

# NCCN Guidelines® Insights

## Palliative Care, Version 2.2017

### Featured Updates to the NCCN Guidelines

Maria Dans, MD<sup>1,\*</sup>; Thomas Smith, MD<sup>2,\*</sup>; Anthony Back, MD<sup>3</sup>; Justin N. Baker, MD<sup>4</sup>; Jessica R. Bauman, MD<sup>5</sup>; Anna C. Beck, MD<sup>6</sup>; Susan Block, MD<sup>7</sup>; Toby Campbell, MD<sup>8</sup>; Amy A. Case, MD<sup>9</sup>; Shalini Dalal, MD<sup>10</sup>; Howard Edwards, MD<sup>11</sup>; Thomas R. Fitch, MD<sup>12</sup>; Jennifer Kapo, MD<sup>13</sup>; Jean S. Kutner, MD<sup>14</sup>; Elizabeth Kvale, MD<sup>15</sup>; Charles Miller, MD<sup>16</sup>; Sumathi Misra, MD<sup>17</sup>; William Mitchell, MD<sup>18</sup>; Diane G. Portman, MD<sup>19,\*</sup>; David Spiegel, MD<sup>20,\*</sup>; Linda Sutton, MD<sup>21</sup>; Eytan Szmulowicz, MD<sup>22</sup>; Jennifer Temel, MD<sup>23</sup>; Roma Tickoo, MD, MPH<sup>24</sup>; Susan G. Urba, MD<sup>25</sup>; Elizabeth Weinstein, MD<sup>26</sup>; Finly Zachariah, MD<sup>27</sup>; Mary Anne Bergman<sup>28,\*</sup>; and Jillian L. Scavone, PhD<sup>28,\*</sup>

#### Abstract

The NCCN Guidelines for Palliative Care provide interdisciplinary recommendations on palliative care for patients with cancer. These NCCN Guidelines Insights summarize and provide context for the updated guidelines recommendations regarding hospice and end-of-life (EOL) care. Updates for 2017 include revisions to and restructuring of the algorithms that address important EOL concerns. These recommendations were revised to provide clearer guidance for oncologists as they care for patients with cancer who are approaching the transition to EOL care. Recommendations for interventions and reassessment based on estimated life expectancy were streamlined and reprioritized to promote hospice referrals and improved EOL care.

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From <sup>1</sup>Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine; <sup>2</sup>The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins; <sup>3</sup>Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance; <sup>4</sup>St. Jude Children's Research Hospital/The University of Tennessee Health Science Center; <sup>5</sup>Fox Chase Cancer Center; <sup>6</sup>Huntsman Cancer Institute at the University of Utah; <sup>7</sup>Dana-Farber Cancer Institute /Brigham and Women's Cancer Center; <sup>8</sup>University of Wisconsin Carbone Cancer Center; <sup>9</sup>Roswell Park Cancer Institute; <sup>10</sup>The University of Texas MD Anderson Cancer Center; <sup>11</sup>Fred & Pamela Buffett Cancer Center; <sup>12</sup>Mayo Clinic Cancer Center; <sup>13</sup>Yale Cancer Center/Smilow Cancer Hospital; <sup>14</sup>University of Colorado Cancer Center; <sup>15</sup>University of Alabama at Birmingham Comprehensive Cancer Center; <sup>16</sup>The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute; <sup>17</sup>Vanderbilt-Ingram Cancer Center; <sup>18</sup>UC San Diego Moores Cancer Center; <sup>19</sup>Moffitt Cancer Center; <sup>20</sup>Stanford Cancer Institute; <sup>21</sup>Duke Cancer Institute; <sup>22</sup>Robert H. Lurie Comprehensive Cancer Center of Northwestern University; <sup>23</sup>Massachusetts General Hospital Cancer Center; <sup>24</sup>Memorial Sloan Kettering Cancer Center; <sup>25</sup>University of Michigan Comprehensive Cancer Center; <sup>26</sup>Case Comprehensive Cancer Center/University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute; <sup>27</sup>City of Hope Comprehensive Cancer Center; and <sup>28</sup>National Comprehensive Cancer Network.

\*Provided content development and/or authorship assistance.

#### 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 to the NCCN Guidelines® recommendations from previous versions. Colored markings in the algorithm show changes and the discussion aims to further the understanding of these changes by summarizing salient portions of the NCCN Guideline Panel 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 the 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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**Genevieve Emberger Hartzman, MA**, Journal Production Specialist, NCCN, has disclosed that she has no relevant financial relationships.

### CE Authors:

**Deborah J. Moonan, RN, BSN**, Director, Continuing Education, NCCN, has disclosed that she has no relevant financial relationships. (Employed by NCCN until 2/17/17.)

**Karen Kanefield**, Manager, Continuing Education Accreditation and Program Operations, NCCN, has disclosed that she has no relevant financial relationships.

**Kathy Smith**, Manager, CE Grant Writing & Project Management, NCCN, has disclosed that she has no relevant financial relationships.

**Kristina M. Gregory, RN, MSN, OCN**, Vice President, Clinical Information Operations, NCCN, has disclosed that she has no relevant financial relationships.

**Rashmi Kumar, PhD**, Director, Clinical Information Operations, NCCN, has disclosed that she has no relevant financial relationships.

### Individuals Who Provided Content Development and/or Authorship Assistance:

**Maria Dans, MD**, Panel Chair, has disclosed that she has no relevant financial relationships.

**Thomas Smith, MD**, Panel Vice Chair, has disclosed that he receives other financial benefit from GEOMC Co., Ltd.

**Diane G. Portman, MD**, Panel Member, has disclosed that she has no relevant financial relationships.

**David Spiegel, MD**, Panel Member, has disclosed that he has no relevant financial relationships.

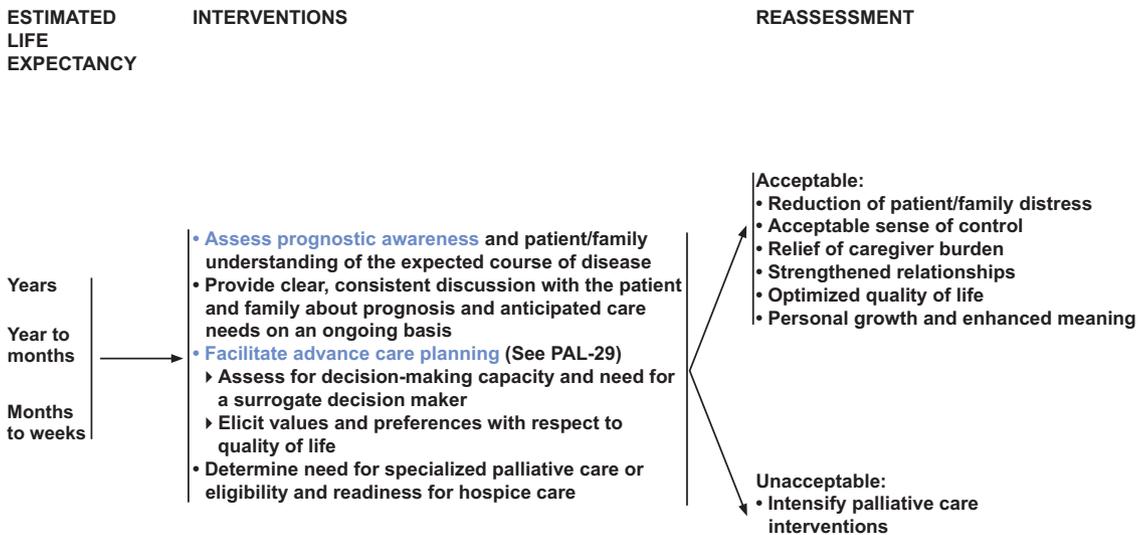
**Mary Anne Bergman**, Guidelines Coordinator, NCCN, has disclosed that she has no relevant financial relationships.

**Jillian L. Scavone, PhD**, Oncology Scientist/Senior Medical Writer, NCCN, has disclosed that she has no relevant financial relationships.

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# Palliative Care, Version 2.2017

## PREPARING PATIENTS AND FAMILIES FOR END-OF-LIFE AND TRANSITION TO HOSPICE CARE



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PAL-27

### 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.

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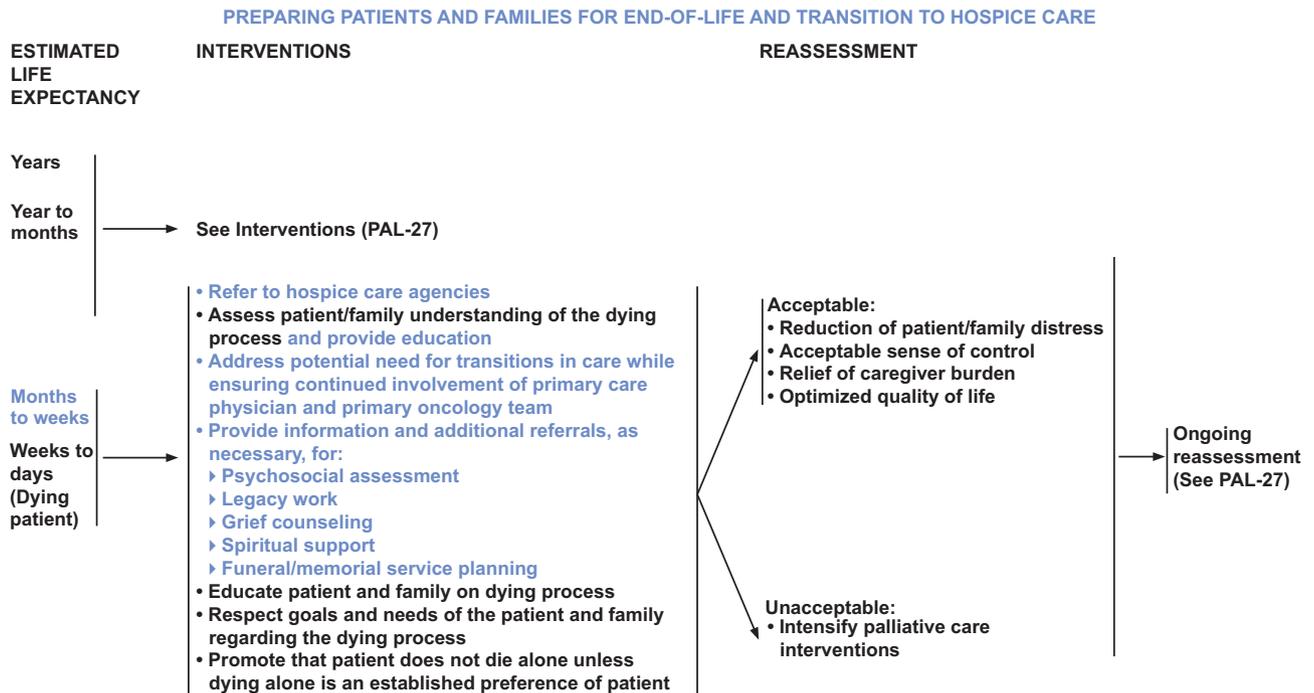
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All recommendations are category 2A unless otherwise noted.

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

### Overview

The aim of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Palliative Care is to help assure that each patient with cancer experiences the best quality of life (QOL) possible throughout the disease trajectory by providing guidance for the primary oncology team. The NCCN Palliative Care Panel is an interdisciplinary group of representatives from NCCN Member Institutions, consisting of experts in medical oncology, hematology and hematology/oncology, pediatric oncology, neurology and neurooncology, anesthesiology, psychiatry and psychology, internal medicine, palliative care and pain management, and geriatric medicine. The NCCN Guidelines for Palliative Care include recommendations for the screening, assessment, and management of palliative care needs of patients with cancer and their families/caregivers. These guidelines were developed and are updated annually—or sooner based on available evidence—by the collaborative efforts of these experts based on their clinical



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PAL-28

cal experience and available scientific evidence. The most recent and full version of these guidelines is available at [NCCN.org](http://NCCN.org).

## Background

More than 1.68 million people are expected to be diagnosed with cancer in the United States in 2017, and 600,920 people are expected to die of the disease.<sup>1</sup> Global cancer rates are increasing, with an associated increase in the number of cancer survivors living with symptoms and disabilities as a result of their disease and/or its treatment (see the NCCN Guidelines for Survivorship, available at [NCCN.org](http://NCCN.org)).<sup>1-3</sup> In a large observational cohort study, more than one-third of patients with cancer reported moderate to severe symptoms in most categories (pain, nausea, anxiety, depression, shortness of breath, drowsiness, well-being, loss of appetite, and tiredness) in the last weeks of life.<sup>4</sup> Improved access to palliative care may help address the challenges faced by patients with

cancer and their families. During the past 20 years, increasing attention has been paid to QOL issues in oncology throughout the disease trajectory.<sup>3,5-10</sup> Palliative care in oncology began as hospice and end-of-life (EOL) care but has developed into an integral part of comprehensive cancer care, often provided early in the disease course, concurrent with active treatment.<sup>3,11-16</sup>

Palliative care should be initiated by the primary oncology team (including physicians, nurses, social workers, mental health professionals, chaplains, physician assistants, pharmacists, and dietitians) and then augmented via collaboration with an interdisciplinary team of palliative care experts to address intractable symptoms and/or complex psychosocial issues. When further anticancer therapy is unlikely to provide additional benefit or is expected to do more harm than good, palliative care becomes the predominant care offered to patients with advanced cancer. Additionally, palliative care efforts should reach beyond the patient to family and caregivers. Several

## Palliative Care, Version 2.2017

groups have described their ideas and approaches for, experience and outcomes with, and barriers to developing successful programs that integrate palliative care into routine oncologic care.<sup>17–31</sup>

### EOL Care in Oncology

When additional anticancer therapy is likely to do more harm than good, palliative care becomes the predominant care offered to patients with advanced cancer. When possible, inpatient palliative care can facilitate transfer to hospice care at home or in a care facility. For those who are too unstable to transfer out of the inpatient setting, palliative care and hospice may provide EOL care for patients in the hospital. Palliative care should continue even after the patient's death in the form of bereavement support for the patient's family and caretakers.

The National Academy of Medicine (formerly the Institute of Medicine) released a consensus report in 2014 entitled “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,” in which experts highlighted the need for improved EOL care. Key findings and recommendations for improved quality of care focused on person-centered, family-oriented care; clinician–patient communication and advance care planning; professional education and development; policies and payment systems; and public education and engagement.<sup>32</sup> EOL care can often be more aggressive than what is supported by current evidence. Generally, Medicare patients with cancer with a poor prognosis have received highly intensive EOL care.<sup>33</sup> Furthermore, chemotherapy administration late in the disease course, including in the last days of life, is becoming more common,<sup>34,35</sup> and oncologists have reported that they have found hospice regulations and reimbursement limitations too restrictive.<sup>36</sup> Overall, provision of EOL care is inconsistent and varies widely across regions, even among comprehensive cancer centers.<sup>33,37,38</sup>

Generally speaking, earlier incorporation of palliative care in the cancer care continuum has been associated with improved EOL outcomes and has been shown to positively impact EOL care trajectories (ie, stability of care setting).<sup>39</sup> Palliative care consultations for patients with advanced cancer have also been shown to reduce the quantity and intensity of life-prolonging care received toward the EOL.<sup>40–44</sup> Conversely, the lack of palliative care team

consultation has been shown to be a predisposing factor for futile life-sustaining treatments at EOL.<sup>45</sup> An observational study suggested that inpatient palliative care led to fewer or no transitions in care settings at EOL.<sup>39</sup> Studies have also shown the potential for community-based or home-based palliative care services to positively influence patient care. These services have been associated with a reduced need for EOL emergency department visits, reduced length and frequency of hospitalization, and fewer intensive care unit (ICU) admissions and in-hospital deaths.<sup>40–44</sup> Palliative care has been shown to reduce symptom burden, improve QOL, and increase the odds of dying at home. Similarly, a 2013 Cochrane Database systematic review that analyzed home palliative care in patients with advanced illness demonstrated a reliable reduction of symptom burden and an increased likelihood of dying at home without a negative impact on caregiver grief.<sup>46</sup> Additionally, a retrospective analysis of patients with advanced cancer highlighted the importance of early palliative care consultations (>3 months before death) and revealed an association between outpatient palliative care and decreased aggressiveness of EOL care.<sup>47</sup>

### Hospice

Hospice is the most established model of EOL palliative care for patients with a prognosis of <6 months and is eligible for coverage by third-party payers and Medicare. Enrollment in hospice has been shown to reduce hospitalization and receipt of high-intensity, nonhospice care toward the EOL. In a matched cohort study of 86,851 patients with cancer with a poor prognosis, receiving hospice care (vs no hospice care) at EOL was associated with significantly lower hospitalization rates, fewer ICU admissions and invasive procedures, and lower healthcare costs in the last year of life.<sup>48</sup> Multiple additional studies have produced similar findings with regard to hospitalizations, emergency department visits, noncancer clinic visits, and cost savings.<sup>49–51</sup> Importantly, hospice care is also linked to important improvements in patient and caregiver QOL.<sup>52</sup>

Unfortunately, underutilization of hospice care is a persistent issue. The Dartmouth Atlas Project examined a 20% sample of Medicare beneficiaries with poor-prognosis cancers who died in 2003–2007 and 2010. In 2010, 61.3% of patients with cancer accessed hospice care during their last month of life

(vs 54.6% in 2003–2007), but the average length of stay (LOS) in hospice care was only 9.1 days (vs 8.7 in 2003–2007).<sup>37,38</sup> According to the 2015 edition of the National Hospice and Palliative Care Organization's *Facts and Figures: Hospice Care in America*, 36.6% of Medicare decedents with a cancer diagnosis accessed  $\geq 3$  days of hospice care in 2001, and this percentage increased to 43.3% by 2007.<sup>53</sup> However, despite the 6-month prognosis eligibility, the median LOS for hospice patients in 2014 was just 17.4 days. Approximately 36% of hospice patients died or were discharged within 7 days of admission to hospice care.<sup>53</sup>

Recent studies suggest there is a continued underuse of hospice services among eligible patients.<sup>54,55</sup> Unfortunately, most US patients who receive hospice care are referred too late for hospice care to exert its full benefit, and many patients are never referred at all.<sup>49,53,56</sup>

Several groups have examined patterns in referrals to hospice care. A recent study at an academic medical center showed marked and unwarranted variation in hospice LOS within divisions and by doctor. For example, in the thoracic oncology division, several oncologists had patients with an average LOS of 36 days, whereas others were clustered around 4 days for the same patient population. However, oncologists were receptive to feedback and training.<sup>57</sup> Through establishing hospice referrals as a quality improvement measure, one health system reported that hospice LOS doubled within a year of implementation.<sup>58</sup> Similarly, another study revealed that educational outreach and implementation of specific triggers for palliative care consultation were associated with increased hospice referrals and LOS.<sup>59</sup> Targeted interventions may lead to enhanced use of hospice care and improved EOL experiences for patients and their families.

## NCCN Recommendations

### Preparing Patients and Families for EOL and Transition to Hospice Care

For patients with an estimated life expectancy of years or years to months (see PAL-27; page 991), providers should assess prognostic awareness and determine patient/family understanding of the expected disease course. The NCCN Guidelines Panel recommends that practitioners engage in clear, consistent discussion with the patient and family about prognosis and

anticipated care needs on an ongoing basis, which includes facilitating advance care planning and assessing decision-making capacity and the potential need for a surrogate decision-maker. Eliciting values and preferences with respect to QOL and determining the need for specialized palliative care or eligibility and readiness for hospice care are also important. When the patient's functional status indicates a 6- to 12-month prognosis, a dedicated "hospice information" visit with the oncologist may ease the transition to hospice care for the patient and family, and ensure that the oncologist remains involved.

Regular reassessment is recommended. Indicators of acceptable patient outcomes from these interventions include reduced distress, acceptable sense of control, relief of caregiver burden, strengthened relationships, optimized QOL, and acceptable personal growth and enhanced meaning. The panel recommends that palliative care interventions be intensified in the absence of these outcomes.

For patients with an estimated life expectancy of months to weeks or weeks to days (see PAL-28; page 992), referral to hospice agencies should be a priority. Clinicians should assess patient/family understanding of the dying process and provide education as desired. Providers should address the potential need for transitions in care while ensuring continued involvement of the primary care physician and primary oncology team. Patients should receive information and additional referrals as needed for psychosocial assessment, legacy work, grief counseling, spiritual support, and funeral/memorial service planning. It is important to respect the goals and needs of the patient and family regarding the dying process and to ensure that the patient does not die alone unless it is their established preference.

Regular reassessment is again recommended. Acceptable outcomes include reduced patient/family distress, acceptable sense of control, relief of caregiver burden, and optimized QOL. In the absence of these outcomes, the NCCN panel strongly recommends that clinicians intensify palliative care interventions.

**Panel Discussion and Updates:** For the 2017 update of the NCCN Guidelines, the panel dedicated considerable efforts to reevaluating recommendations for care transitions and EOL care. As a result, several algorithm pages were restructured and retitled to more clearly deliver the intended message.

## Palliative Care, Version 2.2017

The panel discussion initially began with a review of the algorithm page formerly titled “Goals/Values/Expectations, Educational and Informational Needs, and Cultural Factors Affecting Care for the Patient and Family.” In previous versions, the recommendations in this section addressed a wide variety of important care issues ranging from the assessment and reassessment of prognostic understanding, communication preferences, cultural concerns, and the evolution of these factors over the course of disease. Recommended interventions were separated into groups by estimated life expectancy: years/years to months/months to weeks, or weeks to days (dying patient).

Several panel members expressed concern regarding the wide variety of topics addressed in this section and the density of the information. Others felt that the information already was, or might be, delivered more effectively in other sections of the guideline. The panel then discussed the intent and goals behind certain language and topics they felt were critical. One panel member suggested that the algorithm could more clearly define how often practitioners should discuss prognostic awareness with patients and family/caregivers, whereas another panel member raised the possibility of reframing this information in an algorithm on shared decision-making. It was suggested that the current content provided important guidance on appropriate triggers for reassessment in palliative care and that these concepts were not adequately addressed elsewhere in the guideline. Others viewed this section as an opportunity to provide critical information to help assess “congruence of care,” such as whether the care being provided was congruent with the patient and family’s goals, values, and expectations regarding palliative and EOL care. This point was considered particularly important, because these goals, values, and expectations are likely to shift with disease progression and thus their needs would evolve over the course of the disease.

The discussion next turned to the importance of referral to hospice early enough in the disease course for patients to receive its full benefit. A panel member noted that the average nationwide hospice stay for patients with cancer was 17 to 19 days, and that one-third of hospice patients with cancer die after a LOS of  $\leq 7$  days. It was further emphasized that these statistics fail to account for patients with late referrals to hospice who die between the time of hospice referral and enrollment. Additionally, a panel mem-

ber quoted the worrisome statistic that only 53% to 54% of patients with cancer are dying in hospice care, not because of patient preference but rather because the oncologist did not recommend hospice care early enough.

After significant discussion, the panel arrived at a consensus to shift the focus of these algorithms to help oncologists navigate the patient and family’s needs during the transition to EOL care and/or hospice. Therefore, the title of this section was revised to “Preparing Patients and Families for End-of-Life and Transition to Hospice Care” (see PAL-27 and PAL-28; pages 991 and 992, respectively). The content was reorganized and streamlined, paring down the reassessment criteria. The panel decided to reorganize recommendations per estimated life expectancy, adding the population of patients with an estimated life expectancy of “months to weeks” to the recommendations originally intended only for those with an estimated life expectancy of “weeks to days” (see PAL-28; page 992). The intervention list was reorganized so that the first recommended intervention became “refer to hospice agencies.” This reorganization was established to prompt more timely referrals to hospice and ensure that the care provided at EOL would more closely align with the patient and families’ stated preferences and values.

### Conclusions

Important recent updates to the NCCN Guidelines for Palliative Care regarding the transition to hospice and EOL care are highlighted in these NCCN Guidelines Insights. The NCCN Guidelines are updated at least annually, and in the interim when new, high-quality clinical data become available. The most up-to-date version of these continuously evolving guidelines is available at NCCN.org. The recommendations in the NCCN Guidelines are based on evidence from clinical trials, where available, and 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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## Palliative Care, Version 2.2017

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### Posttest Questions

1. A 63-year-old man with stage IV lung cancer has opted to discontinue chemotherapy. His oncologist anticipates that the patient has a prognosis of 1 to 2 months. Which of the following actions should be taken first to ensure optimal EOL care?
  - a. Educate the patient and family on the dying process
  - b. Refer to a hospice care agency
  - c. Provide grief counseling
  - d. Assess caregiver burden
2. After meeting with the patient and family, an oncology fellow expresses concern to other members of the care team that the patient and family may have unrealistic expectations about prognosis. What response(s) would be recommended based on the NCCN Guidelines?
  - a. Assess whether specialist palliative care is needed
  - b. Evaluate prognostic awareness on an ongoing basis
  - c. Facilitate a discussion on advance care planning
  - d. Provide education to the patient and family on the expected course of disease
  - e. All of the above
  - f. None of the above
3. True or False: The primary physician and oncology team does not need to continue to provide follow-up and remain involved in care once a patient has been transitioned to hospice.

