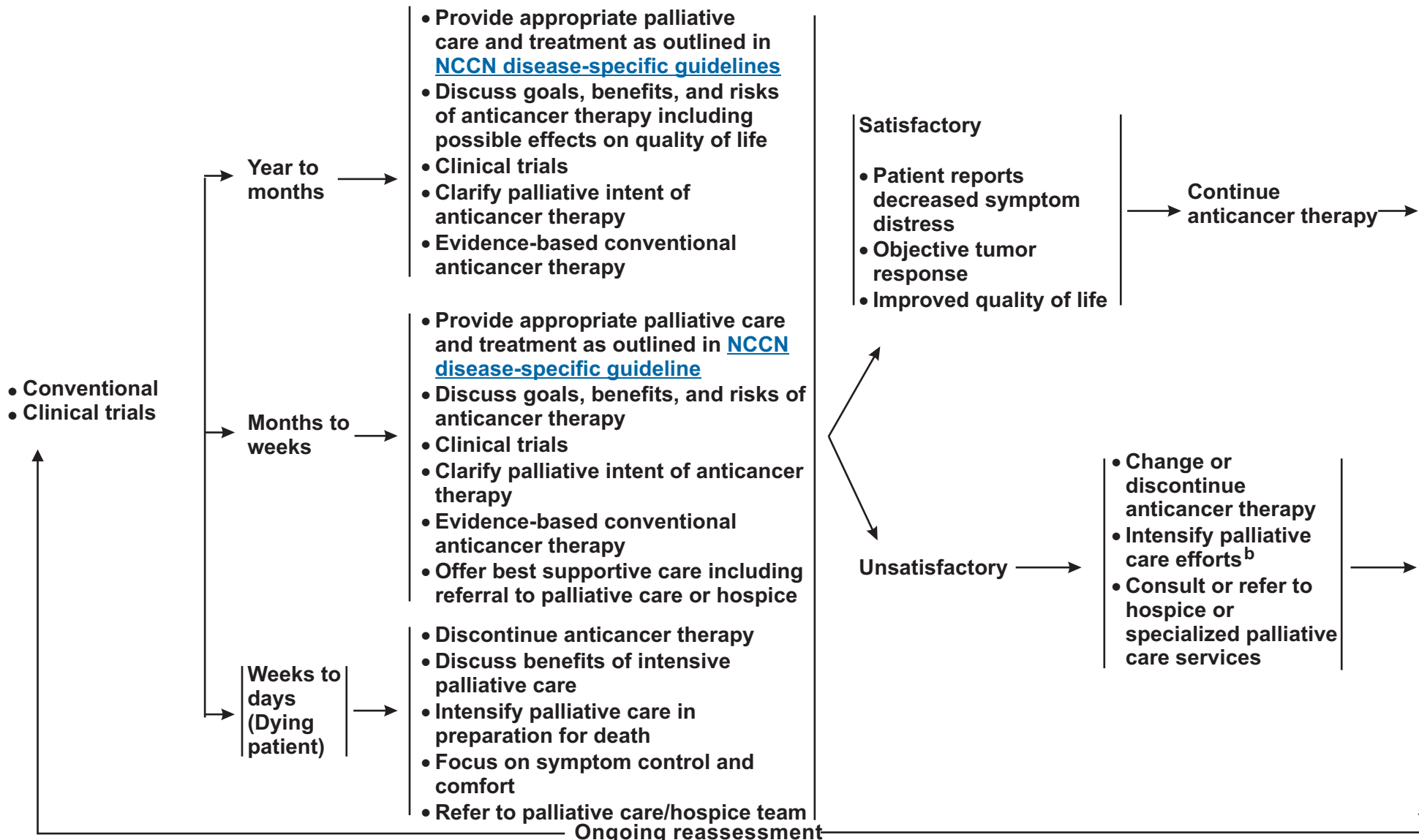
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ANTICANCER THERAPY

ESTIMATED LIFE EXPECTANCY

INTERVENTION

REASSESSMENT



Ongoing reassessment

^bOncologists should integrate palliative care into general oncology care for patients who meet screening criteria.

Consultation/collaboration with a palliative care specialist/hospice team is recommended for patients with more complex issues.

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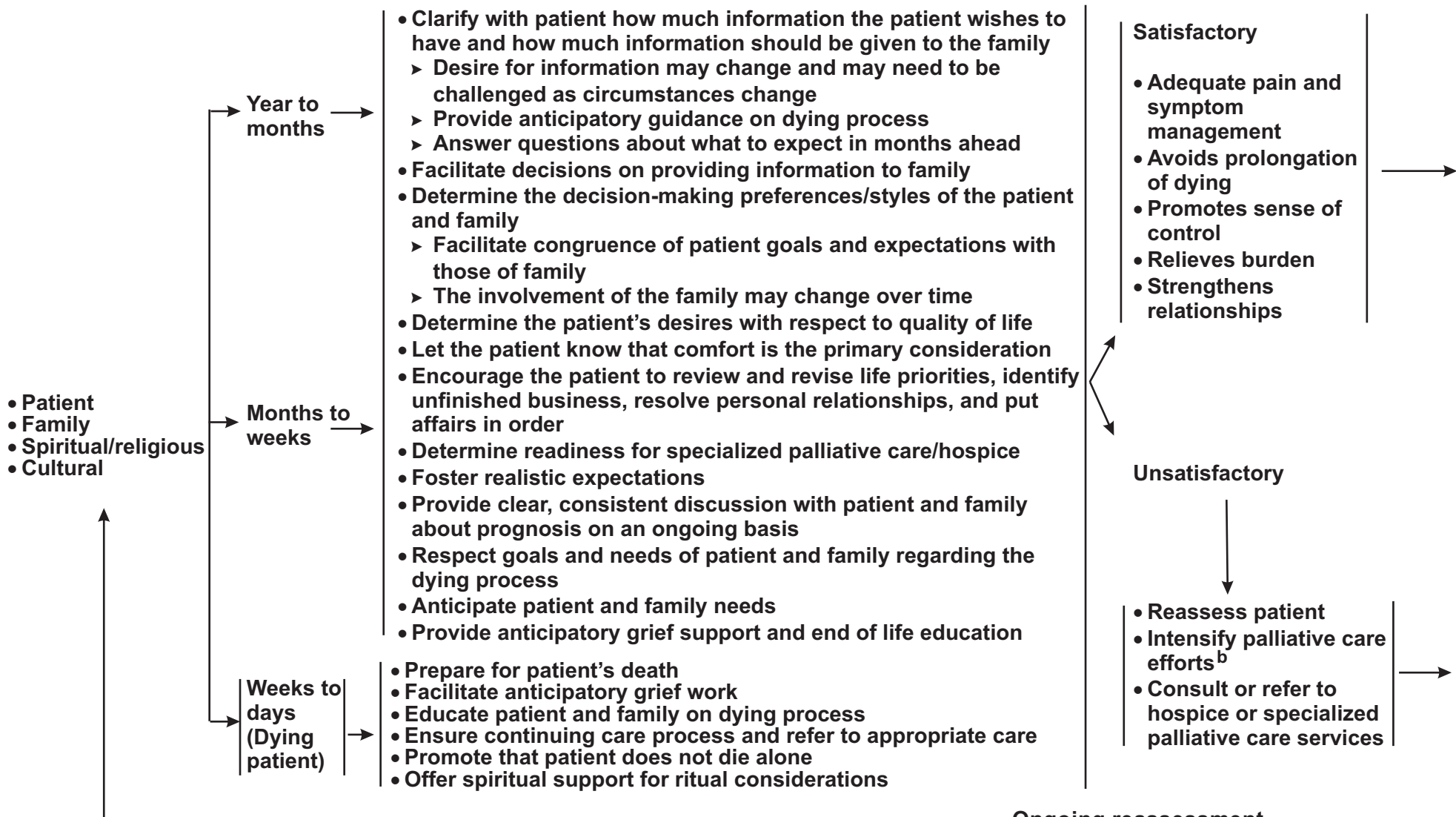
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GOALS AND EXPECTATIONS

ESTIMATED LIFE EXPECTANCY

INTERVENTION

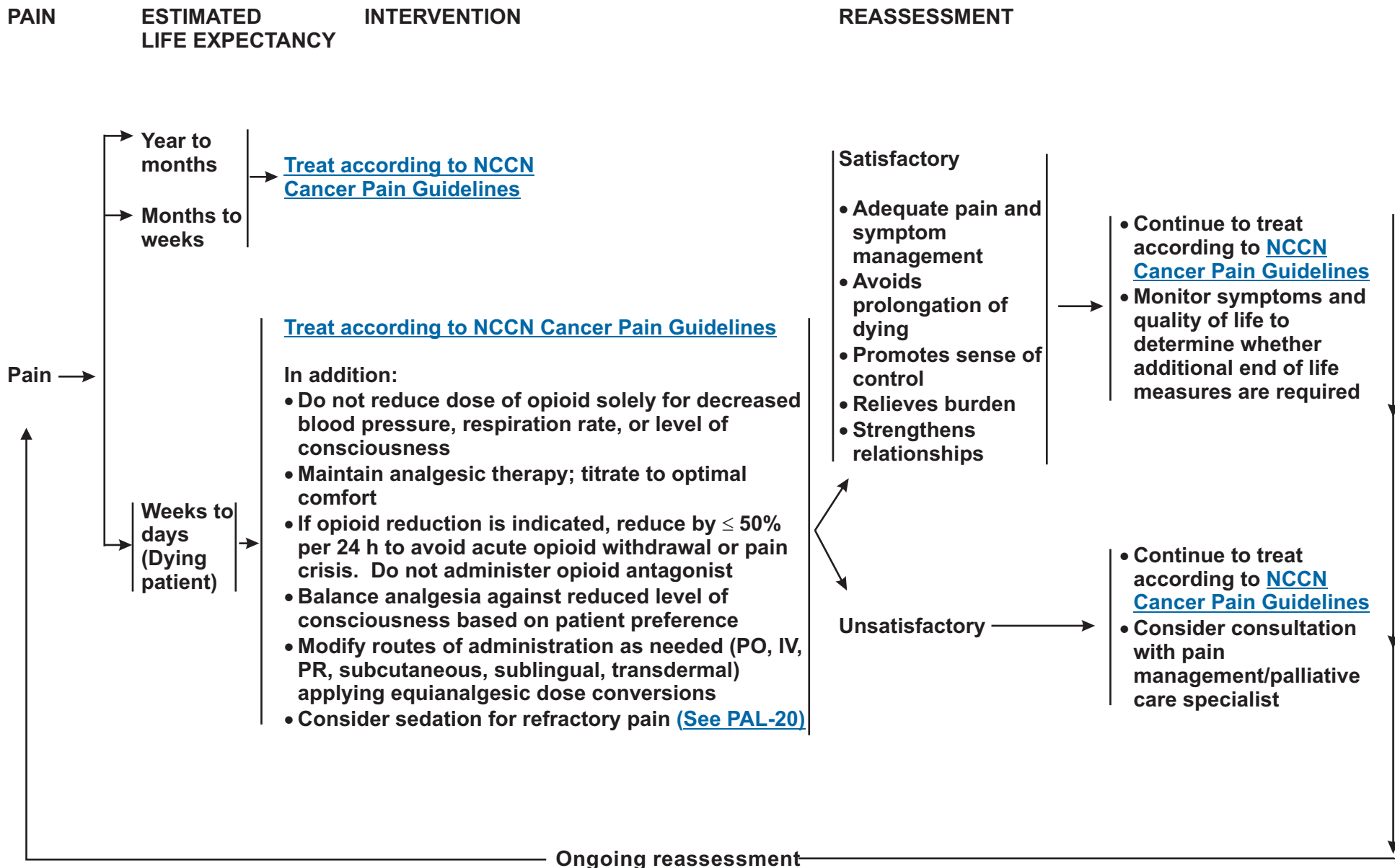
REASSESSMENT



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[See Advance Care Planning \(PAL-14\)](#)



[See Special Palliative Care Interventions: Imminently Dying Patient \(PAL-20\)](#)

[See List of Symptoms in Palliative Care Table of Contents](#)

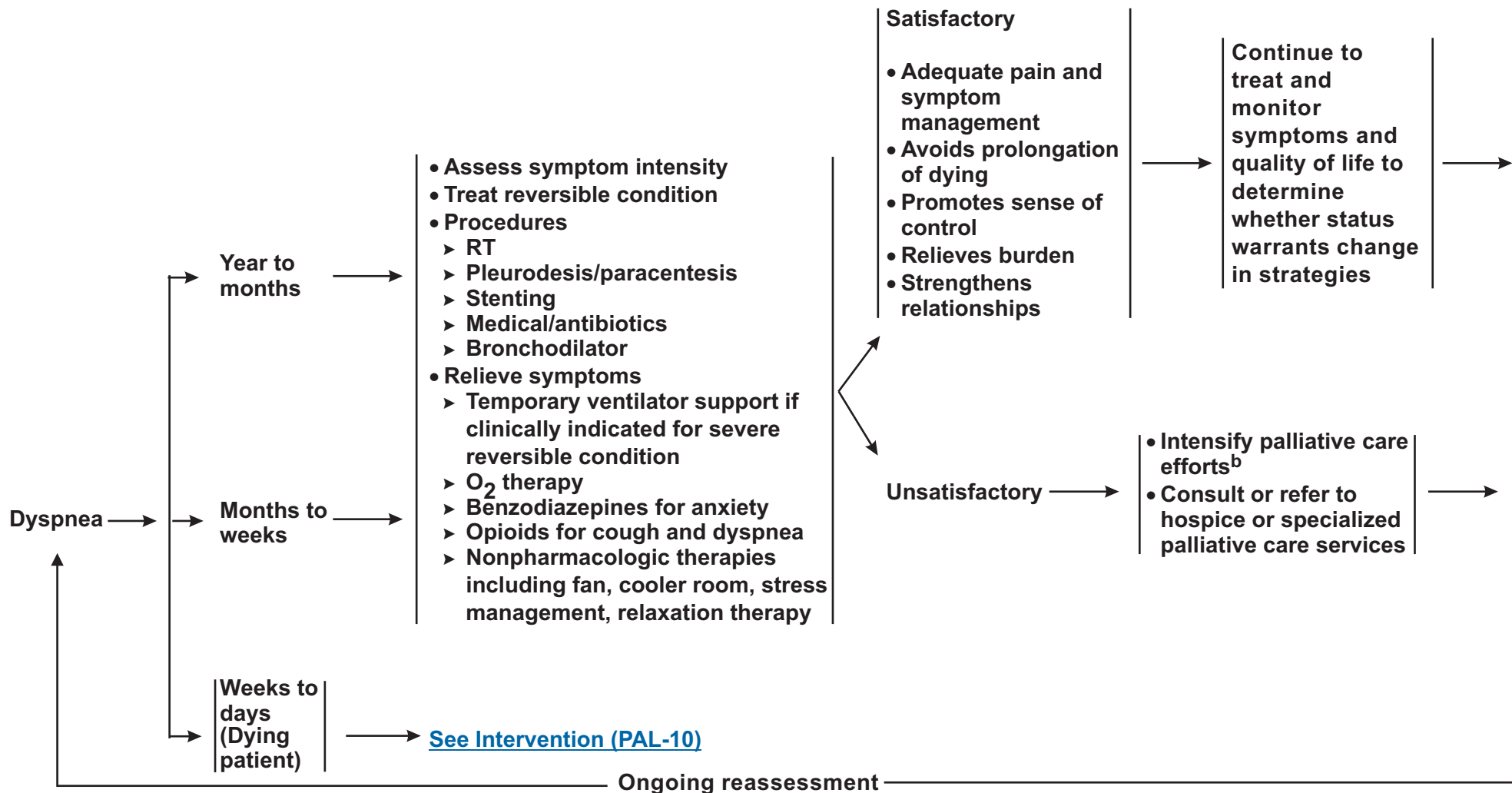
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DYSPNEA

**ESTIMATED
LIFE EXPECTANCY**

INTERVENTION

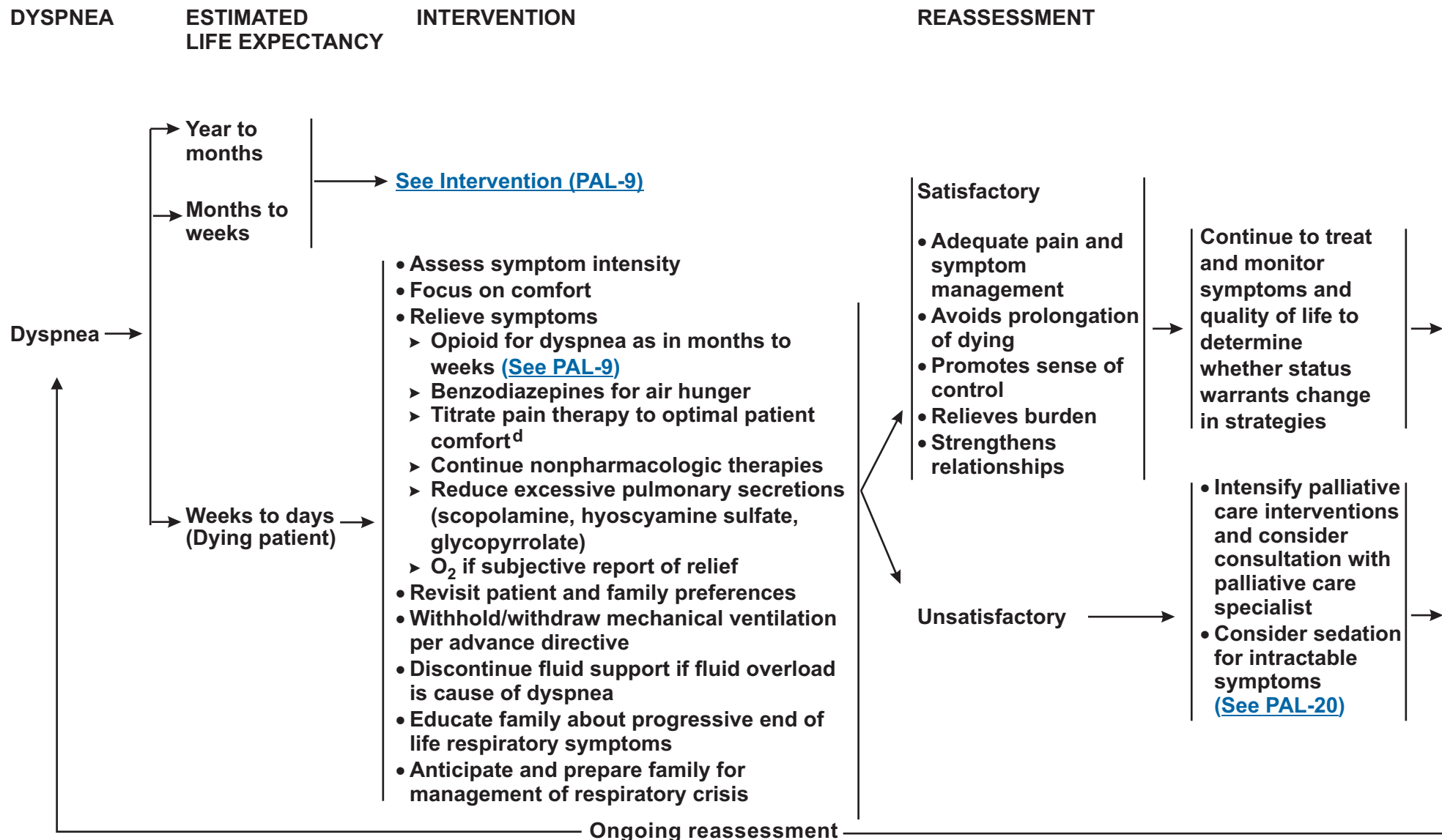
REASSESSMENT



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[See List of Symptoms in Palliative Care Table of Contents](#)

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^dFor further dose titration and alternate routes of administration see the [NCCN Cancer Pain Guidelines](#).

[See Special Palliative Care Interventions: Imminently Dying Patient \(PAL-20\)](#)

[See List of Symptoms in Palliative Care Table of Contents](#)

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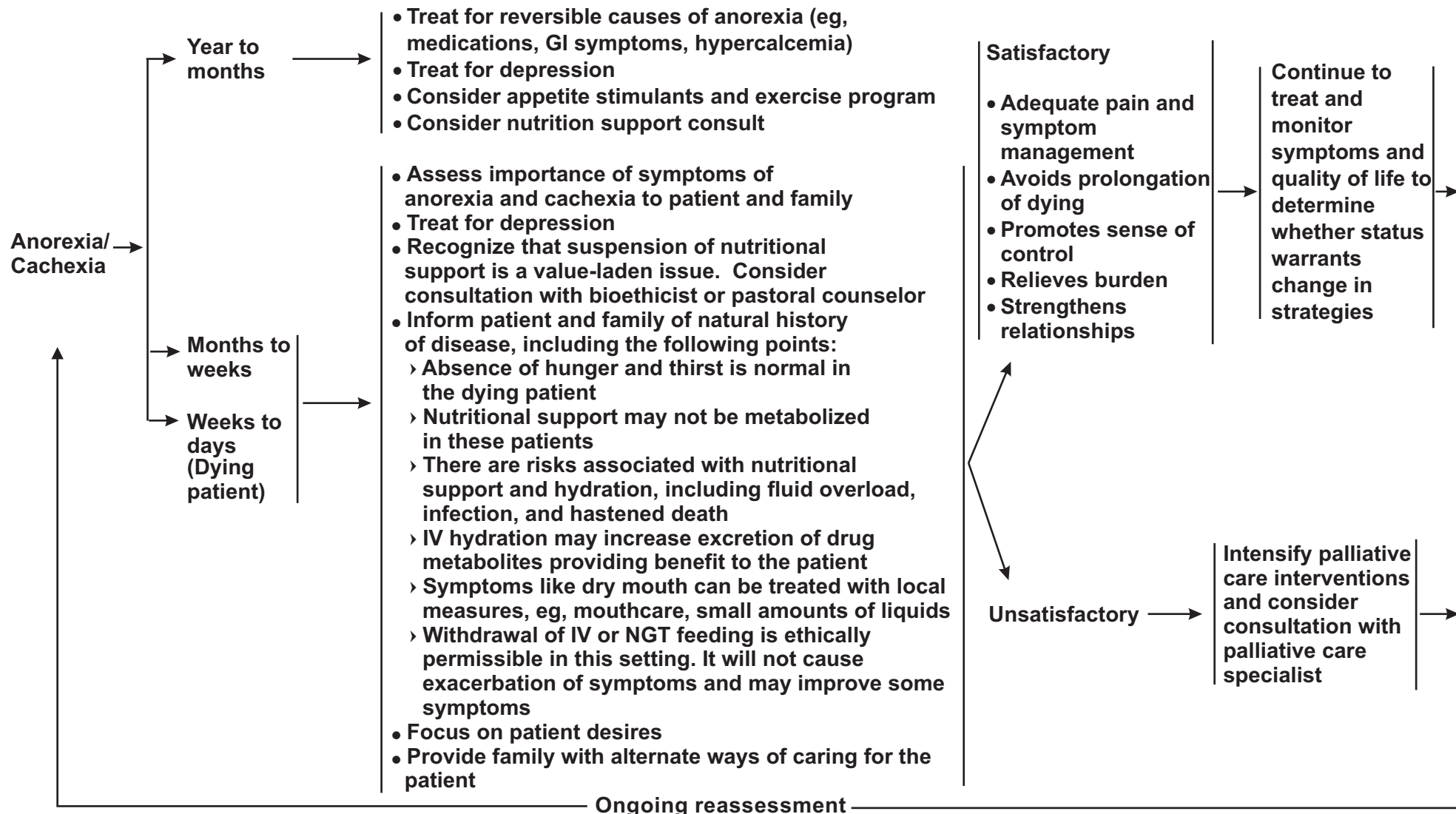
Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

**ANOREXIA/
CACHEXIA**

**ESTIMATED
LIFE EXPECTANCY**

INTERVENTION

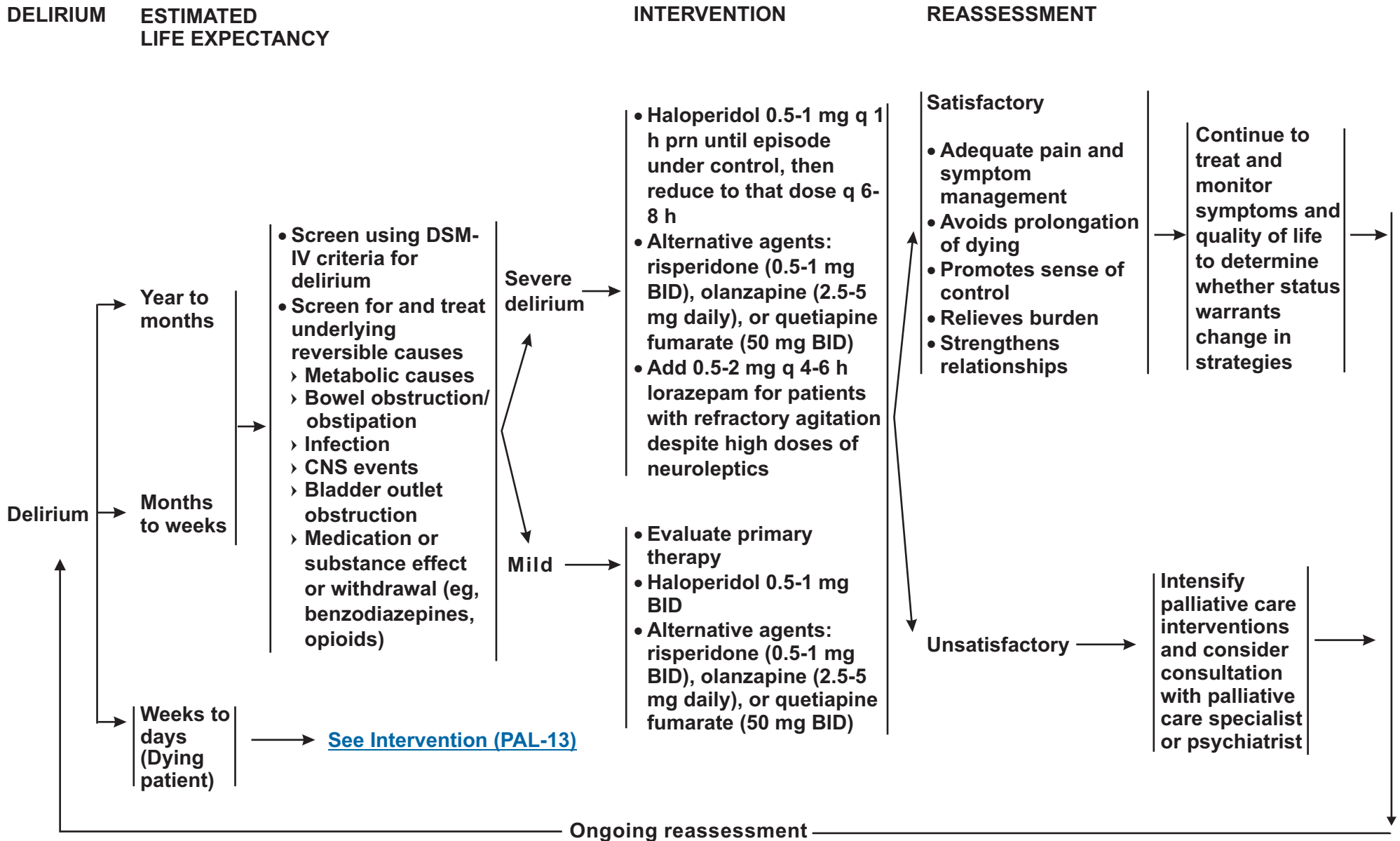
REASSESSMENT



[See Special Palliative Care Interventions: Imminently Dying Patient \(PAL-20\)](#)

[See List of Symptoms in Palliative Care Table of Contents](#)

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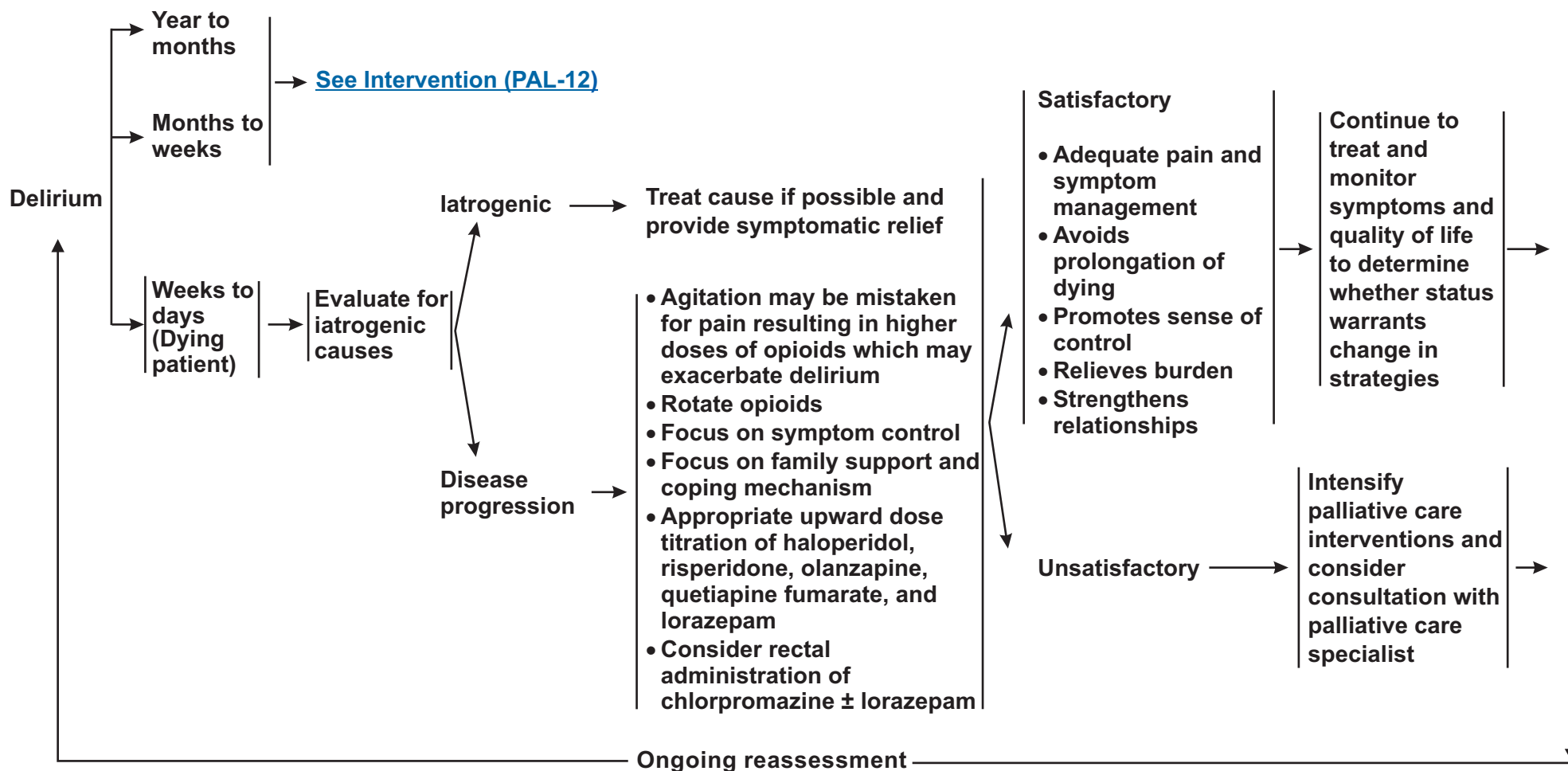
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DELIRIUM

**ESTIMATED
LIFE EXPECTANCY**

INTERVENTION

REASSESSMENT



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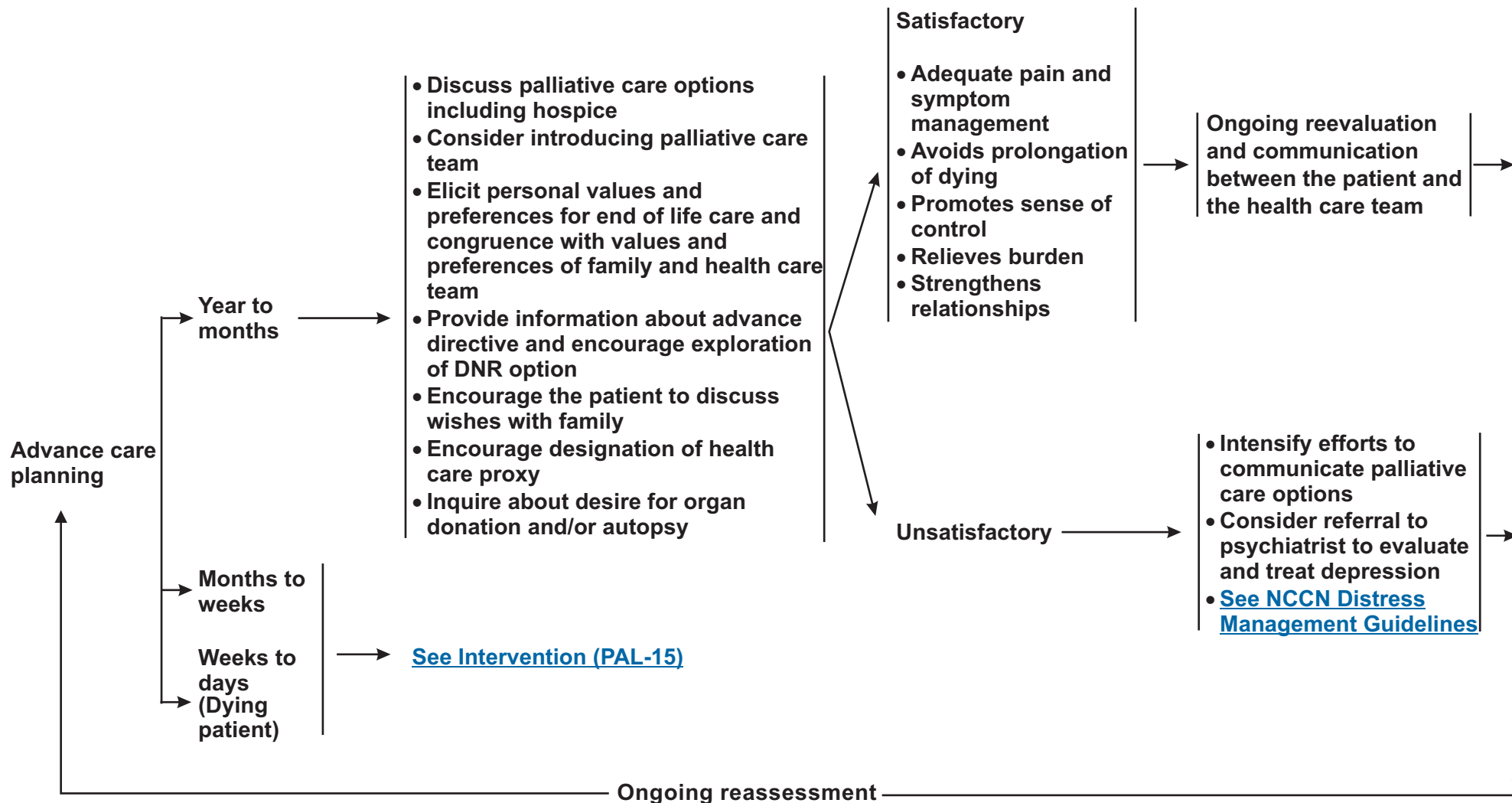
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**ADVANCE
CARE
PLANNING**

**ESTIMATED
LIFE EXPECTANCY**

INTERVENTION

REASSESSMENT



[See List of Symptoms in Palliative Care Table of Contents](#)

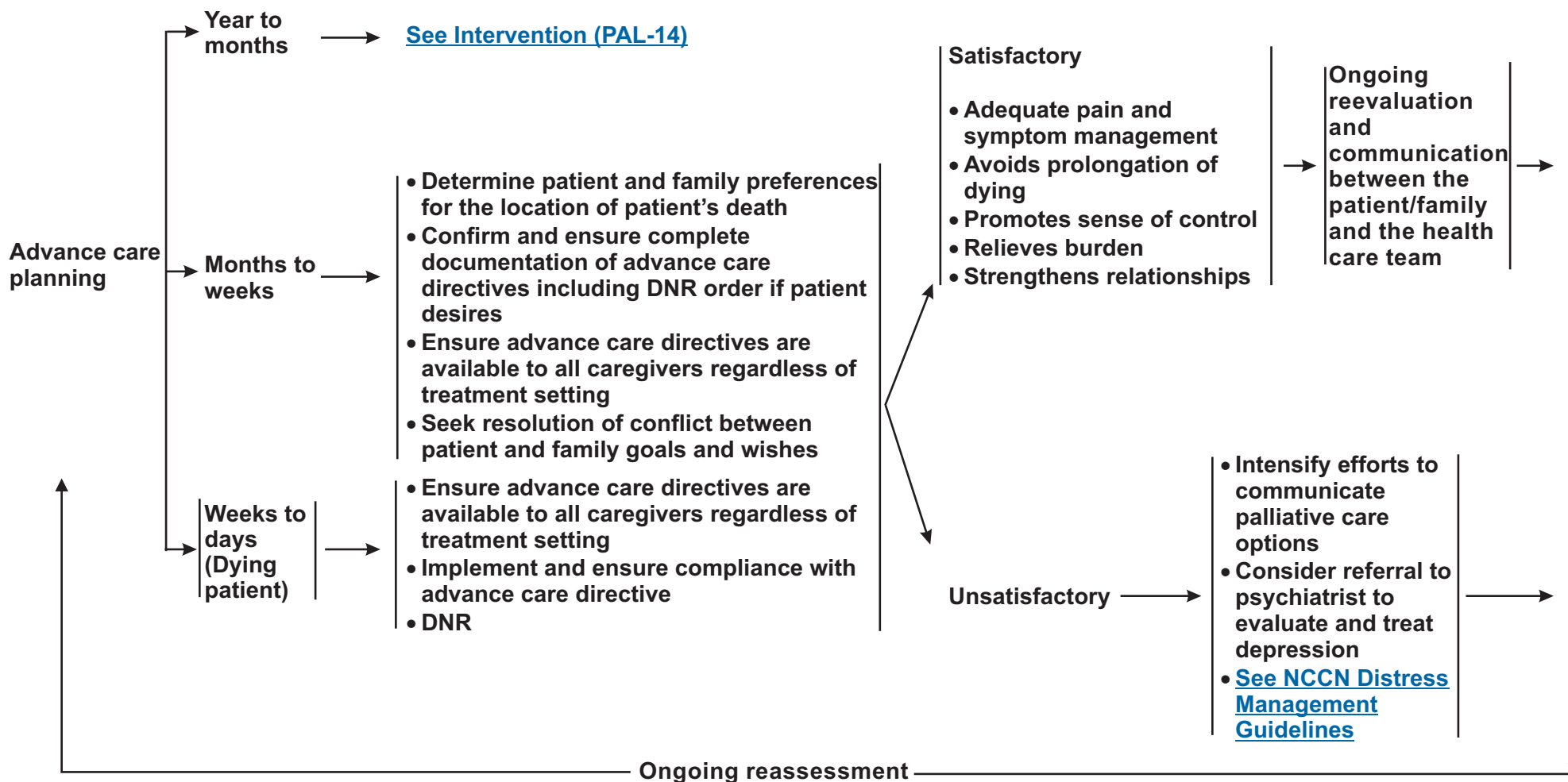
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**ADVANCE
CARE
PLANNING**

**ESTIMATED
LIFE EXPECTANCY**

INTERVENTION

REASSESSMENT



[See Special Palliative Care Interventions: Imminently Dying Patient \(PAL-20\)](#)

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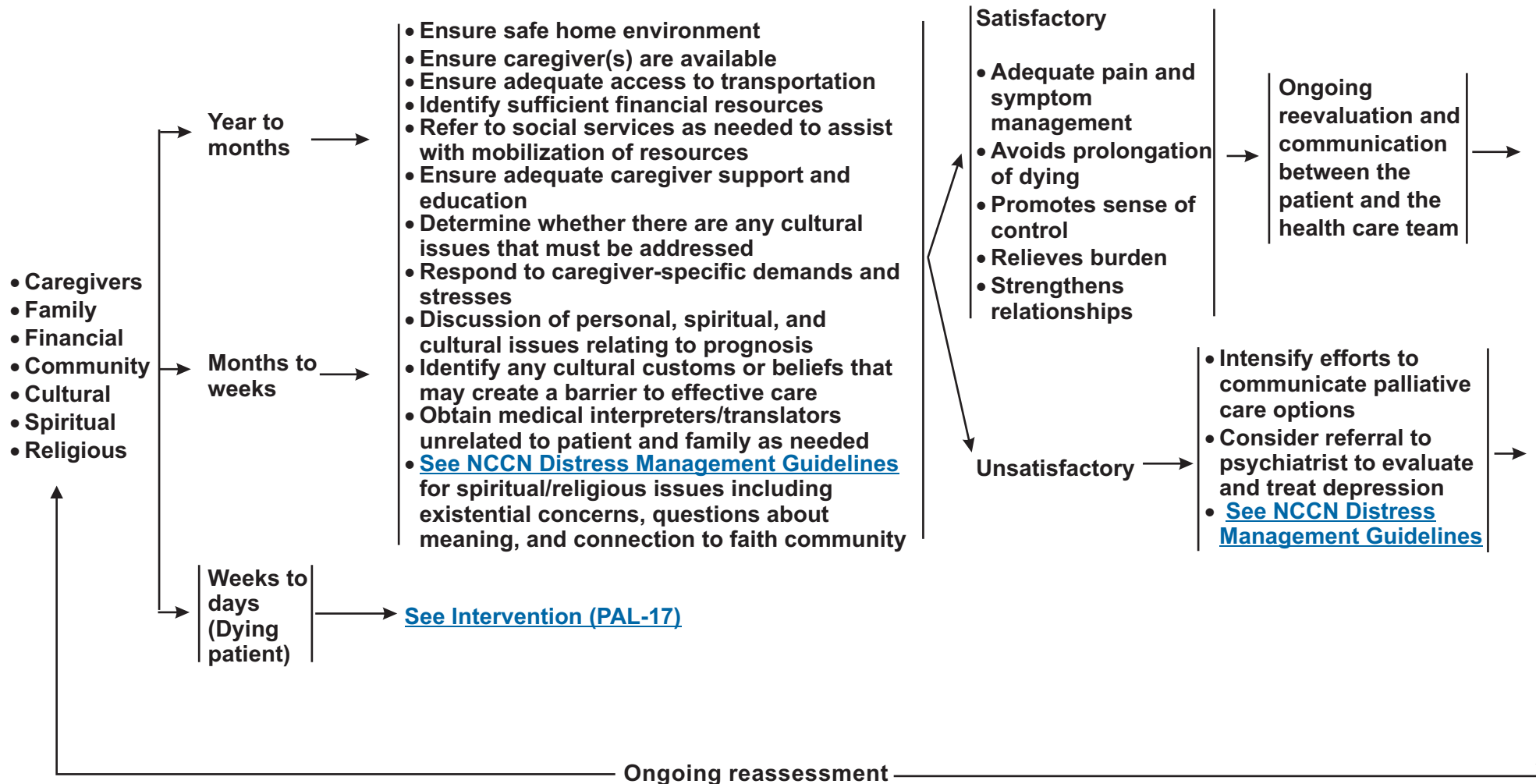
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RESOURCE
MANAGEMENT/
SOCIAL
SUPPORT

ESTIMATED
LIFE EXPECTANCY

INTERVENTION

REASSESSMENT



[See List of Symptoms in Palliative Care Table of Contents](#)

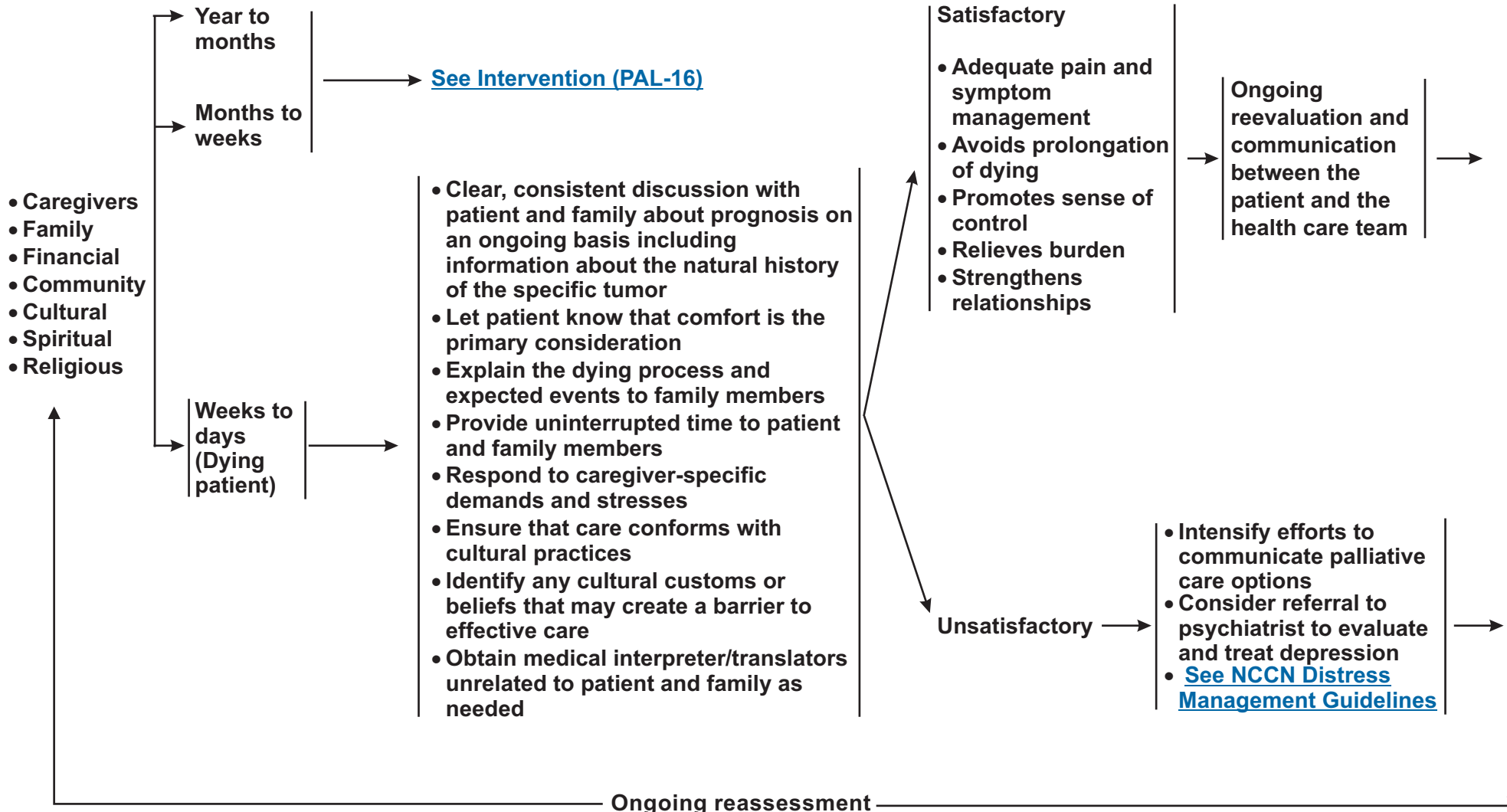
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**RESOURCE MANAGEMENT/
SOCIAL SUPPORT**

ESTIMATED LIFE EXPECTANCY

INTERVENTION

REASSESSMENT



[See Special Palliative Care Interventions: Imminently Dying Patient \(PAL-20\)](#)

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CRITERIA FOR EARLY REFERRAL FOR COMPLEX PALLIATIVE CARE

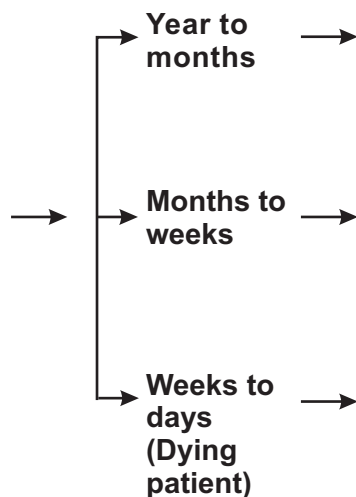
ESTIMATED LIFE EXPECTANCY

INTERVENTION

REASSESSMENT

Patient specific

- History of psychiatric disorder
- History of substance abuse
- High distress score (>5) ([See NCCN Distress Management Guideline](#))
- Cognitive impairment
- Severe comorbid conditions
- Communication barriers
- Repeated requests for hastened death
- Social circumstances
- Caregiver limitations
- Inadequate social support
- Financial limitations
- Limited access to care
- Family discord
- Young children in family



- Early referral to palliative care specialist/team
- Collaborate with other physicians treating the patient
- Refer to appropriate health care professionals
 - Mental health
 - Social services
 - Health care interpreters
 - Others
- Rally community support
 - Religious
 - School
 - Community agencies
- Expedite referral to hospice team when appropriate

Satisfactory

- Adequate pain and symptom management
- Avoids prolongation of dying
- Promotes sense of control
- Relieves burden
- Strengthens relationships

Ongoing reevaluation and communication between the patient and the health care team

Unsatisfactory

- Intensify efforts to communicate palliative care options
- Consider referral to psychiatrist to evaluate and treat depression
- [See NCCN Distress Management Guidelines](#)

Ongoing reassessment

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SPECIAL PALLIATIVE CARE INTERVENTIONS**Response to Requests for Hastened Death (physician-assisted suicide, active euthanasia)**

The NCCN Palliative Care Task Force believes that the most appropriate response to a request for assistance in suicide is to intensify palliative care. However, evaluating a patient's request for physician-assisted suicide is an important skill, even for clinicians who feel this practice is never morally acceptable. A request for hastened death often has important meanings that require exploration. Clarifying these meanings can sometimes enlarge the range of useful therapeutic options aside from providing a lethal prescription.

- Address the request explicitly. If a patient uses a euphemism for death or refers to it indirectly, ask for clarification. Do not assume that a wish for death to come soon is a wish for a lethal prescription.
- Explore the reasons for the request, and find out "why now?"
- Distinguish wishing not to live in their current state from wishing to be killed.
- Reassess symptom control.
- Reassess psychological/psychiatric issues, especially depression, anxiety, grief, psychosis, and delirium.
- Ask about the patient's relationship to family or other important people.
- Ask about individual values and personal views of suffering.
- Offer to explain the dying process.
- Include information about natural history of the disease and dying.
- Address the role of medical caregivers, including hospice if appropriate.
- Discuss alternatives to physician-assisted suicide, treatment withdrawal if appropriate, not eating or drinking if appropriate, and/or sedation for refractory symptoms.
- Request psychiatry consult to rule out reversible causes of psychological suffering.

Know the local legal status of hastened death. Some patients may be confused about legal/ethical distinctions; treatment withdrawal and aggressive treatments for symptoms, such as pain, are not physician-assisted suicide. Hastened death is only legal in Oregon and has specific guidelines. Euthanasia is not legal in any state in the USA.

Examine your own response as a clinician to this particular patient's request. Requests for hastened death can force clinicians to confront their own personal, professional, moral, and legal responsibilities. Dealing with an individual patient can be quite different from thinking about the issue in abstract circumstances. Consider consultation with an Ethics Committee, Palliative Care Service, or experienced colleague. These cases are usually complex and often benefit from consideration of multiple perspectives.

Clarify the care plan. Requests for hastened death should prompt ongoing discussion and active attempts to ameliorate physical, psychological, and spiritual distress. Reemphasize your own commitment to providing continuing care for the patient.

Maintain medications for symptom control.

[See Special Palliative Care Interventions: Imminently Dying Patient \(PAL-20\)](#)

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SPECIAL PALLIATIVE CARE INTERVENTIONS

Imminently dying patient

- Ensure ongoing staff assessment.
- Try to ensure privacy; private room if possible.
- Discontinue diagnostic tests.
- Reposition for comfort as appropriate.
- Avoid unnecessary needle sticks.
- Provide mouth care, (eg, hydrogen peroxide/water solution, KY jelly.)
- Treat for urinary retention and fecal impaction.
- Ensure access to medication even when oral route is not available.
- Allow patient and family uninterrupted time together.
- Ensure the family understands and is supported through the dying process.
- Encourage visits by children if consistent with family values.
- Facilitate around-the-clock family presence.
- Ensure that caregivers understand and will honor advance directives.
- Provide respectful space for families.
- Facilitate closure.

Sedation

- Consider consult from pain/palliative care team.
- Use sedation for control of refractory symptoms in patients who are imminently dying.
- Studies indicate that sedation at the end of life does not significantly hasten death.
- Effective sedation can be achieved through the skilled, judicious use of a variety of medications including:
 - › Opioids
 - › Benzodiazepines
 - › Barbiturates
 - › Propofol
 - › Neuroleptics

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[See After Death
Care \(PAL-21\)](#)

PALLIATIVE CARE OUTCOMES

AFTER DEATH CARE

A “good death”:

Patient:

- Adequate symptom management
- Avoided prolongation of dying
- Promoted a sense of control
- Relieved burden
- Strengthened relationships

Family and Caregiver:

- Respected values and preferences

→ Death →

For family and caregivers:

- Immediate issues for doctor and team
 - › Remove implanted devices
 - › Ensure culturally sensitive, respectful treatment of the body
 - › Provide family time with the body
 - › Address survivor concerns about organ donation and/or autopsy
 - › Facilitate funeral arrangements
 - › File death certificate; complete necessary forms
 - › Inform other health care providers of patient’s death
- Bereavement support
 - › Formally express condolences on patient’s death
 - › Refer to appropriate bereavement services within the institution or in the community
 - › Attend debriefing meeting with family if family desires one
- Discuss cancer risk assessment and modification with family members

For staff

- Provide staff support

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Summary of Guidelines Updates

Highlights of major changes in the 2005 version of the Palliative Care guidelines from the 2004 version include:

- Other psychosocial distress and spiritual distress were added as common symptoms ([PAL-4](#)).
- Clinical trials were added as an intervention for life expectancies of one year to months. Offering best supportive care including referral to palliative care or hospice was added for months to weeks ([PAL-6](#)).
- Opioids for relief of dyspnea was added ([PAL-9](#)).
- Consideration of appetite stimulants and exercise programs were added as interventions in those with one year to months life expectancy ([PAL-11](#)).
- Metabolic causes, infection, CNS events, and effects of substances were added as possible underlying causes of delirium ([PAL-12](#)).
- Alternative agents like risperidone, olanzapine and quetiapine fumarate were added as interventions for mild delirium ([PAL-12](#)).
- Olanzapine was added as an intervention for delirium after disease progression ([PAL-13](#)).
- Consideration for referral to a psychiatrist to evaluate for depression was added for an unsatisfactory reassessment ([PAL 14-18](#)).
- Reassessment of psychiatric issues was added as a special palliative care intervention. Psychosis and delirium were added as specific examples ([PAL-19](#)).
- Propofol and neuroleptics were added to the list of sedation medications ([PAL-20](#)).

Manuscript

NCCN Categories of 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

The aim of the NCCN Palliative Care Guidelines is to provide the best quality of life that is possible for each cancer patient. The Palliative Care Guidelines Panel (an interdisciplinary panel of representatives from NCCN member institutions) includes medical and surgical oncologists, neurologists, anesthesiologists, psychiatrists, internists, palliative care specialists, pastoral care counselors, social workers, and nurses. The NCCN Palliative Care Guidelines were developed from the collaborative efforts of these experts based on their clinical experience and available scientific evidence.

Palliative Oncology

During the past 20 years, increasing attention has been paid to quality-of-life issues in oncology.¹⁻⁴ Statistics reveal that 50% of

patients diagnosed with cancer will die of their disease.^{5,6} More than 85% of patients with advanced disease requiring systemic chemotherapy will die of their disease. As the hospice movement has grown in this country, palliative care has developed into an integral part of (rather than the antithesis of) comprehensive cancer care.⁵⁻⁹ Although 50% of the cancer patients who die each year in this country receive hospice care, most patients are referred too late for comprehensive palliative care to exert its full benefit. Too many patients are never referred at all. In addition, oncologists have reported that they have difficulty obtaining the services they need for their dying patients.¹⁰ Palliative care needs to be integrated earlier into the continuum of cancer care.¹¹⁻¹⁴ Building on the World Health Organization's recommended model of resource allocation in cancer care,⁸ palliative, symptom-modifying therapy should be provided simultaneously with disease-modifying therapy.¹⁵ As the cancer progresses and further anticancer therapy becomes no longer effective, appropriate, or desired, palliative care increases and becomes the major focus of the continuing care of the patient and his or her family.¹⁶ Palliative care should begin with the presentation of symptoms, even before the source of those symptoms has been fully determined. Palliative care continues after the patient's death in the form of bereavement support for the patient's survivors. Palliative care can even begin with the determination of increased risk for cancer, with supportive therapies accompanying risk-modifying therapies.

The NCCN Palliative Care Guidelines were developed to facilitate the appropriate integration of palliative care into anticancer therapy. The Palliative Care Guidelines follow the basic structure of the NCCN disease-oriented guidelines, consisting of screening, assessment, interventions, reassessment, and treatment

modification.¹⁷ The Palliative Care Guidelines are the first NCCN guidelines to include death as an expected outcome and after-death care for the family as an essential part of the continuum of cancer care. A “good death” has been defined as “one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards” (see [PAL-21](#)).¹³ Another definition of a good death is from Singer and colleagues who state that satisfactory palliative care should promote a good death by providing adequate pain and symptom management, avoiding prolongation of dying, promoting a sense of control, relieving burden, and strengthening relationships.¹⁸ Clear, consistent, and empathetic communication with patient and family about the natural history of the cancer and its prognosis is at the core of effective palliative care. Effective palliative care also requires an interdisciplinary team approach. Initially, the primary oncology team can provide most of the palliative care needed by the patient. Intractable symptoms or complex psychosocial problems can benefit from the inclusion of palliative care experts. As the disease progresses and the prognosis becomes a matter of months, collaboration with palliative/hospice teams is usually advised to best meet the many needs of the patient and family.

Palliative Care Guidelines

To develop the initial guidelines, the panel chose to focus on the needs of patients in their last 12 months of life. Despite the earlier opportunities to deliver palliative therapy, the panel chose this period to distill the content of textbooks and curricula into guidelines that could facilitate clinical decision-making in the same way that NCCN disease-oriented and symptom-oriented guidelines have done.

All cancer patients should be screened at each visit for the appropriateness of palliative care interventions. Use of the NCCN Palliative Care Guidelines should be considered for patients with advanced, progressive disease for which there is no effective, curative therapy; those with a life expectancy of 1 year or less; those with serious comorbid conditions; and those patients or families who specifically request palliative care. Patients who do not meet these screening criteria should be re-screened at their next visit. Patients who meet these screening criteria should undergo a comprehensive palliative care assessment, including the identification of patients at high risk for needing complex palliative care. An estimate of life expectancy in terms of a year to months, months to weeks, or weeks to days should be made to guide the use of specific palliative care interventions. Reassessment should be ongoing, with continuation or modification of life expectancy--guided palliative care until the patient's death. The patient's family and caregivers should then be provided with after-death care to help them cope with their loss and to have them undergo their own cancer risk assessment as well as possible risk-modifying and supportive care.

Other resources that may be useful for patients, their caregivers, and/or clinicians include:

- the American Academy of Hospice & Palliative Medicine (www.aahpm.org/),
- Beth Israel Medical Center's Department of Pain Medicine & Palliative Care (www.stoppain.org/palliative_care/palliative.html),
- the Center to Advance Palliative Care (www.capc.org/),
- the Hospice & Palliative Nurses Association (www.hpna.org/),
- the National Hospice & Palliative Care Organization (www.nhpco.org/templates/1/homepage.cfm), and
- People Living With Cancer (www.plwc.org/plwc/Home/1,1743,_12-001029-00_21-008.00.html).

The National Consensus Project has written Clinical Practice Guidelines for Quality Palliative Care (www.nationalconsensusproject.org/Guideline.pdf) for a broad spectrum of patients (ie, not just seriously and terminally ill cancer patients). These guidelines provide an in-depth assessment of many issues surrounding palliative care (eg, cultural, ethical, legal, physical, psychological, social, and spiritual aspects of care). The National Institutes of Health (NIH) held a state-of-the-science conference on Improving End-of-Life Care in December 2004. The final statement from this NIH conference is a useful resource for understanding the complex issues surrounding end-of-life care (<http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>). For example, their conclusions point out that (1) “End-of-life care is often fragmented among providers and provider settings, leading to a lack of continuity of care and impeding the ability to provide high-quality, interdisciplinary care,” and (2) “The design of the current Medicare hospice benefit limits the availability of the full range of interventions needed by many persons at the end of life” (eg, radiation therapy for symptom management).

Palliative Care Screening

The determination of whether any effective, curative therapy is available for a patient who has advanced, progressive cancer should be based on the NCCN disease-specific guidelines for that patient's cancer. The Palliative Care Guidelines should be used for patients receiving life-prolonging or palliative anticancer therapy if their prognosis is believed to be 1 year or less. Potential indicators that patients are in their last year of life include decreased performance status (Eastern Cooperative Oncology Group [ECOG] 3 or more; Karnofsky 50 or less), hypercalcemia, central nervous

system metastases, superior vena cava syndrome, spinal cord compression, cachexia, malignant effusions, liver failure, kidney failure, or other serious comorbid conditions. A final screening criterion is the specific request by the patient or family for palliative care. If none of these criteria are met, the patient should be re-screened at the next visit. If palliative care is appropriate, the patient's primary oncology team should make a full palliative care assessment.

Palliative Care Assessment

A comprehensive palliative care assessment evaluates the benefits and risks of anticancer therapy; the presence of physical and psychosocial symptoms; advance care planning; the patient's personal, spiritual, and cultural goals, expectations, and concerns; social support and cultural issues; and criteria for early referral for complex palliative care.²⁻⁴ Assessment of the benefits and risks of anticancer therapy is based on existing NCCN disease-specific guidelines, with special attention to the natural history of the patient's type of cancer, the potential for response to further treatment, the functional status of the patient's vital organs, the patient's overall performance status, and serious comorbid conditions. Symptom assessment should look for common symptoms, such as pain, dyspnea, anorexia, cachexia, gastrointestinal symptoms, fatigue, weakness, asthenia, insomnia, sedation, delirium, depression, anxiety, other psychosocial distress, and/or spiritual distress. Patients and their families should be asked about their goals and expectations; priorities for palliative care; goals of anticancer therapy; and spiritual, religious, and cultural aspects of their quality of life. Patients should be asked if they have completed any advance care planning such as living wills, power of

attorneys, or specific limitations regarding cardiopulmonary resuscitation (see [PAL-14](#) and [PAL-15](#)). Patients requiring early referral for complex palliative care include those with a history of psychiatric disorders, including substance abuse, a score greater than 5 on the NCCN distress thermometer (see [NCCN's Distress Management Guidelines](#)), cognitive impairment, severe comorbidity, communication barriers, or repeated requests for hastened death. Social circumstances that indicate a need for early referral for complex palliative care include caregiver limitations, inadequate social support, financial limitations, limited access to care, family discord, and young children in the family.

Palliative Care Interventions

The panel addresses the effect of life expectancy on the delivery of palliative care interventions by delineating how these interventions would be constrained or facilitated in three groups of patients: (1) those with 1 year to months to live, (2) those with months to weeks to live, and (3) dying patients in their final weeks to days. A subset of these patients in their final hours of life are referred to as “imminently dying” and may require special interventions. The panel recognizes the lack of precision of estimating life expectancy but believes that this delineation is useful and that clinical judgment is usually adequate to make these estimations. The panel recognizes that optimal provision of palliative care requires ongoing reassessment and modification of strategies. Criteria include adequate pain and symptom management, avoidance of prolongation of dying, promotion of a patient's sense of control, alleviation of burden, and strengthening of relationships.^{18,19} An example of adequate pain management can be found in [NCCN's Adult Cancer Pain Guidelines](#).

Patients who have months to live and a good performance status may be interested in continuing anticancer therapy to try to live

longer and/or to try to reduce their cancer-related symptoms.^{20,21} Anticancer therapy may be conventional treatment or treatment within the context of a clinical trial. Physicians, patients, and their families should consider the range of anticancer choices and discuss the benefits and risks of anticancer therapy on quality of life. Patients with months to weeks to live are typically tired of therapy, homebound, and more concerned about the side effects of more treatment. They shift the focus of treatment from prolonging life towards maintaining quality of life. Patients should be offered best supportive care, including referral to palliative care or hospice.²² Palliative care should not be described as “just hospice” to avoid demeaning its value. Patients with weeks to days to live (ie, dying patients) should not be given anticancer therapy but should be given intensive palliative care to help control symptoms and to provide comfort.

The patient and family's personal, spiritual, cultural, and religious goals and expectations throughout these three time frames may vary. Anticipation of patient and family needs is important. For patients whose life expectancy is “a year to months” or “months to weeks,” it is also important to determine how much information a patient wishes to have and how much of that information should be shared with the patient's family. These preferences may change over time. Patients will also require anticipatory guidance on the death process as well as answers to any questions about what to expect in the next few months. In addition, it is necessary to determine the decision-making styles of patients and their families. This will help facilitate congruence of a patient's goals and expectations with those of the family. It is also important to determine their desires with respect to quality of life. Throughout this process, patients should be aware that comfort is the primary consideration.

Patients should be assisted in reviewing and revising their life priorities, resolving their unfinished business, and putting their affairs in order (including resolving their personal relationships). Families should be guided through their anticipatory grief, and arrangements should be made to ensure that the patient's and family's needs and goals regarding the dying process are respected. Throughout treatment, discuss the patient's prognosis with patients and their families clearly and consistently to help them develop realistic expectations. Reuben and Naeim have shown that seriously ill middle-aged and older patients tend to be more optimistic and less accurate about their prognosis than their physicians, which can affect their preferences for cardiopulmonary resuscitation and for measures extending life.²³ The delivery of clear and consistent prognostic information can help patients make the most appropriate decisions. Information about the natural history of the specific tumor and the realistic goals of anticancer therapy should be included in the discussion. For dying patients, it is important to prepare for the patient's death and to facilitate anticipatory grief work. Both the patient and the family benefit from education on the dying process. Planning to ensure continuing care and referrals to appropriate care are important. Arrangements should be available to ensure that the patient does not die alone unless that is the patient's preference.

Spiritual and cultural issues are often best addressed through collaboration with pastoral care counselors, professional translators, the patient's personal clergy, and representatives from the patient's cultural community. Religious and cultural issues surrounding the beliefs and practices around the time of death must be anticipated and managed carefully. Finally, social support and resource management interventions should be provided to

ensure a safe end-of-life care environment, a competent primary caregiver, and access to necessary medications and treatments.

Palliative care of physical and psychosocial symptoms should follow existing [NCCN Supportive Care Guidelines](#) for pain, psychosocial distress, and fatigue; a nutrition support consult may also be considered.^{24,25} Special considerations in the implementation of these guidelines based on life expectancy are delineated in the algorithms. The major focus of these special considerations is the withholding and withdrawal of aggressive interventions, the elimination of long-term adverse effects as restrictions on some palliative care interventions, the acceptance of loss of function for the sake of relief of symptoms, and the treatment of the unique symptoms of patients in their final hours of life. The goals and intensity of nutritional support change as prognosis shortens. Overly aggressive enteral or parenteral nutrition therapies can actually increase the suffering of dying patients. Palliative care regarding hydration and nutrition in the final weeks of life typically includes the treatment of dry mouth and thirst, along with family education and support to deal with the psychosocial aspects of discontinuing feeding. In the management of dyspnea, as the life expectancy decreases, the role of mechanical ventilation and oxygen diminishes while the role of opioids, benzodiazepines, and scopolamine increases (see [PAL-9](#) and [PAL-10](#)). More-specific palliative care interventions for other symptoms will be developed as deemed necessary after institutional review of these guidelines.

Advance care planning in patients with a year to months to live should include the open discussion of the option of palliative care, the elicitation of personal values and preferences for end-of-life care, the exploration for congruence between the patient's wishes/expectations and those of the family/health care team, and the provision of information about advance directives (see [PAL-14](#) and [PAL-15](#)). When

the patient's life expectancy is reduced to months to weeks, the oncology team should actively facilitate completion of appropriate advance directives and should ensure their availability in all care settings. Where the patient wants to die should also be determined. Dying in a hospital can be traumatic for patients and their families; palliative care has been shown to decrease deaths in an intensive care unit.²⁶ Most cancer patients wish to die at home; however, a study in Houston showed that only about 34% died at home,²⁷ although the percentage varies by region. As the patient's life expectancy decreases down to weeks to days, compliance with advance directives should be ensured and a Do Not Resuscitate order should be obtained and honored.

Special palliative care interventions include the response to requests for hastened death (physician-assisted suicide/euthanasia) (see [PAL-19](#)), the use of sedation for the relief of intractable symptoms in the imminently dying, and the care of dying patients in their final hours (see [PAL-20](#)). The most appropriate response to a request for hastened death is to intensify palliative care. Open exploration of the patient's request for aid in dying can often identify unmet needs and new palliative care interventions. Alternatives to hastened death (such as treatment withdrawal, voluntary cessation of eating and drinking, sedation) should be presented. The patient should be assured of the commitment of his or her health care team to providing continuing care. Intentional sedation with infusions of benzodiazepines, barbiturates, or anesthetics can be considered for patients with refractory symptoms and with a life expectancy of hours to days. Such sedation is best performed by palliative care experts and has its ethical justification in the Doctrine of Dual Effect.²⁸⁻³¹ As patients are actively dying in their final hours of life, allow the patient and family to spend uninterrupted time together.

Diagnostic tests should be discontinued, the family should be prepared and supported, and advanced directives should be honored. Secretions should be minimized and delirium controlled with regular administration of appropriate medications by whatever route of administration is feasible. Make sure the patient is repositioned regularly for comfort, and monitor the patient for urinary retention and fecal impaction. Privacy and respectful space for the family should be provided to facilitate closure.

Palliative Care Reassessment of Outcomes

The outcome measures for these Palliative Care Guidelines are much more difficult to define than those for NCCN disease-specific guidelines. The panel adapted a list of end-of-life outcomes from several surveys of North American citizens.¹⁸ For the purpose of these guidelines, the NCCN panel has chosen Singer's outcomes until more precise outcome measures are available. Satisfactory palliative care should provide adequate pain and symptom management, avoid prolongation of dying, promote a sense of control, relieve burden, and strengthen relationships. Research is ongoing regarding better ways to measure "dying well."³² For now, patients should be reassessed regularly for these five outcomes, and palliative care efforts should be intensified as appropriate. Consultation with palliative care/hospice experts and teams should be considered for most patients.

After Death Care

Comprehensive palliative care for the patient's family and caregivers continues after the patient's death. Immediate issues include ensuring culturally sensitive and respectful treatment of the body including removal of implanted devices, providing family time with

the body, addressing survivor concerns about organ donation or autopsy, facilitating funeral arrangements through completion of necessary paperwork, and informing insurance companies and other health care providers of the patient's death. Bereavement support should be offered, beginning with a condolence letter from the patient's primary oncology team. Funeral attendance can be considered for individual patients. Grief should be normalized, and pathologic grief should be identified and treated. The family may request a debriefing meeting and require assistance identifying community bereavement resources. Such bereavement care is often best provided by an experienced hospice team or a skilled mental health care professional. The completion of cancer care for the patient can lead to the initiation of cancer care for the family. A well-supported end-of-life care experience by the family will facilitate the family's acceptance of appropriate referral for cancer risk assessment and risk modification. Psychosocial support should also be provided for the staff.

Putting Palliative Care Guidelines into Practice

The natural history of what a cancer patient experiences throughout the course of the disease begins with meeting the oncologist. The oncologist and patient should discuss at the outset whether the treatment will be curative or palliative. These Palliative Care Guidelines were developed to accompany appropriate antineoplastic therapy. As the cancer progresses and the value of further anticancer therapy diminishes, palliative therapy should be intensified. While patients remain interactional (ie, able to communicate), the issue of whether they want more anticancer therapy must be openly addressed. Patients usually move from being ambulatory to being sedentary as their disease advances and

their performance status lowers. When life expectancy is a matter of days or hours, patients are often noninteractional (ie, not able to communicate). Such patients may be at home, living with a family member, or in a health care facility. By understanding where a patient realistically stands on this natural disease trajectory and by using these Palliative Care Guidelines, the oncology team can provide the most appropriate treatment for each patient.

Many palliative care questions must be considered early in each patient's comprehensive cancer care. It is the responsibility of the primary oncology team to work with the patient to raise and answer these questions. It is important to identify the patient's goals for the rest of his or her life. The answers provided by patients will give the oncologist a sense of whether patients understand and accept their diagnosis and prognosis. Additionally, the oncologist must explain the types of therapies that are available and how these therapies can affect the patient's daily life. The Palliative Care Guidelines are aimed at providing the best quality of life that is possible for each patient. This is a particularly important concept to keep in mind when determining if anticancer therapy should be offered or continued. By processing realistic information, the patient can then make an informed decision with regard to therapy and establish achievable goals and appropriate hope. It is important that patients understand that receiving anticancer therapy does not have to sidetrack them from addressing end-of-life issues. Palliative care extends the oncologist's therapeutic repertoire and diminishes the stress of caring for patients who have incurable disease. Increasing emphasis on palliative care in oncology should improve patient outcomes and provide new avenues for clinical research and reward.

When discussing palliative care options with patients, it is helpful to introduce members of the institutional or community palliative care

team. Timely introduction allows patients to meet the individuals who will help them and their families through their experience. Because the diagnosis of cancer and impending death is such a frightening experience, it is important to try to alleviate those fears by telling the patient that the members will work to make things less troublesome. Additionally, it is important to discuss the patient's natural history and disease prognosis with the family and palliative care team to anticipate and to manage symptoms and problems commonly seen in patients with the same type and extent of cancer.

Palliative care is designed to help guide the patient and family to understand the disease and to begin to make end-of-life plans. However, sometimes the patient and family do not accept the prognosis or do not begin to make end-of-life preparations.^{33,34} This is usually a sign that the patient does not fully understand the disease. Palliative care provides education so the patient can better understand the disease. The oncologist must ensure that the advance care plans are in place when the estimated life expectancy of a patient is a limited number of months or weeks. This focus on the patients' wishes assures patients that they will be provided with no more and no less aggressive care than they desire. By

understanding the goals and expectations of their patients, oncologists are better able to treat them. The combined efforts of the oncology team and the hospice/palliative care team can actually improve the overall outcome for patients and their families.

Hope

These NCCN Palliative Care Guidelines are intended to help oncology teams provide the best care possible for their patients with incurable cancer. During the next few years, the panel will complete the details of specific palliative care interventions and will refine the palliative care reassessment outcome measures. The panel will also incorporate information from the institutions that review and implement these Palliative Care Guidelines. Additionally, the panel will try to address barriers in current insurance coverage for end-of-life care. These guidelines provide a different kind of hope than additional anticancer therapy affords. These guidelines provide hope for closure and hope for growth at the end of life.

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