

## NCCN Guidelines® Insights

## Palliative Care, Version 1.2014

## Featured Updates to the NCCN Guidelines

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**Abstract**

The NCCN Guidelines for Palliative Care provide interdisciplinary recommendations on palliative care for patients with cancer. These NCCN Guidelines Insights summarize the NCCN panel's discussions and guideline updates from 2013 and 2014. These include modifications/additions to palliative care screening and assessment protocols, new considerations for discussing the benefits and risks of anticancer therapy, and approaches to advance care planning. Recent updates focus on enhanced patient-centered care and seek to promote earlier integration of palliative care and advance care planning in oncology. (*J Natl Compr Canc Netw* 2014;12:1379–1388)

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**Please Note**

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are a statement of consensus of the authors regarding their views of currently accepted approaches to treatment. **The NCCN Guidelines® Insights highlight important changes in the NCCN Guidelines® recommendations from previous versions. Colored markings in the algorithm show changes and the discussion aims to further understanding of these changes by summarizing salient portions of the panel's discussion, including the literature reviewed.**

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### Learning Objectives:

Upon completion of this activity, participants will be able to:

- Integrate into professional practice the updates to NCCN Guidelines for Palliative Care
- Describe the rationale behind the decision-making process for developing the NCCN Guidelines for Palliative Care

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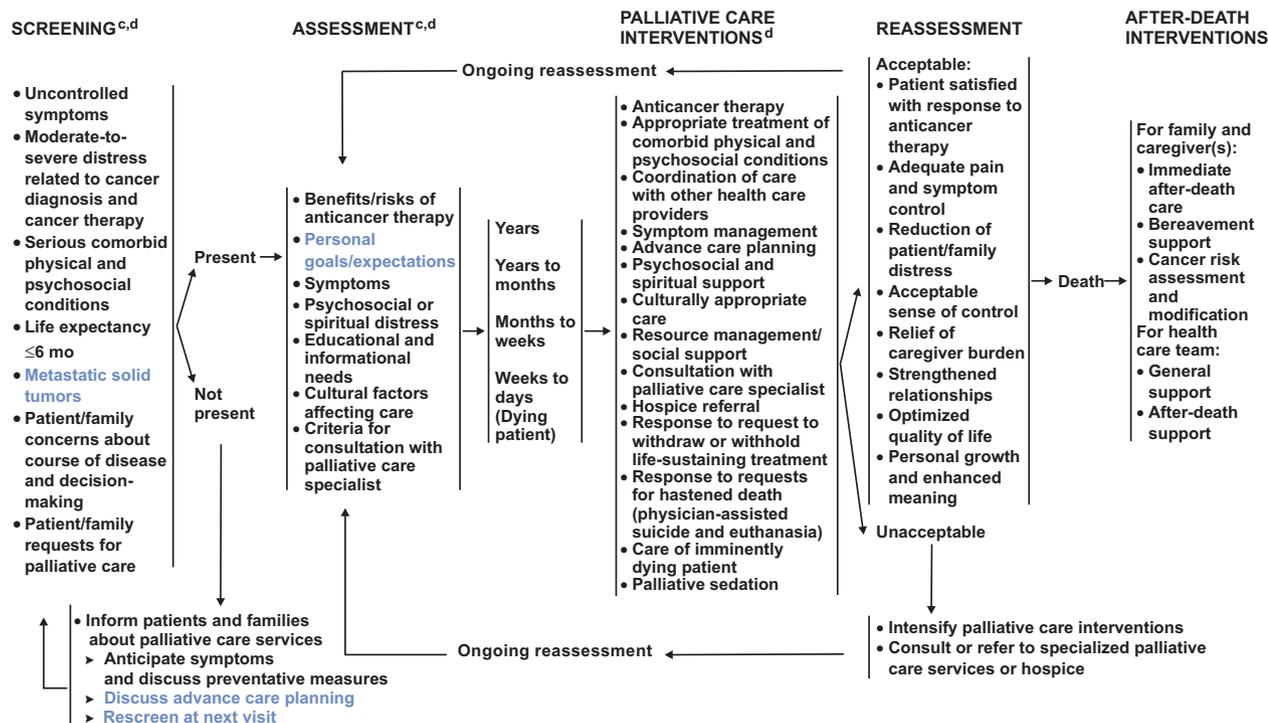
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<sup>c</sup>Management of any patient with positive screening requires a care plan developed by an interdisciplinary team of physicians, nurses, social workers, and other mental health professionals, chaplains, nurse practitioners, physician assistants, and dietitians.

<sup>d</sup>Oncologists should integrate palliative care into general oncology care. Early consultation/collaboration with a palliative care specialist/hospice team should be considered to improve quality of life and survival.

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## NCCN Categories of Evidence and Consensus

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

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

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

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

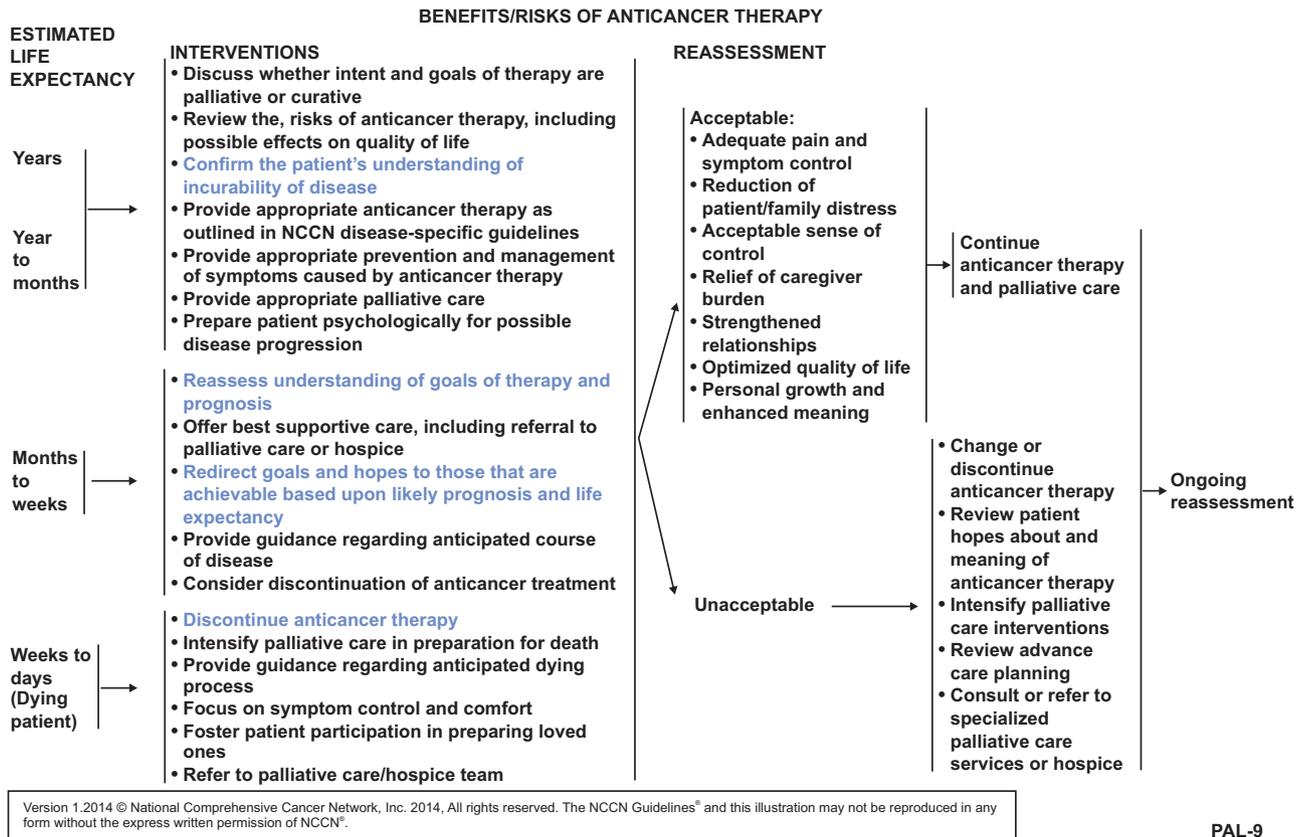
All recommendations are category 2A unless otherwise noted.

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

## Overview

Global cancer rates are increasing and the need for comprehensive care for patients with cancer and their families is significant. A significant percentage of patients with cancer report experiencing moderate to severe symptoms that would benefit from palliative care, including pain, nausea, anxiety, depression, dyspnea, fatigue, psychosocial distress, and loss of appetite.<sup>1</sup> Palliative care in oncology began as hospice and end-of-life care. During the past 20 years, increasing attention has been paid to the benefit of palliative care in improving quality-of-life in oncology throughout the disease trajectory.<sup>2-7</sup> As the hospice movement has expanded in this country, palliative care has developed into an integral part of comprehensive cancer care.<sup>5,8-12</sup>

The NCCN Palliative Care Panel is an interdisciplinary group of representatives from NCCN Member Institutions consisting of medical oncologists, hematologists and hematologic oncologists.

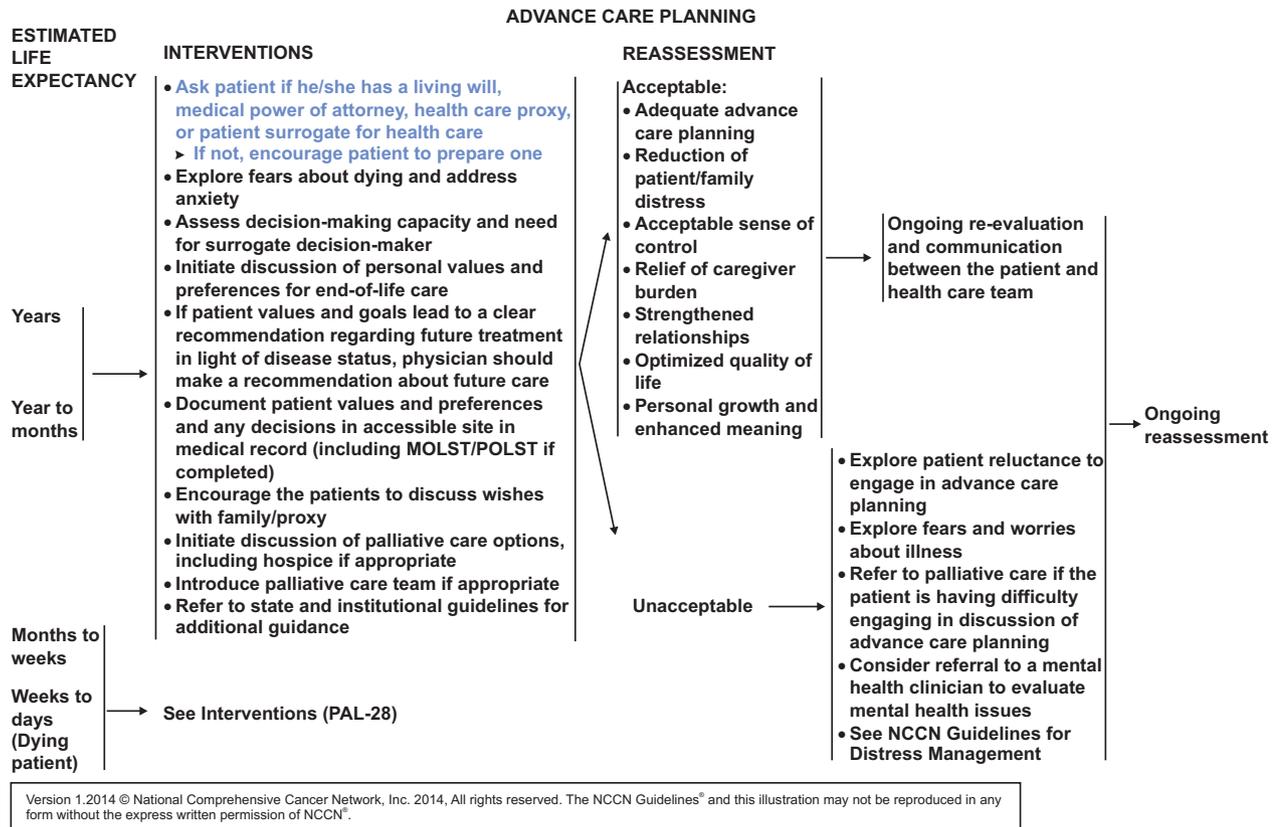


gists, pediatric oncologists, neurologists and neuro-oncologists, anesthesiologists, psychiatrists and psychologists, internists, palliative care and pain management specialists, and geriatric medicine specialists. The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Palliative Care include recommendations regarding screening, assessment, and management of the palliative care needs of patients with cancer and their families/caregivers. The panel continually updates these guidelines. Notable updates from 2013 and 2014 include modifications to screening and assessment criteria to promote timely initiation of palliative care, updated priorities for patient discussions on the benefits/risks of anticancer therapy, and recommendations to promote advance care planning earlier in the disease course. Additionally, a new section on psychosocial concerns for oncology health care providers was added. The most recent and complete version of these guidelines is available at [NCCN.org](http://NCCN.org).

## Timely Integration of Palliative Care in Oncology

Early introduction of palliative care can improve patient and caregiver outcomes, quality of life, and even survival. A notable study showed that early introduction of palliative care not only improved the quality of life for patients with advanced cancer but also improved survival.<sup>13</sup> Secondary analyses of the data showed that patients receiving early palliative care were less likely to receive chemotherapy in the last 60 days of life (odds ratio, 0.47; 95% CI, 0.23–0.99;  $P=.05$ ),<sup>14</sup> likely because these patients had a more accurate understanding of their prognosis, which impacted decisions about their care.<sup>15</sup> In another study, early referral to community-based palliative care services reduced the number of emergency department visits in the last 90 days of life in patients with cancer.<sup>16</sup> Additionally, the lack of palliative care team consultation was shown to be a predisposing factor for futile life-sustaining treatments

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PAL-27

at the end of life.<sup>17</sup> In a cohort of 6076 patients with advanced pancreatic cancer, patients who had received at least one palliative care consultation had lower odds of intensive care unit admission, multiple emergency department visits, and multiple hospitalizations near death.<sup>18</sup>

Palliative care has been shown to reduce symptom burden, improve quality of life, and increase the odds of dying at home. In a recent study comparing standard care with ongoing palliative care in patients with advanced cancer and a prognosis of 6 to 24 months to live, palliative care resulted in improved patient quality of life, satisfaction with care, and decreased symptom severity.<sup>19</sup> A study by Kamal et al<sup>20</sup> revealed that provider conformance with supportive care quality measures significantly improved quality of life for patients with cancer who were receiving palliative care. Furthermore, a recent Cochrane Database systematic review analyzing home-based palliative care in patients with advanced illness showed

decreased symptom burden and increased the likelihood of dying at home without negatively impacting caregiver grief.<sup>21</sup>

Overall, research suggests that successful integration of palliative care early in the continuum of care reduces morbidity for patients with cancer and enhances patient and family/caregiver satisfaction.<sup>22,23</sup> Despite the demonstrated benefits of palliative care, studies have shown that consultations for palliative care and advance care planning are often provided too late in the disease course to achieve maximum benefit.<sup>24-28</sup> Still other patients receive no referral to palliative care services before death. A retrospective review of patients with advanced cancer seen at MD Anderson Cancer Center found that only 45% of patients had a palliative care consultation before death, many of which occurred close to death.<sup>29</sup> Similarly, a retrospective study of 6076 patients with advanced pancreatic cancer revealed that only 52% of patients received a palliative care consultation.<sup>18</sup> In a recent

survey, only 37% of physicians reported that they had access to a specialized palliative care service that accepted patients on chemotherapy.<sup>30</sup> Thus, barriers to early referrals still exist.<sup>31</sup>

### **NCCN Recommendations**

During the 2013 and 2014 guideline updates, the panel made several modifications to the guidelines' screening and assessment protocols to promote timely and efficient integration of palliative care into oncology and to enhance patient/caregiver understanding of its benefits. Panel members discussed the importance of early integration of palliative care by the primary oncology team, and a lack of timely advance care planning in many patients.

The panel recommends that patients be screened by the primary oncology team for palliative care needs on a regular basis. Screening should include evaluation of the following: uncontrolled symptoms; moderate-to-severe distress related to cancer diagnosis; serious comorbid physical and psychosocial conditions; life expectancy of less than 6 months; metastatic solid tumors; patient/family concerns about disease course and decision-making; and patient/family requests for palliative care. In 2013, the panel voted to include metastatic solid tumors among the screening criteria that prompt a comprehensive assessment (see PAL-2, page 1381). This decision was driven by data demonstrating unmet palliative care needs in patients with metastatic solid tumors. By expanding the palliative care assessment criteria to include these patients, the panel hopes to enhance accessibility of palliative care at first diagnosis of metastatic disease.

The panel discussed the need to promote earlier discussions on advance care planning and to ensure regular assessment/reassessment of palliative care needs in oncology. Panel members recognized the desire of many providers to establish a relationship with the patient before discussing palliative care and advance care planning, thus delaying these important discussions. Additionally, the panel acknowledged the hesitance of many providers to pursue palliative care and/or advance care planning earlier in the disease course for fear of discouraging patients, families, and caregivers. However, the panel agreed that early and effective discussions about palliative care and advance care planning would provide the opportunity to deliver optimal care in accordance with patient, family, and caregiver goals and expectations.

For patients in whom no palliative care screening criteria were present, recommendations were added in 2014 to discuss advance care planning, and repeat palliative care screening at the next patient visit (see PAL-2, page 1381). Any patient with positive screening should undergo a comprehensive palliative care assessment to review benefits/risks of anticancer therapy, symptoms, psychosocial or spiritual distress, personal goals/expectations, educational and informational needs, cultural factors affecting care, and criteria for consultation with a palliative care specialist. Also in 2014, the panel voted to advance "Personal goals/expectations" in the assessment protocol so that this item precedes symptom assessment (see PAL-2, page 1381). By assessing the patient's goals and expectations for treatment early in the assessment process, the panel seeks to promote a patient-centered approach to assessment, treatment planning, and care.

### **Discussing the Benefits and Risks of Anticancer Therapy**

A recent Institute of Medicine (IOM) report, "Communicating with Patients on Health Care Evidence," found that 90% of Americans surveyed want to know their options for tests and treatments and to be involved in decision-making, with almost 50% wanting to discuss the option of doing nothing.<sup>32,33</sup> However, the report also found that far fewer respondents had these discussions with their physicians. In patients queried regarding preferences about receiving prognostic information and detailed information on their disease, studies show that most express a desire to receive this information.<sup>34-37</sup> Despite these preferences, research reveals that a significant percentage of patients with cancer have an inadequate understanding about the curability of their disease and prognosis.

A recent survey of 1193 patients in the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) study found that 69% of patients with advanced lung cancer and 81% of those with advanced colorectal cancer thought that their palliative chemotherapy could cure them.<sup>38</sup> Although it is unclear whether these patients were told their prognosis, they did not understand or choose to understand the information, or if they merely answered the survey with a high degree of optimism,<sup>39</sup> this

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result shows a need for improved physician–patient communication. Data suggest that similar misconceptions apply to palliative radiation therapy. In a study of 384 patients with inoperable lung cancer, 64% of patients did not understand that their radiation therapy was not curative.<sup>40</sup>

Clear, consistent, and empathetic communication with the patient and family about the natural history of the cancer and its prognosis is at the core of effective palliative care.<sup>41–43</sup> Effective patient–physician communication can decrease patient stress, increase adherence to treatment, and improve outcomes.<sup>44,45</sup> It is important to assess and reassess patient goals and preferences regarding communication of difficult news over the course of disease.<sup>46</sup> When patients understand prognosis and the goals of treatment, they can make choices that are consistent with life goals and form realistic expectations.

Patients with incurable disease should consider potential discontinuation of anticancer treatment and be offered best supportive care, including referral to palliative care or hospice.<sup>47,48</sup> Sometimes patients and families do not accept the prognosis or do not begin to make preparations.<sup>49,50</sup> These things may be a sign that patients do not fully understand the disease, and may lead patients and families to desire aggressive treatments that may be futile and toxic.<sup>50</sup> Palliative care supports education so that patients and their families can better understand the disease.

### NCCN Recommendations

The NCCN Guidelines for Palliative Care divides patients into 3 groups to address the effect of life expectancy on the delivery of palliative care interventions: (1) patients with years to months to live; (2) patients with months to weeks to live; and (3) dying patients in their final weeks to days. The panel recognizes the lack of precision in estimating life expectancy but believes that this delineation will be useful for the delivery of appropriate palliative care interventions.

Optimal provision of palliative care requires ongoing reassessment and modification of strategies, and ongoing communication among the patient, family, and health care team to ensure awareness of the patient and family's current personal, spiritual and existential, cultural, and religious goals and expectations.

For patients with an estimated life expectancy of years to months, physicians, patients, and their families should discuss intent, goals, and range of choices; benefits and risks of anticancer therapy; and poten-

tial effects on quality of life. In addition, the oncology team should prepare the patient psychologically for possible disease progression. The panel discussed the concerns of many providers that patients may not understand or fully process information provided in these discussions. As such, in 2014, the panel members included an additional recommendation for patients with years to months of life expectancy: “confirm the patient's understanding of incurability of disease” (see PAL-9, page 1382). In doing so, providers can identify patients who require additional education, and ensure maximal understanding so that the patient and family can establish appropriate goals and expectations for anticancer therapy.

Providers should recognize that patients' treatment goals, expectations, and preferences for prognostic information may evolve as disease progresses. The panel discussed the importance of reassessing the benefits and risks of anticancer therapy for patients with months to weeks to live. Additionally, the panel agreed that providers should reassess patient preferences regarding prognostic information. Accordingly, updates to the 2014 version of the guidelines include a specific recommendation to reassess patient understanding of goals of therapy and prognosis for all patients with months to weeks to live (see PAL-9, page 1382). Once this knowledge has been ascertained, providers should redirect patient goals and expectations to those that are achievable. Additions to this recommendation in the 2014 update emphasize the importance of redirecting patient's goals and hopes to those that are achievable based on likely prognosis and life expectancy (see PAL-9, page 1382). In doing so, providers can provide improved patient-centered care and shift the focus of treatment from prolonging life to maintaining quality of life.

As the cancer progresses and the value of further anticancer therapy diminishes, palliative therapy should be intensified. The issue of whether patients want more anticancer therapy must be openly addressed. For patients with a life expectancy of weeks to days, previous iterations of the guidelines recommended that providers encourage discontinuation of anticancer therapy. However, multiple panelists expressed the need for stronger language surrounding this recommendation to prevent unnecessary or futile treatments that may diminish quality of life. In 2014, this language was amended to recommend that

providers discontinue anticancer therapy in patients with weeks to days to live (see PAL-9, page 1382). Instead, providers should deliver intensive care focusing on symptom control and help patients and families prepare for the dying process.

### Advance Care Planning

Timely initiation of advance care planning early in the disease course promotes delivery of care in line with patients' wishes and preferences regarding treatment at end-of-life. Unfortunately, recent studies have shown that advance care planning discussions frequently occur too late in the trajectory of disease, often during acute hospital care and often with health professionals other than the primary oncologist.<sup>51-53</sup> Earlier end-of-life care discussions have been associated with less-aggressive care and increased use of hospice,<sup>54,55</sup> whereas less-aggressive care has been linked to an improved quality of life.<sup>56</sup>

Studies suggest that most patients with cancer would prefer to die at home,<sup>57,58</sup> but lack of timely advance care planning can render this impossible. A prospective study showed that patients dying in intensive care units had higher levels of physical and emotional distress compared with patients dying at home or in hospice. Additionally, caregivers of these patients had a greater incidence of prolonged grief disorder.<sup>59</sup> A recent retrospective cohort study showed that patients who wanted to die at home were more likely to do so if they had daily hospice visits, were married, had advance directives, did not have moderate or severe pain, or had good performance status.<sup>58</sup>

### NCCN Recommendations

The oncology team should initiate discussions of personal values and end-of-life care preferences while patients have a life expectancy of years to months. To promote earlier discussion of end-of-life preferences, the panel voted to strengthen the recommendations regarding advance care planning in patients with years to months of estimated life expectancy. In the 2014 guideline update, the panel now recommends that providers directly ask patients if they have a living will, medical power of attorney, health care proxy, or patient surrogate for health care. If not, providers should encourage them to prepare one (see PAL-27, page 1383).

Advance care planning should include an open discussion about palliative care options, such as hospice, personal values and preferences for end-of-life

care, congruence between the patient's wishes/expectations and those of the family/health care team, and information about advance directives. Discussions on advance care planning should address living wills, power of attorney, or delineation of specific limitations regarding life-sustaining treatments, including cardiopulmonary resuscitation, mechanical ventilation, and artificial nutrition/hydration. The patient's values and preferences and any decisions should be documented in the medical record, including MOLST or POLST (medical orders for life-sustaining treatment or physician orders for life-sustaining treatment) if completed.

### Psychosocial Support for Palliative Care Providers

Oncology and palliative care teams commonly encounter patient loss and deal with grief, and over time, the resultant emotional distress can lead to provider burnout, compassion fatigue, and/or moral distress.<sup>60-63</sup> These syndromes can manifest as symptoms of depression, anxiety, fatigue, and low mental quality of life.<sup>64</sup> Although considerable research has been dedicated to evaluating patterns and interventions to mediate patient, family, and caregiver distress and grief, much less attention has been devoted to these same issues among health care providers and teams. However, ongoing panel discussions have highlighted increasing literature on burnout, compassion fatigue, and moral distress among oncology providers. As a result, the panel decided to include a discussion of these issues and the current literature in the NCCN Guidelines for Palliative Care. As these discussions progress and additional data become available, the panel intends to address these issues and develop recommendations for future versions of the guidelines. For an overview of the literature on provider compassion fatigue in oncology, see reviews by Najjar et al,<sup>60</sup> Shanafelt and Dyrbye,<sup>64</sup> and Sherman et al.<sup>65</sup>

### Conclusions

These NCCN Guidelines Insights highlight important recent updates to the NCCN Guidelines for Palliative Care. The NCCN Guidelines are updated at least annually, and more often when new high-quality clinical data become available in the interim.

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The most up-to-date version of these continuously evolving guidelines is available online at [NCCN.org](http://NCCN.org). The recommendations in the NCCN Guidelines are based on available evidence from clinical trials, combined with expert consensus of the NCCN panel. Independent medical judgment is required to apply these guidelines individually to provide optimal care. The physician and patient have the responsibility to jointly explore and select the most appropriate option from among the available alternatives. When possible, consistent with NCCN philosophy, the NCCN panel strongly encourages participation in prospective clinical trials.

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## Posttest Questions

1. Which of the following interventions are recommended when discussing the benefits/risks of anticancer therapy with patients who have a life expectancy of years or years to months?
  - a. Prepare patient psychologically for possible disease progression
  - b. Provide guidance regarding anticipated dying process
  - c. Confirm the patient's understanding of incurability of the disease
  - d. All of the above
2. True or False: Patients with metastatic solid tumors should be screened at each visit for palliative care needs.
3. For patients with negative screening for palliative care assessment, providers should:
  - a. Rescreen at next visit
  - b. Discuss advance care planning
  - c. Anticipate symptoms and discuss preventative measures
  - d. All of the above
- e. A and C
- f. None of the above

