

**Fourth Edition  
November 2011**

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- health care teaching institutions;
- health care information technology departments;
- medical specialty and professional societies;
- researchers;
- federal, state and local government health care policy makers and specialists; and
- employee benefit managers.

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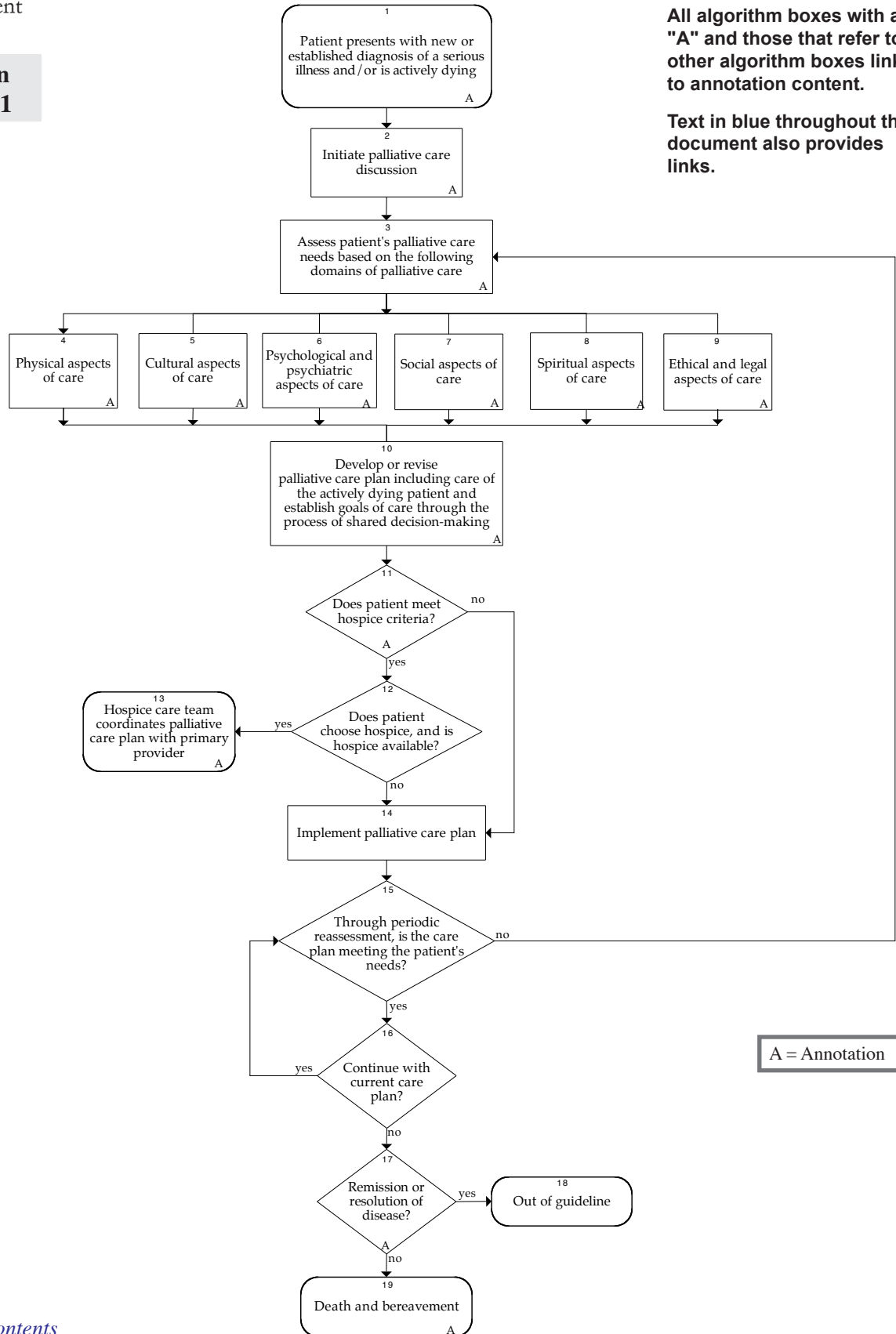
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All algorithm boxes with an "A" and those that refer to other algorithm boxes link to annotation content.

Text in blue throughout the document also provides links.



A = Annotation

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<p><b>Work Group Leader</b>          Martha McCusker, MD,          FACP  <i>Internal Medicine/          Geriatrics, Hennepin County          Medical Center</i></p> <p><b>Work Group Members</b></p> <p><b>Chaplain</b>          Rob Ruff, BCC  <i>HealthPartners Regions          Hospital</i></p> <p><b>Family Medicine/Geriatrics</b>          Lyn Ceronsky, DNP, GNP-          BC, FPCN  <i>Fairview Health Services</i></p> <p>Ken Kephart, MD  <i>Fairview Health Services</i></p> <p>Mabel Rohr, CNP  <i>HealthPartners Medical          Group</i></p> <p><b>Family Medicine/Palliative          Care</b>          Becky Nosan, NP  <i>Allina Medical Clinic</i></p> <p>Kristina Schlecht, MD  <i>Essentia Health</i></p> <p><b>Nursing</b>          Joe Halvorson, RN  <i>Essentia Health</i></p> <p><b>Pharmacist</b>          Bryan Schuler, PharmD  <i>Park Nicollet-Methodist</i></p> <p><b>Social Worker</b>          Danielle TenCate, MSW  <i>HealthPartners Regions          Hospital</i></p> <p><b>Facilitators</b>          Kari Retzer, RN  <i>ICSI</i></p> <p>Linda Setterlund, MA,          CPHQ  <i>ICSI</i></p>	<p><b>Algorithms and Annotations</b> ..... 1-34</p> <p style="padding-left: 20px;">Algorithm .....1</p> <p style="padding-left: 20px;">Disclosure of Potential Conflict of Interest .....3</p> <p style="padding-left: 20px;">Review of Evidence.....3-6</p> <p>Foreword</p> <p style="padding-left: 20px;">Introduction ..... 7-9</p> <p style="padding-left: 20px;">Scope and Target Population.....10</p> <p style="padding-left: 20px;">Aims .....10</p> <p style="padding-left: 20px;">Clinical Highlights ..... 10-11</p> <p style="padding-left: 20px;">Implementation Recommendation Highlights .....11</p> <p style="padding-left: 20px;">Related ICSI Scientific Documents .....11</p> <p style="padding-left: 20px;">Annotations ..... 12-34</p> <p><b>Quality Improvement Support</b> ..... 35-42</p> <p style="padding-left: 20px;">Aims and Measures ..... 36-37</p> <p style="padding-left: 20px;">Implementation Recommendations .....38</p> <p style="padding-left: 20px;">Resources.....38</p> <p style="padding-left: 20px;">Resources Table ..... 39-42</p> <p><b>Supporting Evidence</b>..... 43-59</p> <p style="padding-left: 20px;">References ..... 44-48</p> <p style="padding-left: 20px;">Appendices ..... 49-58</p> <p style="padding-left: 40px;">Appendix A – Myths about Palliative Care.....49-50</p> <p style="padding-left: 40px;">Appendix B – ICSI Shared Decision-Making Model .....51-54</p> <p style="padding-left: 40px;">Appendix C – Pediatrics .....55-56</p> <p style="padding-left: 40px;">Appendix D – Comparison between Palliative Care and Hospice .....57</p> <p style="padding-left: 40px;">Appendix E – Medicare Hospice Benefit: Eligibility and Treatment Plan ..... 58-59</p> <p><b>Document History, Development and Acknowledgements</b>..... 60-62</p> <p style="padding-left: 20px;">Document History .....61</p> <p style="padding-left: 20px;">ICSI Document Development and Revision Process .....62</p>
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## Disclosure of Potential Conflict of Interest

In the interest of full disclosure, ICSI has adopted a policy of revealing relationships work group members have with companies that sell products or services that are relevant to this guideline topic. It is not assumed that these financial interests will have an adverse impact on content. They are simply noted here to fully inform users of the guideline.

Ken Kephart is on the Advisory Committee for TC Medical Society Honoring Choices Minnesota ACP project (unpaid).

Mabel A. Rohr received payment from Augsburg College for geriatric program content for PA students.

Kristina Schlecht is a board member for Hospice of the Red River Valley (unpaid).

No other work group members have potential conflicts of interest to disclose.

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## Review of Evidence

A consistent and defined process is used for literature search and review for the development and revision of ICSI guidelines. Literature search terms for the current revision of this document include palliative care assessments, cultural influence in medical care, depression in serious illness, spiritual influences in medical care, ethics in dying patients, advance care planning, patient and family involvement, care conferences, shared decision-making, early palliative care interventions, advance directives and end-of-life planning from July 2009 through July 2011.

In 2011, ICSI began its transition to the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system as a method of assessing the quality of evidence and writing recommendations.

GRADE has many advantages over other systems including:

- development by a widely representative group of international guideline developers;
- explicit and comprehensive criteria for downgrading and upgrading quality of evidence ratings;
- clear separation between quality of evidence and strength of recommendations that includes a transparent process of moving from evidence evaluation to recommendations;
- clear, pragmatic interpretations of strong versus weak recommendations for clinicians, patients, and policy makers;
- explicit acknowledgement of values and preferences; and
- explicit evaluation of the importance of outcomes of alternative management strategies.

In the GRADE process, evidence is gathered related to a specific question. Systematic reviews are utilized first. Further literature is incorporated with randomized control trials or observational studies. The evidence addresses the same population, intervention, comparisons and outcomes. The overall body of evidence for each topic is then given a quality rating.

Once the quality of the evidence has been determined, recommendations are formulated to reflect their strength. The strength of a recommendation is either strong or weak. Low quality evidence rarely has a strong recommendation. Only outcomes that are critical are considered the primary factors influencing a recommendation and are used to determine the overall strength of this recommendation. Each recommendation answers a focused health care question.

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## Review of Evidence

Category	Quality Definitions	Strong Recommendation	Weak Recommendation
<b>High Quality Evidence</b>	Further research is very unlikely to change our confidence in the estimate of effect.	The work group is confident that the desirable effects of adhering to this recommendation outweigh the undesirable effects. This is a strong recommendation for or against. This applies to most patients.	The work group recognizes that the evidence, though of high quality, shows a balance between estimates of harms and benefits. The best action will depend on local circumstances, patient values or preferences.
<b>Medium Quality Evidence</b>	Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.	The work group is confident that the benefits outweigh the risks, but recognizes that the evidence has limitations. Further evidence may impact this recommendation. This is a recommendation that likely applies to most patients.	The work group recognizes that there is a balance between harms and benefit, based on moderate quality evidence, Or that there is uncertainty about the estimates of the benefits and harms of the proposed intervention that may be affected by new evidence. Alternative approaches will likely be better for some patients under some circumstances.
<b>Low Quality Evidence</b>	Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change. The estimate or any estimate of effect is very uncertain.	The work group feels that the evidence consistently indicates the benefit of this action outweighs the harms. This recommendation might change when higher quality evidence becomes available.	The work group recognizes that there is significant uncertainty about the best estimates of benefits and harms. Very weak recommendation, other alternatives may be equally reasonable.

### Supporting Literature

In addition to evidence that is graded and used to formulate recommendations, additional pieces of literature will be used to direct the reader to other topics of interest. This literature is not given an evidence grade and is instead used as a reference for its associated topic. These citations are noted by (*author, year*) and are found in the references section of this document.

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**Recommendations Table**

The following table is a list of evidence-based recommendations for Palliative Care.

Note: Other recommendation language may appear throughout the document as a result of work group consensus, but is not included in this evidence-based recommendations table.

<b>Topic</b>	<b>Quality of Evidence</b>	<b>Recommendation(s)</b>	<b>Strength of Recommendation</b>	<b>Annotation Number</b>	<b>Relevant References</b>
Actively dying patients	Low	Clinicians should recognize patients with signs of imminent death or those patients who are receiving non-beneficial, low-yield therapy.	Strong	1	<i>Balaban, Brody, Chochinov</i>
	Low	Clinicians should discuss the likelihood of disease progression to death with patients and/or their families.	Strong	1, 10	<i>Brody, Lamont, SUPPORT</i>
Advance care plans	Low	Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes.	Strong	2	<i>Balaban, Block, Gries, Lee, Sinclair, Vandekieft, Weissman</i>
	Low	An advance care plan that includes the designation of a health care agent and completion of a health care directive with the preferences and goals of the patient and family should be created and used.	Strong	9	<i>Dunn, Levy, Hickman, Warm</i>
Assessment tools	Low	Clinicians should use a validated assessment tool to assess palliative care needs.	Strong	3	<i>Chang, Moro, Phillip</i>
Care conferences	Low	Care conferences with the patient, family and an interdisciplinary health care team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, goals and plan of care.	Strong	3	<i>Curtis, Gries, McDonagh, Moneymaker</i>
Care of the dying patient	Low	Ongoing communication with the patient and/or family regarding the dying process and the treatment plan is recommended.	Strong	10	<i>Brody</i>
Communication	Low	Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes.	Strong	2	<i>Balaban, Block, Gries, Lee, Sinclair, Vandekieft, Weissman</i>
Cultural aspects	Low	A cultural assessment should be an integral component of the palliative care plan.	Strong	5	<i>Kagawa-Singer, Searight</i>

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**Review of Evidence**

<b>Topic</b>	<b>Quality of Evidence</b>	<b>Recommendation(s)</b>	<b>Strength of Recommendation</b>	<b>Annotation Number</b>	<b>Relevant References</b>
Early intervention	Low	Palliative care should begin at the time of diagnosis of a serious condition and continue through cure, or until death and then into the bereavement period.	Strong	1	<i>Kass-Bartelmes; Morrison, 2004; Steinhauer; Temel</i>
Informed consent	Low	Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker.	Strong	9	<i>Arnold, Silveria</i>
Interpreters	Low	The clinician should utilize professional medical interpreters whenever possible.	Strong	5	<i>Norris, Searight</i>
Psychological and psychiatric status	Low	A psychological assessment should be an integral component of the palliative care plan.	Strong	6	<i>Bakitas, Block, Chochinov, Werth</i>
Referral to palliative care specialists	Low	Palliative care discussion or referral should be considered whenever the patient develops a serious illness.	Strong	2	<i>Weissman</i>
Social assessment	Low	A social assessment should be an integral component of the palliative care plan.	Strong	7	<i>Curtis; Gries; Morrison, 2004</i>
Spiritual needs	Low	A spiritual assessment should be an integral component of the palliative care plan.	Strong	8	<i>Sulmasy, Pulchaski, Reed, Post</i>
	Low	Clinicians should utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support.	Strong	8	

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# Foreword

## Introduction

The World Health Organization in 2002 stated that "palliative care is an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." The National Consensus Guidelines for Palliative Care initially released in 2004 state the goals of palliative care are to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands the traditional disease-modifying medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with the decision-making and providing opportunities for personal growth. Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care. Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient and family needs, values, beliefs and culture(s) (Lorenz, 2008).

Nearly all health care professionals offer palliative care to their patients, much the same way they offer varying degrees of many different medical specialties. Indeed there is a presumption that providers will all be able to provide a primary level of palliation for symptoms commonly encountered in their respective practices. Depending on individual interest and prevalence of specific symptoms or situations in a given practice, many providers develop additional skills and provide a secondary level of palliative care. More challenging cases of distressing symptoms or complicated communication systems would be appropriate for referral to tertiary palliative care to a multidisciplinary team that includes board certified specialists where available. These specialists are also responsible for teaching other providers and building systems to guarantee the highest possible level of palliative care expertise for a population of patients.

Palliative care may be provided simultaneously with other medical interventions that treat the underlying disease process, but the intensity of palliative care services provided accelerates as the illness progresses.

The word "palliate" is derived from the Latin word *palliatum*, which means to "cloak or cover." Thought of in this way, it is meant to convey care that wraps the patient with support to reduce the burden of illness. Broadly defined as the reduction of suffering, palliative care is part of everyday practice for health care professionals. By intervening with patients at the onset of a serious illness, health care professionals can assure that appropriate interventions offered meet the goal of reducing the burden of disease. Examples of illnesses that meet this definition would include heart failure, chronic obstructive lung disease, chronic renal failure, metastatic cancer, dementia, amyotrophic lateral sclerosis, multiple sclerosis, advanced HIV infection, and others. Sometimes these conditions and diseases are reversible, but most are progressive at different and occasionally unpredictable rates.

In America, "palliative care" and "hospice care" are terms often used interchangeably. That is not only incorrect, but it also limits access to appropriate services early in the course of illness and treatment. Hospice care is a philosophy of care with health care benefits under most insurance payers. It is designed for patients with a limited life expectancy of six months or less (according to Medicare hospice coverage criteria) and is chosen by patients who want comfort rather than life-prolonging care. Hospice is a defined CMS benefit with explicit enrollment criteria, interdisciplinary practice guidelines, and quality assurance and performance improvement requirements. The majority of the medical community is not well versed in this.

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**HOSPICE:** The patient has *both*

- a limited life expectancy (specifically six months or less)
- *and* the goals for care are exclusively to achieve and maintain comfort, regardless of the symptom burden

**PALLIATIVE CARE:** The patient has *either*

- a limited life expectancy (regardless of symptom burden or goals for care)
- *or* a significant symptom burden (regardless of prognosis or goals for care) *or* goals for care exclusively to achieve and maintain comfort (regardless of prognosis or symptom burden)



All hospice is palliative care, but not all palliative care is hospice.

By defining appropriate evaluations and outcomes, this guideline attempts to assist the clinician with the appropriate discussions, clinical interventions, and utilization of palliative care and hospice expertise when necessary. Early recognition of life-limiting illness by clinicians and an understanding of disease progression by patients and families are both critical for appropriate interventions and use of this guideline. As illness progresses and the need for interdisciplinary approaches to the relief of suffering increases, the intensity of palliative interventions will also increase. Due to escalating burden, ongoing communication and reassessment are critical to achieving satisfactory outcomes.

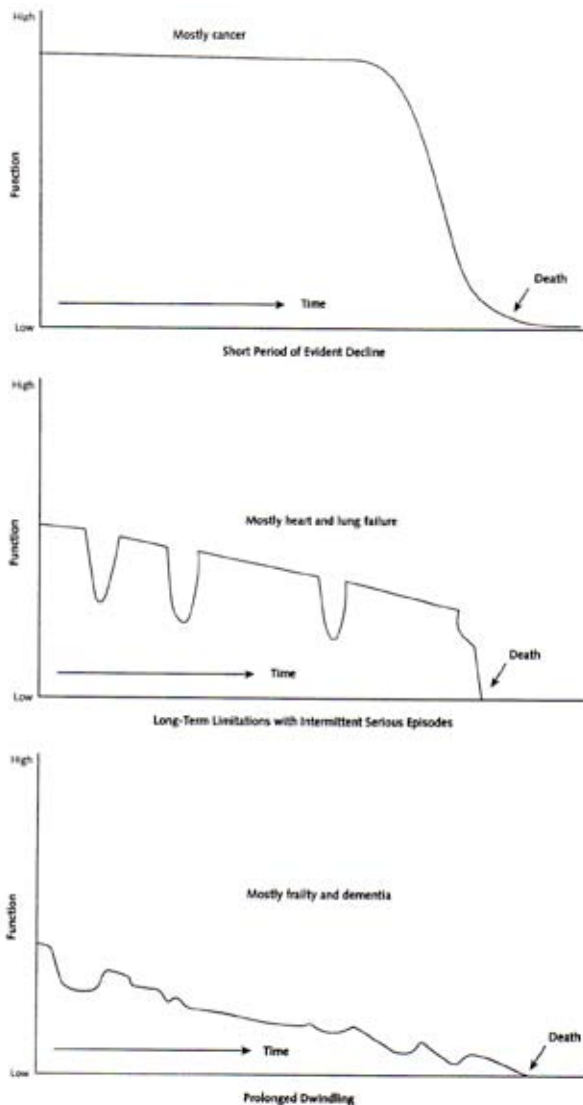
#### **Efficacy and cost-effectiveness of palliative care**

In 2006, the National Quality Forum identified 38 preferred practices in palliative care. Quality measurement tools have been developed for symptom management, patient and family satisfaction and financial impact. There is a clear need for continuing research addressing outcomes of palliative care – whether that care is delivered in hospitals or outpatient settings. Positive outcomes have been demonstrated by hospital-based programs in three areas: relief of physical and emotional suffering, improved patient and family satisfaction, and reduced costs (*Gade, 2008; Morrison, 2008; Ciemins, 2007; Campbell, 2006; Elsayem, 2004; Smith, 2003; Higginson, 2002*).

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**Trajectories of late-life illness (see following graphs)**

The natural history of most cancers, without treatment, is generally marked by a period, which may be prolonged, where patients enjoy good functional status and symptoms are readily treated. At some point, as the disease advances, function begins to decline, and from there the trajectory of the illness tracks steadily downward. It was this model that informed the inclusion of a limited life expectancy as a criterion for hospice services. Other chronic medical conditions, however, manifest different patterns. Patients with conditions such as congestive heart failure and chronic obstructive pulmonary disease have periodic exacerbations where they may become quite ill, and even pre-morbid. Medical treatment may successfully improve their status, although functional recovery may not return quite to the pre-episode level. A graph would show a sawtooth pattern, with the sharp downward inflections marking the acute illnesses, during which death may occur, with an overall slow downward slope in the curve. Progressive neurologic illnesses, such as Parkinson's and Alzheimer's diseases, generally show a slow overall decline in slope, which may occur over years, with occasional downward spikes marking episodes of infection (e.g., pneumonia) during which a patient might die (*Lorenz, 2008*). See [Appendix D, "Comparison between Palliative Care and Hospice,"](#) for disease-specific conditions and symptoms.



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## Scope and Target Population

This guideline will assist primary and specialty care providers in identifying and caring for adult patients with a serious (potentially life-limiting, life-threatening or chronic, progressive) illness who may benefit from palliative care. This guideline is appropriate for patients who still desire curative or life-prolonging treatments, or patients who are best served by active end-of-life management. It will outline key considerations for creating a plan of care to meet patient, family and other caregivers' needs throughout the continuum of care.

This guideline will not assist providers in the identification or care for pediatric patients with life-threatening or chronic progressive illness. See [Appendix C, "Pediatrics,"](#) for a brief overview of consideration for pediatric patients.

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## Aims

1. Increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care. (*Annotations #1, 2*)
2. Improve the effectiveness and comfort level of primary care clinicians in communicating the necessity and benefits of palliative care with those patients with a serious illness. (*Annotation #2*)
3. Improve the assessment of the identified patient's palliative care needs, utilizing the domains of palliative care. (*Annotations #3, 4-9*)
4. Increase the percentage of patients in the early stages of a serious illness who have a care plan identified and/or documented. (*Annotations #3, 10*)
5. Improve the ongoing reassessment and adjustment of the patient's plan of care as the condition warrants, utilizing the domains of palliative care. (*Annotations #3, 4-9*)
6. Increase the completion, documentation and ongoing utilization of advance directives for patients with a serious illness. (*Annotations #3, 9*)

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## Clinical Highlights

- Planning for palliative care should begin early in the patient's journey of a serious illness. (*Annotations #1, 2; Aim #1*)
  - Where palliative care consultation is available, referral to this service should be considered early on in the patient's care if there are complex needs. Primary care clinicians should begin palliative care planning early through palliative care conversations with their patients. (*Annotations #1, 2; Aim #1*)
- Health care providers should complete a systematic review of patients' palliative care needs and document patients' goals for care and advance directives. (*Annotations #3, 4-9; Aims #3, 6*)
- Suffering is common in this patient population. It commonly presents itself in physical symptoms, thus controlling symptoms to maximize patient comfort is a cornerstone function of palliative care. Also important are the recognition, assessment and management of non-physical areas of suffering that are important to the patient. These include cultural, psychological, social, spiritual, financial, ethical and legal issues. Where available, consultation with palliative care specialists should be considered for all of these symptoms. (*Annotations #4-9; Aim #3*)

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- The ability to address these issues depends on the quality of communication with patients and families. Setting realistic goals of care and providing realistic hope are essential. Engaging patients in decisions about their care increases their involvement and satisfaction. Shared Decision-Making (SDM) is one method to engage patients. (*Annotations #2, 3, 10; Aim #2*)
- Palliative care is compatible with all other medical treatments. (*Introduction*)
- Health care providers play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the patient's death. (*Annotation #19*)

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## **Implementation Recommendation Highlights**

The following system changes were identified by the guideline work group as key strategies for health care systems to incorporate in support of the implementation of this guideline.

1. Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice.
2. Develop a process that will allow clinicians to identify and assess patients who would benefit from palliative care services. This process should include the use of a screening tool that utilizes the domains of palliative care.
3. Develop scripts for health care professionals that will assist them in initiating and discussing palliative care services.
4. Develop a process for timely referral to palliative care consultation for patients with a serious illness.

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## **Related ICSI Scientific Documents**

### **Guidelines**

- [Assessment and Management of Chronic Pain](#)
- [Heart Failure in Adults](#)
- [Major Depression in Primary Care](#)
- [Management of Chronic Obstructive Pulmonary Disease \(COPD\)](#)

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## Algorithm Annotations

### 1. Patient Presents with New or Established Diagnosis of a Serious Illness and/or Is Actively Dying

#### Recommendations:

- Palliative care should begin at the time of diagnosis of a serious condition and continue through cure, or until death and then into the family's bereavement period (*low quality evidence, strong recommendation*).
- Clinicians should recognize patients with signs of imminent death or those patients who are receiving non-beneficial or low-yield therapy (*low quality evidence, strong recommendation*).
- Clinicians should discuss the likelihood of disease progression to death with patients and/or their families (*low quality evidence, strong recommendation*).

Both clinicians and patients generally don't recognize early on those individuals who would benefit from palliative care planning. Early identification of patients with conditions that would benefit from palliative care can be accomplished by considering conditions and symptoms that are appropriate for palliative care services.

General considerations clinicians should use to identify patients who would benefit from palliative care include:

- Disease progression, especially with functional decline
- Pain and /or other symptoms not responding to optimal medical treatment
- Need for advance care planning

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**Algorithm Annotations**

Conditions that may prompt the initiation of palliative care discussions include these (this is not intended to be an all-inclusive list):

<b>Debility/Failure to Thrive</b>	<ul style="list-style-type: none"> <li>• Greater than three chronic conditions in patient over 75 years old</li> <li>• Functional decline</li> <li>• Weight loss</li> <li>• Patient/family desire for low-yield therapy</li> <li>• Increasing frequency of outpatient visits, emergency department visits, hospitalizations</li> </ul>
<b>Cancer</b>	<ul style="list-style-type: none"> <li>• Uncontrolled symptoms due to cancer or treatment</li> <li>• Introduced at time of diagnosis – if disease likely incurable</li> <li>• Introduced when disease progresses despite therapy</li> </ul>
<b>Heart Disease</b>	<ul style="list-style-type: none"> <li>• Stage III or IV heart failure despite optimal medical management</li> <li>• Angina refractory to medical or interventional management</li> <li>• Frequent emergency department visits or hospital admissions</li> <li>• Frequent discharges from implanted defibrillators despite optimal device and antiarrhythmic management</li> </ul>
<b>Pulmonary Disease</b>	<ul style="list-style-type: none"> <li>• Oxygen-dependent, O<sub>2</sub> sats less than 88% on room air</li> <li>• Unintentional weight loss</li> <li>• Dyspnea with minimal to moderate exertion</li> <li>• Other pulmonary diagnoses, e.g., pulmonary fibrosis, pulmonary hypertension</li> </ul>
<b>Dementia</b>	<ul style="list-style-type: none"> <li>• Refractory behavioral problems</li> <li>• Feeding problems – weight loss</li> <li>• Caregiver stress – support needed</li> <li>• Frequency of emergency department visits</li> <li>• Increased safety concerns</li> </ul>
<b>Liver Disease</b>	<ul style="list-style-type: none"> <li>• Increased need for paracentesis for removal of ascitic fluid</li> <li>• Increased confusion (hepatic encephalopathy)</li> <li>• Symptomatic disease</li> </ul>
<b>Renal Disease</b>	<ul style="list-style-type: none"> <li>• Dialysis</li> <li>• Stage IV or Stage V kidney disease</li> </ul>
<b>Neurologic</b>	<ul style="list-style-type: none"> <li>• Stroke</li> <li>• Parkinson's</li> <li>• ALS – amyotrophic lateral sclerosis</li> <li>• MS – multiple sclerosis</li> </ul>

Many residents in long-term care facilities and patients with poor social support have these symptoms and should be assessed for palliative care.

The work group offers a comparison of conditions and symptoms appropriate for palliative care and hospice. See [Appendix D](#).

Unfortunately, accurately predicting death can only be identified by retrospective measures. Multiple studies have shown that physicians overestimate prognosis by a factor of two or more. The medical literature also shows that patients with terminal illness often don't recognize that they are dying, or are unable to acknowledge the fact even to themselves until very late. Life-limiting illness is usually defined as the question "*Would you be surprised if your patient died within the next two years?*" This definition significantly broadens the identified population associated with hospice care to those who would benefit from palliative care. Appropriate medical interventions need to address suffering that occurs due to pain, and other physical symptoms, and psychological issues. Other domains that should be addressed by an interdisciplinary team include cultural, spiritual, ethical, legal and social issues. The care plan created includes the caregivers

and family (*National Consensus Project, 2009; National Quality Forum, 2006*). Palliative care can occur simultaneously with curative therapies, or may be the sole focus of care.

### **Actively Dying Patient**

The point in time at which the death of a patient appears inevitable is often very difficult for health care providers, as the health education system is geared much more toward "cure" and the prolonging of life rather than "palliation" or "comfort care," with little training in communication among providers, patients and their families. This may result in a continuation of invasive treatments that have only a small chance of effectiveness yet may add significantly to patient discomfort, or result in provider withdrawal from the patients and family during the terminal phase of an illness.

The care of seriously ill patients is often fragmented, inconsistent, lacking needed coordination and communication among health care providers and patients, and providing inadequate emotional support. Studies document deficiencies in the care of seriously ill patients in communication and treatment of pain and other symptoms.

Diagnosing dying is a complex process. Physicians are frequently inaccurate about the length of time left to a patient before he/she dies. Each individual patient is different. Physicians are trained to cure patients and will often continue aggressive, invasive procedures and treatments at the expense of making the patient comfortable. There is often a reluctance to make the diagnosis of dying if any hope of improvement exists and even more so if no definite diagnosis has been made. When recovery is uncertain, it is better to discuss this rather than giving false hope to the patient and family.

This portion of the guideline is meant to aid providers in identifying those patients actively dying or those to whom aggressive therapy is no longer the best option. These patients may not have been previously identified as palliative care patients. Also see [Annotation #10, "Develop or Revise Palliative Care Plan Including Care of the Actively Dying Patient and Establish Goals of Care through the Process of Shared Decision-Making,"](#) for care of the dying patient.

The following signs and symptoms may indicate that death is approaching. Not all individuals will show all of these signs.

- Delirium, often manifested by increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently.
- Withdrawal from active participation in social activities.
- Increased periods of sleep, lethargy.
- Decreased intake of food and liquids.
- Periods of pausing in breathing (apnea) whether awake or sleeping. Very rapid breathing or cyclic changes in the patterns of breathing (Cheyne-Stokes respirations). Other abnormal breathing patterns.
- Patient reports seeing persons who have already died.
- Patient states that he or she is dying.
- Patient requests family visit to settle unfinished business and tie up loose ends.
- Inability to heal or recover from wounds or infections.
- Increased swelling (edema) of either the extremities or the entire body.
- Inability to arouse patient at all (coma) or ability to arouse patient only with great effort, but patient quickly returns to severely unresponsive state (semicoma).

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- Severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality.
- Increased respiratory congestion or fluid buildup in the lungs. Shortness of breath.
- Inability to swallow any fluids at all. Not taking food by mouth. Vomiting.
- Patient breathing through wide open mouth continuously and no longer can speak even if awake.
- Urinary or bowel incontinence in a patient who was not incontinent before.
- Marked decrease in urinary output and darkening color of urine or very abnormal color of urine, such as red or brown.
- Blood pressure dropping dramatically from patient's normal blood pressure range (more than a 20-30 point drop).
- Systolic blood pressure below 70. Diastolic blood pressure below 50.
- Patient's extremities feel very cold to the touch.
- Fever.
- Patient complains that his or her legs/feet are numb or cannot be felt at all.
- Cyanosis, or a blue or purple coloring to the patient's arms and legs, especially the hands and feet (mottling).
- Patient's body is held in a rigid unchanging position.

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## 2. Initiate Palliative Care Discussion

### Recommendations:

- Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes (*low quality evidence, strong recommendation*).
- Palliative care discussion or referral should be considered whenever a patient develops a serious illness (*low quality evidence, strong recommendation*).

While all patients who develop a serious illness can benefit from a palliative care approach, currently work force shortages and resource constraints present barriers to meeting all needs. In some diseases like cancer, involving palliative care at the time of diagnosis is becoming a measure of clinical excellence. Efforts are also underway in several areas to regularly initiate advance care planning at age 50 (See Resources, Honoring Choices Minnesota). For many patients a hospital admission is a common trigger to consider a palliative care discussion or referral. A recent consensus panel convened by the Center to Advance Palliative Care developed primary and secondary criteria for two checklists – one upon admission and one for daily rounds – to be used to screen patient for unmet palliative care needs (*Weissman, 2011*). The hope is that a checklist approach combined with educational initiatives and other system-change work will allow hospital staff and clinicians engaged in day-to-day patient care to identify and begin to address palliative care needs themselves while reserving specialty palliative care services for more complex problems.

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## Algorithm Annotations

### \*Criteria for a Palliative Care Assessment at the Time of Admission

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A potentially life-limiting or life-threatening condition *and* . . .

#### Primary Criteria<sup>a</sup>

- The "surprise question": *You would not be surprised if the patient died within 12 months or before adulthood*
- Frequent admissions (e.g., more than one admission for same condition within several months)
- Admission prompted by difficult-to-control physical or psychological symptoms (e.g., moderate-to-severe symptom intensity for more than 24–48 hours)
- Complex care requirements (e.g., functional dependency; complex home support for ventilator/antibiotics/feedings)
- Decline in function, feeding intolerance, or unintended decline in weight (e.g., failure to thrive)

#### Secondary Criteria<sup>b</sup>

- Admission from long-term care facility or medical foster home
  - Elderly patient, cognitively impaired, with acute hip fracture
  - Metastatic or locally advanced incurable cancer
  - Chronic home oxygen use
  - Out-of-hospital cardiac arrest
  - Current or past hospice program enrollee
  - Limited social support (e.g., family stress, chronic mental illness)
  - No history of completing an advance care planning discussion/document
- 

<sup>a</sup>Primary Criteria are global indicators that represent the minimum that hospitals should use to screen patients at risk for unmet palliative care needs.

<sup>b</sup>Secondary Criteria are more-specific indicators of a high likelihood of unmet palliative care needs and should be incorporated into a systems-based approach to patient identification if possible.

### \*Criteria for a Palliative Care Assessment During Each Hospital Stay

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A potentially life-limiting or life-threatening condition *and* . . .

#### Primary Criteria<sup>a</sup>

- The "surprise question": *You would not be surprised if the patient died within 12 months or did not live to adulthood*
- Difficult-to-control physical or psychological symptoms (e.g., more than one admission for same condition within several months)
- Intensive Care Unit length of stay  $\geq 7$  days
- Lack of Goals of Care clarity and documentation
- Disagreements or uncertainty among the patient, staff, and/or family concerning . . .
  - major medical treatment decisions
  - resuscitation preferences
  - use of nonoral feeding or hydration

#### Secondary Criteria<sup>b</sup>

- Awaiting, or deemed ineligible for, solid-organ transplantation
  - Patient/family/surrogate emotional, spiritual, or relational distress
  - Patient/family/surrogate request for palliative care/hospice services<sup>c</sup>
  - Patient is considered a potential candidate, or medical team is considering seeking consultation, for:
    - feeding tube placement
    - tracheostomy
    - initiation of renal replacement therapy
    - ethics concerns
    - LVAD<sup>d</sup> or AICD<sup>e</sup> placement
    - LTAC<sup>f</sup> hospital or medical foster home disposition
    - bone marrow transplantation (high-risk patients)
- 

<sup>a</sup>Primary Criteria are global indicators that represent the minimum that hospitals should use to screen patients at risk for unmet palliative care needs.

<sup>b</sup>Secondary Criteria are more-specific indicators of a high likelihood of unmet palliative care needs and should be incorporated into a systems-based approach to patient identification if possible.

<sup>c</sup>These matters are included based on a consensus panel opinion.

<sup>d</sup>LVAD = Left ventricular assist device.

<sup>e</sup>AICD = Automated implantable cardioverter-defibrillator.

<sup>f</sup>LTAC = Long-term acute care hospital.

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Many clinicians believe they lack confidence and experience in discussing with patients the issues and decisions that come with having a serious illness – specifically recommendations about palliative care and hospice services. This may involve delivering "bad news," as well as answering questions that may not have specific answers. A useful definition of "bad news" is information that "results in a cognitive, behavioral,

or emotional deficit in the person receiving the news that persists for some time after the news is received" (Ptacek, 1996). Another definition of bad news is "any news that drastically and negatively alters the patient's view of her or his future" (Buckman, 1984). Implicit in these definitions is that a terminal diagnosis is not the only form of bad news; it may also refer to disclosing the diagnosis of a serious chronic condition such as multiple sclerosis, ultrasound-verified fetal demise to a pregnant woman, and other scenarios.

In the absence of more formal education, the more a clinician prepares for discussions surrounding palliative care and puts that preparation into practice, the more skilled and comfortable that clinician can become in this aspect of medical care.

There are several excellent mnemonics available to help providers increase their knowledge, practice examples of these discussions, and generally obtain a better understanding of the emotions, questions and problems that may arise with patients and families at this time in their lives.

**One mnemonic found useful for this guideline includes:**

- ABCDE (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions) (Vandekieft, 2001)

**Advance preparation:** Obtain the patient's medical information and test results, if possible, so that you are fully aware of the situation. Mentally rehearsing the way you wish to present the information and options can give you a sense of how the conversation may go. Remember to individualize your approach for each patient and family based on how much they know at that point and how they prefer to receive information. Make sure that you have an appropriately private location in which to have the discussion, and that the session will be free of interruptions, including setting the pager to silent or leaving it with a colleague.

**Build a therapeutic environment/relationship:** Try to find out how much the patient and family understands, how they want to be told (bluntly, gently, etc.), and how much they want to know at that time.

- "If this condition turns out to be something serious, are you the kind of person who likes to know what is going on?"
- "Would you like me to tell you the full details of the diagnosis?"
- "If your condition is serious, how much would you like to know?" If the patient indicates that he/she does not want any information, it is important to "leave the door open." For example you may say, "That's OK. If you change your mind, at any time, please feel free to talk to me or one of my colleagues."
- Have family members or friends present as per the patient's preference, and take time to learn names and relationships of each support person present. Use touch and humor where appropriate, taking into consideration your relationship with the patient. Reassure the patient of your availability, set up follow-up appointments, and contact other providers about the situation where appropriate.

**Communicate well:** Ask the patient for any questions. Speak truthfully but compassionately and avoid using medical terms or euphemisms. Say the words "cancer," "dying," "death," etc. Although a care provider may be uncomfortable with these terms, they help with clarity of communication and accurate understanding by the patient and family of what is being said.

Adapt the communication style to the education level and personal preference of the patient and family. For example, if the patient is a company executive who is used to calling the shots, this person may benefit more if provided with several different options to choose from rather than being told what to do. If the education level and preferred style are unknown, a good rule of thumb is to present information at a sixth through eighth grade level.

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Don't rush the process; allow time for silence, tears and questions. This allows the patient and family (if present) time to react to the news and to discuss concerns of the patient, and allows the patient to receive the news at his or her own pace (*Ellis, 1999*). Remember that the patient may not retain much of the information given beyond that of the diagnosis or prognosis, and may have to wait to "digest" what information can be absorbed. Strong emotions elicited in difficult conversations may distract the patient from hearing the full communication. Repeat important points, write things down and periodically assess the patient's understanding of the information and reactions to what was heard. Think out loud; help the patient and family feel they are part of the team. Visual aids, written question prompts (suggesting possible questions that a patient or family may want to ask), and the provision of audio tapes of the conversations may aid communication and recall of important points.

Communicate any bad news to the patient and family. The clinician may want to deliver a "warning" statement prior to the bad news itself to prepare the patient (and family if present) for the communication that follows. For example, "I'm afraid I have (difficult/bad) news to share on (your/his/her) condition." Additionally, it may be advisable to ask a few open-ended questions prior to delivering the actual bad news to assess what the patient and family already know and their readiness to hear the news (*Baile, 2000*).

**Deal with patient and family reactions:** Be sensitive to the emotional reactions of the patient and family. Recognize that denial, blame, intellectualization, disbelief and acceptance may be present to varying degrees and time frames. Watch for signs of depression and suicidality in subsequent visits. Be empathetic. Crying may occur but make sure that your tears are empathic in nature and not reflective of personal issues on your part. There may be anger from the patient and family about care received from you or another colleague; resist becoming defensive or argumentative about these issues. Try to deal with that particular patient's and family's cultural and ethnic norms.

- "I was probably raised differently than you. Can you tell me how your family deals with these situations?"

**Encourage and validate emotions:** During the discussion, periodically ask the patient and family how and what they are feeling, and respond with empathy. If the patient (and family if present) is ready, discuss treatment options and arrange for follow-up to put those options into action. Talk with the patient about what this means for him/her, and what needs outside of the traditional medical scope he/she may have. It is important that the patient and family do not lose their sense of hope. Offer realistic hope. Communicating hope, even though a "cure" may not be possible, may be done by redirecting the focus of hope to keep the patient comfortable and as symptom-free as possible. Reassure the patient that every effort will be made to promote comfort, dignity and quality of life as defined by the patient.

- "I know this is not what you were hoping to hear."
- Don't say, "*There is nothing more we can do;*" instead say, "What we are going to focus on now is \_\_\_ (comfort, pain relief, etc.)" (*Baile, 2000*).

See [Appendix A, "Myths about Palliative Care."](#)

Additional considerations pertaining to the initial discussion between clinician, patient and family (based on expert consensus) include the following:

- Discussing prognosis is a difficult issue, and little attention is given to this issue in most training programs, leaving clinicians relatively unprepared to handle this task. The prognosis for a patient is based on multiple factors with complex interactions, including diagnoses, medications and therapeutics, social issues, functional status, patient preferences, and physician knowledge and experience. The communication of prognosis should be individualized to the needs and desires of the particular patient and family. As mentioned elsewhere, physicians tend to significantly overestimate prognosis, which may lead to delays in palliative treatments in favor of unnecessary curative or invasive

treatments. Clinicians may build additional trust by acknowledging limitations in providing a prognosis. It may be best to provide a range of dates or times, or tie prognoses to hypothetical situations.

- Encourage continual communication for status updates, to assess comprehension of information, and to respond and empathize with new emotions as they come up.
- Coordination of communication is essential among clinicians, especially when there is a change in care setting or a transfer to another facility such as skilled nursing or home care, as patient preferences may not be known to the clinicians in the new setting.
- Document details of all discussions in the medical record.

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### **3. Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care**

#### **Recommendations:**

- Clinicians should use a validated assessment tool to assess palliative care needs (*low quality evidence, strong recommendation*).
- Care conferences with the patient, family and an interdisciplinary team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, goals and plan of care (*low quality evidence, strong recommendation*).

Perform a thorough assessment based on the domains of palliative care and address needs, values and resources of the patient and family.

It is important, especially in the development of recommendations for care of patients' palliative care and end-of-life needs, that there is recognition of patient autonomy in choosing care. One goal of this annotation is to discuss how clinicians can create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered. Only then can a reasonable determination be made of what services are required to meet the physical, psychological, social, cultural, legal/ethical and spiritual needs of patients and their families. Clinicians recognize that assessment of these domains of care is important to a patient's care but, in a busy practice, may find it difficult to address all domains. The work group recognizes this and suggests that clinicians could incorporate key aspects of palliative assessment with existing assessment processes. They also encourage using a team approach. Routine assessment has been shown to identify symptoms that may otherwise have been overlooked or unreported, facilitate treatment and treatment planning, and enhance patient and family satisfaction.

For patients to make informed choices regarding palliative care, it is important for both patient and providers to have a realistic understanding of the options available. The patient must have the capacity to understand the choices available, especially when some of the choices are not likely to benefit the patient to any great extent. Further, it should be recognized by providers and communicated to patients that the realistic choices available for care may change as the patient's medical condition changes. Accordingly, assessment of palliative care needs will necessarily be ongoing and may require at some point, if the patient's decision-making capacity is impaired, the assistance of family or other well-informed surrogates to provide the information needed to assess the patient's ever-changing palliative care needs. The role of surrogate for assessment of patient condition and expression of patient wishes should be anticipated at the time of initial assessment and care planning. Bringing together, as much as possible, those who may impact decision-making should be integral to the initial plan of care development. Careful clarification for all present at initial care planning will help anticipate and prevent discord as the patient and surrogate(s) make future care choices. The initial

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meeting for care planning is also useful for identifying availability and limitations of caregivers and other resources for meeting patient needs in implementing the plan of care.

When discussing goals of care or a patient's end-of-life wishes, the "ask – tell – ask" model provides a useful and effective structure for such conversations. In this model, providers begin by asking patients and/or family members what they already know about the clinical situation (e.g., "What have the doctors told you about your illness?"). Clinicians can then add additional clinical information as needed or clarify any misconceptions, remembering to use plain, everyday language instead of "medicalese" (e.g., say "The cancer has spread" rather than "The cancer has metastasized"). Clinicians should always assume patients and family member have questions instead of asking whether they do (e.g., don't ask "Do you have any questions?" but rather ask "What questions do you have?") Finally, providers should ask the patient and/or family to restate the information discussed to assess their understanding. This can be normalized by saying "To make sure I did a good job explaining everything, can you tell me, in your own words, what we just talked about (or decided)?" (*Smith, 2009*).

Patient and family expectations, goals for care and for living (quality of life), understanding of the disease and prognosis, as well as preferences for the type and site of care should be assessed and documented. This assessment needs to be reviewed on a regular basis, with consideration given to the patient's capacity to represent himself/herself. Also see [Annotation #10, "Develop or Revise Palliative Care Plan Including Care of the Actively Dying Patient and Establish Goals of Care Through the Process of Shared Decision-Making."](#)

Among the available assessment tools, it was the decision of this work group to recommend the Edmonton Symptom Assessment System (ESAS) because it is thorough yet simple in clinical application, it has a robust evidence-based foundation for validation in various clinical settings, and is readily available via the Internet.

As patient and clinician conditions change, there may be need for change of site or clinicians of care. It is helpful in care planning if the community has a uniform system to communicate patient wishes so that the continuity of care makes a smooth transition between clinicians in these circumstances. In this regard, communitywide agreement on recognition of particular advance directive forms and Physician/Provider Orders for Life-Sustaining Therapy (POLST) enhances the quality of care available. See [Annotation #9, Ethical and Legal Aspects of Care.](#)

See the Quality Improvement Support [Resources Table](#) section for the POLST and ESAS Web sites.

Documentation of the goals of care, patient preferences and advance directive in an electronic medical record promotes accessibility and portability across care settings.

Clinicians should be aware of their individual state, provincial or national forms and requirements.

### Care conferences

Patient and family meetings or care conferences allow the treatment team an opportunity to meet with the patient and/or family to discuss the patient's diagnosis, condition, course of illness and treatment options and to answer questions and establish both the goals and plan of care. The level of formality of these conferences is likely to vary depending on the focus or goals. These conferences may involve the primary provider and part of the care team or the entire team.

Most guidelines for care conferencing are based on expert recommendations. Family counseling literature and studies of giving bad news and end-of-life discussions form the basis for these expert recommendations.

A step-by-step model for care conferences outlines four goals for a family meeting or conference. These goals focus on:

- Gaining knowledge of the person experiencing the illness and understanding this person's goals.
- Promoting communication between the care team and patient/family.

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- Decreasing stress and suffering by reviewing realistic goals and establishing a realistic plan that aligns with these goals.
- Establishing trust and support to work with the patient/family throughout the course of illness.

Incorporating time for this assessment can be done in either the inpatient, outpatient or home settings. In the inpatient setting, this assessment may be done by the palliative care team or by the clinician during daily rounds. In the outpatient setting, this assessment can be accomplished over a series of visits or during an extended visit. In the home setting, this can be accomplished in one or more home visits.

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## **4. Physical Aspects of Care**

### **Recommendation:**

- The physical aspects of the patient's serious illness should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).

The control of physical symptoms is an important part of the palliative care plan. Common symptoms include, but are not limited to pain, anorexia and cachexia, constipation, delirium, diarrhea, dyspnea and secretion, fatigue, agitation, nausea and vomiting, cough, fever, gastroesophageal reflux disease, hiccups, ascites and pleural effusions, skin and wound care, prurities, sleep disturbances and insomnia, urinary incontinence and urinary retention.

Each patient should be frequently evaluated for these issues. Therapy should be individualized for each patient's unique circumstances.

The work group recognizes that there is not a single order set that covers all patient situations. Multiple sources are available to assist in symptom management. Some possible resources include but are not limited to:

PAL-MED CONNECT <http://www.palmedconnect.org>

1-877-PAL-MED4, 1-877-725-6334

<http://www.hospicecare.com/resources/emedicine.htm>

[http://www.stoppain.org/palliative\\_care/content/symptom/pain.asp](http://www.stoppain.org/palliative_care/content/symptom/pain.asp)

Fast Facts: <http://www.EPERC.mcw.edu/EPERC/FastFactsandConcepts>

### **Pain**

Control of pain in order to improve quality of life is an important aspect of palliative care. However, the approach toward pain management in palliative care is different from those of chronic pain and acute pain management. While cures of underlying disease may still be possible, they may no longer be the primary goal, because of life-limiting illness. Disease progression may necessitate increased dosing of opioids to control pain; this should not be confused with "tolerance." In fact, when a patient with previously well-controlled pain develops the need for increasing opioid doses to achieve comfort, advancing illness is almost always the cause (*Emanuel, 1999*).

**Pain is a subjective symptom; there is no test to measure pain.** Pain is what the patient says it is, and it needs to be addressed adequately in order to improve quality of life. The patient, along with family members, should be actively involved in establishing the goals of palliative pain management.

Opioid rotation, especially for patients with cancer, should be considered when opioid side effects are difficult to manage or if inadequate analgesia is present. If symptoms of delirium and confusion are present and are attributable to opioids, a switch to a different opioid may be advisable.

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[www.icsi.org](http://www.icsi.org)

## 5. Cultural Aspects of Care

### Recommendations:

- A cultural assessment should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).
- The clinician should utilize professional medical interpreters whenever possible (*low quality evidence, strong recommendation*).

Patient and family reactions to serious illness and decisions about end-of-life care are influenced by cultural factors. Cultural assessment should be an integral component of the palliative care plan. The assessment should include:

- Locus of decision-making
- Preferences regarding disclosure of information
- Truth telling and decision-making
- Dietary preferences
- Language, family communication
- Perspectives on death, suffering and grieving
- Physical care of the deceased, funeral and burial rituals

Specific cultural assessment promotes patient/family-centered decision-making and offers the opportunity to identify care preferences.

With this in mind, clinicians should respect the important role culture plays in shaping the way people make meaning of illness, suffering, and dying and in guiding decisions people make about health care. Clinicians should avoid stereotyping and the assumption that we know what any one individual thinks or does because we assume we know what people of that group tend to think. There is, in fact, wide variation in beliefs, attitudes and behaviors within every cultural group (*Smith, 2009*).

Several key clinical recommendations that providers should consider have been identified:

- Many ethnic groups prefer not to be directly informed of a life-threatening diagnosis.
- In cultural groups in which patients are not directly informed about a serious prognosis, family members may want the clinician to discuss the patient's condition with family members only.
- When considering therapeutic options, clinicians should consider that members of many cultural groups prefer that family members, rather than patients, make treatment decisions.
- Direct discussions of advance directives and therapeutic support levels may be undesirable in situations in which they are viewed as potentially harmful to a patient's well-being.

Whenever possible the clinician should utilize professional medical interpreters (*Smith, 2009*). If medical interpreters are not available, the clinician may need to use bilingual health care workers or family members. This, however, is less desirable due to misinterpretation of medical phrases, censorship of sensitive or taboo topics, and the tendency to filter or summarize discussions rather than translate them directly. The following recommendations are suggested for clinicians utilizing interpreters:

- Meet briefly with interpreters prior to and after delivery of bad news or difficult discussions to help prepare the interpreter and to allow the interpreter to provide information about the patient, family and culture.

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- Establish with the interpreter, patient and family members at the outset of a conversation or care conference that everything spoken will be translated word for word.
- After making a complete statement, clinicians should pause to allow for translation.
- Clinicians should speak to and look at the patient/family rather than the translator: "Where is your pain?" rather than "Can you ask him where he hurts?"
- Consider meeting with the interpreter after the discussion to allow for any necessary debriefing.
- Use non-verbal forms of education such as drawing or showing pictures.
- Understand that not all tools (such as pain scales) are universal and clinicians should use terms that are culturally relevant.
- Avoid using jokes or humor because they may be misunderstood or considered offensive.

A learning module on cultural and spiritual sensitivity and a quick guide to cultural and religious traditions can be found at this Web address: <http://www.professionalchaplains.org/uploadedFiles/pdf/learning-cultural-sensitivity.pdf>

The University of Washington's "Culture Clues" tip sheets contain information for clinicians about the needs and preferences of patients from diverse cultures: <http://depts.washington.edu/pfes/CultureClues.htm>.

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS Standards), 2001 are directed at health care organizations and individual clinicians to make their practices more culturally and linguistically accessible. This includes sign language: <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15>.

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## 6. Psychological and Psychiatric Aspects of Care

### Recommendation:

- A psychological assessment should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).

It may seem obvious to say psychological and emotional issues are present near the end of life, but too often these issues and their symptoms go undetected and untreated. For example, anxiety disorders in terminally ill cancer patients range from 15% to 28%, and approximately 25% of all cancer patients will experience severe depressive symptoms, with increasing symptoms as the disease progresses. This further burdens patients and may prolong suffering and undermine their quality of life. Routine ongoing assessment of a patient's psychological status is critical to provide quality palliative care.

Pain and other physical symptoms are commonly the initial focus of treatment. Psychosocial issues are more difficult to evaluate and address if the patient has distressing or poorly controlled physical symptoms (*Strickland, 2004*).

Patients come to advanced illness with issues of worry, insomnia, panic, anxiety, nervousness, paranoia and lack of energy. Psychological symptoms may also present as physical symptoms such as pain, constipation, nausea and vertigo. Difficulty in improving physical symptoms should lead one to look at psychological or other causes. Clinicians must be aware of psychological symptoms of depression and anxiety. Use of standardized assessments to diagnose (e.g., PHQ-9) may be helpful; however, no screening tool for depression has been validated for palliative care. Questions like "How are you coping?" "What are you doing to cope?" "Are you having trouble thinking?" "Are you depressed?" "Do you think about ending your own

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life?" or "Do you feel your situation is hopeless?" are good questions. Refer to the ICSI [Major Depression in Adults in Primary Care](#) guideline for more information about depression and the depression assessment tool (PHQ-9).

Affective disorders such as anxiety and depression are common in seriously ill patients, and they adversely affect their quality of life. Not only can they cause physical symptoms such as nausea, dyspnea and insomnia, but conversely, experiencing such symptoms can exacerbate anxiety, as well. Under treated pain can exacerbate psychological distress. Some recent data suggest that depression is associated with a higher risk of death in cancer patients, as well as decreased treatment adherence, longer hospital stays, reduced quality of life and requests to hasten death.

Anxiety can contribute to suffering and decreased quality of life. The anxiety may be due to medications, social, psychological or unidentifiable reasons, fears or pain. Anxiety may result in insomnia, gastrointestinal upset, dysphagia, fatigue, palpitations, diaphoresis, fear and isolation, and may escalate as disease progresses. Patients with a history of panic disorder, phobia, obsessive-compulsive disorder or other anxiety disorders will have an increased risk of symptoms of anxiety. Causes of anxiety should be identified and treated if possible. Physical and emotional issues should be addressed. Social and spiritual resources should be utilized. Frank discussions of fears may help alleviate anxiety.

It is important to differentiate grief from depression. Grieving can be an appropriate response to loss, but persistence of the symptoms mandates consideration of depression. Simply asking a patient, "Are you depressed?" can be a useful screening tool and provides a reasonably sensitive and specific assessment of depression in patients with terminal illnesses. This may be preceded by educating the patient about the difference between clinical depression and appropriate reactive feelings to the situation.

The clinicians must inquire if the patient is at risk for suicide. There is no evidence that asking the patient about suicide increases the risk that the patient will carry out his or her plan.

More information can be found in the following Fast Facts at the Web site <http://www.eperc.mcw.edu>. #07 Depression in Advanced Cancer, #59 Dealing with the Angry Dying Patient, #145 Panic Disorders at the End of Life, and #186 Anxiety in Palliative Care – Causes and Diagnosis provide up-to-date, easy-to-access references for psychological aspects of palliative care.

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## 7. Social Aspects of Care

### Recommendation:

- A social assessment should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).

The comprehensive assessment should include family structure and geographic location; relationships and family dynamics; lines of communication and need for counseling for self and family; existing social and cultural network; perceived social support; medical decision-making/advance directives and quality of life; work and school settings; finances including filing for disability and ability to pay for medications and treatments; sexuality; intimacy; living arrangements; caregiver availability; access to transportation, medications, needed equipment and nutrition; community resources; and legal issues.

The impact of a chronic progressive disabling disease extends beyond the patient to the "family," defined in its broadest sense. Children, spouses, parents, co-workers, friends, neighbors, employers and even health care providers are all affected by an individual patient's condition. Financial concerns, caregiver coping, communication with family and friends and discussion/decision-making on advance treatment plans all fall under the domain of social aspects of care. Lack of knowledge about the social aspects of care influencing

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the patient can frustrate clinicians regarding decisions or lack thereof that the patient makes. Poor communication among patient, family and clinicians undermines effective decision-making.

The interdisciplinary team of professionals including social workers should have patient-population specific skills in assessment and development of a social care plan. Often the social worker is involved in coordinating the care conference and its attendees. In situations where loved ones are making decisions regarding withdrawal of life support for patients, there are reports that suggest that family members feel more satisfied and supported in the decision-making process where there is a family conference exploring the patient's wishes, clinician's recommendations for withdrawing life support, and assessment of the spiritual care needs of family members. Further information and documents of support can be found at <http://www.capc.org/>. Also see [Annotation #3, "Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care."](#)

- Make referrals to meet identified social needs and to remove barriers to care. This includes but is not limited to transportation for treatment and appointments, caregiver service options to meet patient's needs at home, counseling, financial resources and community clubs/services for support.
- Understand that advance care planning is rarely fixed in time with specific treatment decisions but rather a dynamic process emerging from the clinical context of the disease and the social context of the patient (*Prendergast, 2001*). Clear and honest communication, trust over time, and working within the patients' most important relationships are needed to improve the quality and outcome of this process.

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## **8. Spiritual Aspects of Care**

### **Recommendations:**

- A spiritual assessment should be an integral part of the palliative care plan (*low quality evidence, strong recommendation*).
- Clinicians should utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support (*low quality evidence, strong recommendation*).

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred. Given this broad definition, it can be said that everyone is spiritual in one form or another.

Illness and the prospect of dying can impact the meaning and purpose of a person's life. Thus, illness and dying have a spiritual dimension and are often perceived by patients as spiritual experiences. As people face serious illness or death, they often ask questions of meaning, value and relationships such as:

#### **Meaning:**

- Why is this happening to me? Why now?
- What is the meaning of my illness, my suffering, my death?
- What will happen to me after I die?

#### **Value:**

- Do I still have value despite changes in my appearance, productivity, independence?
- Is there anything valuable about me that will persist beyond death?

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### Relationships:

- Do I need to forgive or be forgiven by anyone?
- Am I loved? By whom?
- Will I be remembered after I die? Will I be missed?

Other spiritual issues and concerns encountered in palliative care include life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, legacy, and life completion tasks.

Patients often draw on their spirituality as they make health care decisions and to help them cope with illness and the experience of dying (*Balboni, 2007*). Spiritual and religious beliefs can also at times create distress and increase the burden of illness. It is therefore important for clinicians to attend to patients' spirituality, especially any spiritual concerns, questions or distress. Attending to a patient's spirituality can deepen the relationship between patient and clinician and build trust (*Ehman, 1999*).

All palliative care patients should receive a simple spiritual screening on admission. Spiritual screening is a quick determination of a patient's spiritual resources and concerns. Models of spiritual screening use a few simple questions that can be asked in the course of an overall patient and family interview. Examples of such questions include "Are spirituality or religion important in your life?" and "How well are those resources working for you at this time?" Based on information from the spiritual screening, clinicians can identify the presence of spiritual issues (including spiritual distress or spiritual resources of strength) and make the appropriate referrals to chaplains in the inpatient setting or to other spiritual care providers in an outpatient setting.

There are a number of spiritual assessment tools created for use by clinicians in the clinical setting. Some of these tools include:

- H:** Sources of hope, meaning, comfort, strength, peace, love, connection
- O:** Member of an organized religion?
- P:** Personal spirituality, practices
- E:** Effects of beliefs on medical care and end-of-life issues

(*Anandarajah, 2001*)

- F:** Do you have spiritual beliefs or faith that has helped you cope with difficult times in the past?
- I:** Are these beliefs important to you, and how do they influence the way you care for yourself?
- C:** Are you involved in a spiritual or religious community or church?
- A:** How would you like your health care providers to help you address spiritual issues and concerns?

(*Puchalski, 2000*)

- S:** Spiritual belief system
- P:** Personal spirituality
- I:** Integration with a spiritual community
- R:** Ritualized practices and restrictions
- I:** Implications for medical care
- T:** Terminal events planning

(*Maugans, 1996*)

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In addition, clinicians can attend to patient's spiritual needs and concerns in the following ways:

- Offer compassionate presence – strive to be present with and attentive to patients. Relate to patients not only as a professional expert but also as a fellow human being.
- Listen to the patient's fears, hopes, pain and concerns – listening is a powerful healing tool.
- Asking about hope and peace can be a simple, brief, yet effective way to assess spiritual concerns. (*Steinhauser, 2006*)
  - Do you have hope?
  - Where does your hope come from?
  - What are you hoping for now as you look ahead?
  - Are you at peace with the care decisions you've made?
  - Do you feel at peace – in your heart, your spirit?
  - Where does peace come from for you?
  - Does that peace come from a spiritual or religious source?

Utilize clinically trained chaplains as members of the interdisciplinary health care team – chaplains are experts in spiritual care. They offer interfaith support to all who are in need and have specialized education to mobilize spiritual resources to help patients cope more effectively (*VanderCreek, 2001*). Working with and making referrals to these spiritual care providers are important aspects of holistic care.

Clinicians should always be respectful of a patient's spiritual beliefs, should keep spiritual discussions patient centered and should never proselytize or impose beliefs onto a patient.

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## **9. Ethical and Legal Aspects of Care**

### **Recommendations:**

- An advance care plan that includes the designation of a health care agent and completion of a health care directive with the preferences and goals of the patient and family should be created and used (*low quality evidence, strong recommendation*).
- Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker (*low quality evidence, strong recommendation*).

The patient's goals, preferences and choices should form the basis for the plan of care. They should be respected within the limits of applicable state and federal laws. Informed consent for any treatment or plan of care requires a patient with decision-making capacity or an appropriate surrogate decision-maker. Informed consent is based on the principle that patients should be allowed to make decisions for themselves. When a patient lacks this ability, a surrogate is needed.

Note: **Competency** is a legal term referring to a decision made by a judge, although a physician's opinion carries a large amount of weight in a competency hearing. In contrast, **decision-making capacity** (aka decisional) refers to a clinician's determination, based on clinical examination, whether a patient is able to make medical decisions relative to the discussion for themselves. Most state power of attorney for health care documents require a clinician to document that a patient has lost decision-making capacity for the surrogate to become the legal agent for medical decisions.

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To be deemed **decisional**, a clinician must be satisfied that a patient is able to:

- receive information (e.g., must be awake, but not necessarily oriented);
- evaluate, deliberate and mentally manipulate information; and
- communicate a treatment preference (i.e., the comatose patient by definition is not decisional).

### **Decision-making capacity is:**

**Understanding.** Does the patient truly understand the information about the risks, benefits and alternatives of what is being proposed? The patient does not have to agree with your interpretation but should be able to repeat what you have said. Ask, "**Can you repeat to me the options for treatment I have just discussed with you?**" "**Can you explain to me why you feel that way?**"

**Task specific.** Deciding if the patient is decisional means weighing the degree to which the patient has decision-making capacity against the objective risks and benefits to the patient. Some decisions are more complex than others, requiring a higher level of decision-making capacity. Thus, a moderately demented patient may be able to make some decisions (e.g., antibiotics for pneumonia) but not others (e.g., chemotherapy for colon cancer). This sliding scale view of decisionality holds that it is proper to require a higher level of certainty when the decision poses greater risk.

**Logical.** Is the logic the patient uses to arrive at the decision "not irrational"? One wants, as much as possible, to make sure the patient's values are speaking, rather than an underlying mental or physical illness. Note: Severe depression or hopelessness may make it difficult to interpret decisionality; consult psychiatry for assistance with this or other complex cases.

**Time specific.** When encephalopathic, a patient may not be decisional, while after treatment, decisionality may be regained.

**Consistent.** Is the patient able to make a decision with some consistency? This means not changing one's mind every time one is asked. Is the decision consistent with the patient's values? If there is a change in the patient's values, can the patient explain the change?

*(Arnold, 2001)*

### **Non-Beneficial/Low-Yield Therapy (formerly named Medical Futility)**

The term "medical futility" has previously been used by clinicians to discuss the appropriateness of a medical treatment option. The public, policy makers, ethicists and the medical profession have been unable to agree on a clear, concise definition of futility that can be applied to all medical situations. One commonly used definition is that a futile intervention is one that a) is unlikely to be of any benefit to a particular patient in a particular medical situation, and b) will not achieve the patient's intended goals. The sticking point in all futility definitions is the concept of **benefit**, as the perception of benefit is highly subjective. Clinicians, patients and families often have very different views on what is potentially beneficial. Medical futility can be easily misunderstood as health care rationing. While economic issues may impact shared decision-making, the ultimate question is not "How much does this therapy cost?" but rather "Do the advantages of this therapy outweigh the disadvantages in a given patient?"

Clinicians are not legally, professionally or ethically required to offer medically futile treatments, **as defined by the standard of care of the medical community**. Ethics committees, hospitals and local/state medical organizations can provide resources to understand non-beneficial/low-yield therapy and professional responsibilities in one's practice area. For critically ill patients who ultimately died during hospitalization, Schneiderman has shown lower utilization of ICU resources in patients when ethics consultation occurred *(Schneiderman, 2003)*.

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Most literature on futility is based on the perspective of clinicians. Patients and families may have different perspectives that must be recognized and acknowledged. A multicenter qualitative study, based on semi-structured interviews with surrogate decision-makers for critically ill patients, found that 64% of the surrogates did not fully accept the physicians' determinations of physiologic futility. They were equally divided between those with religious objections, and those who either doubted the ability of physicians to make these predictions or who needed more information from other sources (*Zier, 2009*).

Reframing the discussion from "futility" or non-beneficial/low-yield therapy to a clarification of goals of care allows the clinician to identify potential disagreement and customize discussions to address these areas.

### Suggestions

- Check with your health care institution about the presence of an existing futility policy.
- Avoid using the term "futility" in discussion with patients/families; rather, speak in terms of benefits/burdens of treatment and patient- or family-specific goals of care.
- Involve a palliative care and/or ethics consultant in any situation where "futility" will be invoked as a process step in formulating decisions.

(*Cuezze, 2005*)

### Advance Care Planning

While the process of advance care planning often results in the completion of a written health care directive, the main focus of advance care planning is on the discussion between the patient and health care agent regarding the patient's wishes. Written advance directives are legal in every state; however, laws and forms vary from state to state. See [Resources Table](#) for additional information regarding advance directives. It is important to remember that travelers should be aware of differing laws in whichever state they plan to travel, and bring a copy of their document with them so that they may present their health care directive to a facility where they intend to receive medical care.

Advance care planning always consists of conversations between patient, family and clinician about who should make decisions if the patient is unable, and what type of care the patient desires. It is recommended to document that plan with a legal advance directive and/or POLST.

Legal advance directive consists of:

- Designation of a **health care agent** (aka durable power of attorney for health care, health care agent, etc.) – The patient appoints someone to make decisions about his/her medical care if he/she cannot make those decisions. Ongoing communication between the patient and his/her health care agent is imperative so that the agent can participate fully as an advocate when the patient is no longer able to communicate.
- Writing a formal **health care directive** – a written document in which a patient's wishes regarding the type or extent of medical treatment to be administered or withheld are described. A DNR form is not a sufficient health care directive. A health care directive goes into effect only when the patient becomes unable to communicate his/her preferences.

There are programs designed to support and spread the use of advanced care planning (*Schwartz, 2002*). See [Resources Table](#) for more information.

The POLST (Physician/Provider Order for Life-Sustaining Treatment) is designed as a communication tool to translate the patient's advance care plan into clinician orders that clinicians (including EMTs, ER staff and hospitalists) can follow in emergencies and review with patients and families at transitions of care. It is becoming more widespread in its acceptance in many parts of the country. POLST was developed as

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an advance care planning document, to be completed by health care clinicians, together with a patient or surrogate decision-maker. The actual form should consist of these sections:

- Resuscitation decision
- Medical intervention decisions
- Antibiotics
- Medically administered nutrition
- Signatures from the clinician and if possible, the patient/surrogate

(Dunn, 2007)

The major advantages of the POLST form over standard advance directives is that, when adopted as the community standard, the information is clear, unambiguous, flexible, portable, available across all sites of care, and more likely to be honored by all clinicians when needed (<http://www.polst.org>). Minnesota is currently adopting a statewide version of POLST.

A similar form is called Medical Orders for Life Sustaining Treatment (MOLST). Like POLST, it is an order sheet based on the patient's current medical condition and wishes. It is intended to summarize any advance directive. Both forms are based on communication between the patient and surrogate (the health care agent or other legally designated decision-maker) and health care clinicians. It facilitates informed medical decision-making by communicating an individual's wishes regarding care across health care settings.

### **Barriers to completing advance directives:**

- Many clinicians believe it is not appropriate to begin advance care directive planning on an outpatient basis. In reality, multiple studies have shown that **patients want their clinicians to discuss advance care planning** with them **before** they become ill. Many others have shown a positive response from patients when advance directive discussions are held during outpatient visits.

**Overcoming this barrier:** When beginning a discussion of advance care planning, simply ask, "Do you know what an advance directive is? Do you have one?" If you are afraid the patient may respond negatively, perhaps saying to you, "Is there something wrong with me? Am I sicker than you are letting on?" respond by saying, "I ask all of my patients this question, sick or well." The Patient Self-Determination Act of 1991 mandates that every person be asked about advance directives when first seen (inpatient and outpatient).

- Many people believe that if a loved one has financial power of attorney, he/she doesn't need a separate medical power of attorney. This is not true. **Most often these are separate legal roles.**

**Overcoming this barrier:** When discussing power of attorney with your patient, assess his/her understanding. Have literature in your office to clear up discrepancies.

- Many clinicians and patients feel that having an advance directive means "Don't treat." Unfortunately, advance directives can be a trigger for disengagement by the clinicians.

**Overcoming this barrier:** Make sure your patient and staff understand that advance directives don't mean "Don't treat me" but **instead "Treat me the way I want to be treated."**

- Patients often fear that once a person names a proxy in an advance directive, he/she loses control of his/her own care.

**Overcoming this barrier:** When explaining advance directives to your patients, make sure he/she understand that as long as he/she retains decision-making capacity, he/she retains control of

his/her medical destiny. Advance directives become active only when a person cannot speak for himself or herself.

- Many people believe that only elderly people need advance directives.

**Overcoming this barrier:** The stakes may actually be higher for younger people if tragedy strikes. Use the example of the Terry Schiavo case (a young person who had a tragic accident and left in a vegetative state with no directives) as a trigger to enlighten the discussion. Ask, "What would you want if you were in a similar situation?"

(Warm, 2005)

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## **10. Develop or Revise Palliative Care Plan Including Care of the Actively Dying Patient and Establish Goals of Care Through the Process of Shared Decision-Making**

(See [Appendix B](#) for the ICSI Shared Decision-Making Model.)

### **Recommendations:**

- Clinicians should discuss the likelihood of disease progression to death with patients and/or their families (*low quality evidence, strong recommendation*).
- Ongoing communication with the patient and/or family regarding the dying process and the treatment plan is recommended (*low quality evidence, strong recommendation*).

Use "shared decision-making" when developing or revising the plan or care. This promotes collaboration between the clinician and patient in making treatment decisions, where the clinician shares information and knowledge about the treatment options and the patient uses his/her values to weigh the risks and benefits of the different care options. Note that this does not preclude the clinician making a strong treatment recommendation based on clinical knowledge and experience. However, level of interest in medical information tends to be stronger with younger age and increased educational attainment; older patients may prefer less information and want to rely more on the clinician's expertise alone. More acutely ill patients may have limited ability to successfully weigh risks and benefits of the different options and thus may rely more on family members or on the clinician's recommendation. This underscores the need to individualize care option discussions to patient preferences and illness status. Discussions on treatment preferences should be periodically revisited to account for changes in patient preferences and course of illness, especially given that treatment strategies at one stage of the illness may be inappropriate for another stage. Also see [Annotation #3, "Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care."](#)

Although patients and family members should have a say in treatment options, the clinician should make a clear recommendation based on his/her expertise and experience. It is important that the patient does not feel rushed into deciding between treatment options, as he/she may need to digest the initial bad news first (Back, 2005).

### **Care of the Actively Dying Patient**

Care of the actively dying patient is an intense interval for the patient, family and the health care team. Initiating discussion with the patient and family is the first step in establishing the individual plan of care for the actively dying patient (Ellershaw, 2003). This allows for clarification of prognosis, identification of end-of-life goals, and identification of care preferences (Ngo-Metzger, 2008).

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The patient's transition to the dying phase should be consistently communicated by all members of the health care team. Mixed messages should be avoided as they can lead to loss of trust, miscommunication and poor care management. The National Consensus Project Clinical Practice Guidelines and the National Comprehensive Cancer Network Advance Care and Palliative Care Treatment Guidelines for Patients endorse open communication among the patient, family and care team regarding the dying phase and plan of care (*National Consensus Project, 2009; National Quality Forum, 2006; National Comprehensive Cancer Network and American Cancer Society, 2005*).

Care of the actively dying patient requires an intensive plan of care. Essential to this plan is recognition of the dying patient. Recognizing the dying patient requires a set of clinical skills. There are key signs and symptoms that indicate that death will occur in hours to days. Patients and family members need clear information about the physical and psychological aspects of the dying process. Diagnosing dying is complex and at times uncertain. Agreement between care team members that the patient is dying, and communicating this to the patient and family improve satisfaction and foster trust.

Establishing a treatment plan takes into account individual and family goals and preferences. Despite barriers, it is important to have this treatment plan available at the point of care, regardless of the site of care (inpatient, long-term care, home care, assisted living, ED, etc.) (*Solloway, 2005*).

The treatment plan should include education for the patient and family. This education should include the signs and symptoms of imminent death. Attention to developmental, cultural and religious needs is critical. Patient and family wishes regarding the site of death should be discussed. Studies show that from 70% to 90% of people indicate that they prefer to die at home; despite this, about 75% of all deaths in the United States occur in hospitals or nursing homes. Referral to a hospice program may be appropriate. (See Annotation #11, "Does Patient Meet Hospice Criteria?")

The comprehensive treatment plan must be medically sound and concordant with the patient's wishes and values. Attention to adequate symptom management allays fears and allows comfort during the dying process. The treatment plan includes physical, psychological, social and spiritual care. Ongoing communication remains key. There are several example order sets and nursing care plans on the Center to Advance Palliative Care (CAPC) Web site:

<http://www.capc.org/tools-for-palliative-care-programs/clinical-tools/>

Also see Annotation #4, "Physical Aspects of Care."

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## **11. Does Patient Meet Hospice Criteria?**

Hospice care, now available in most communities in the United States, offers palliative medical care from a multidisciplinary team and serves patients and families as a unit with emotional, social and spiritual support.

Medicare patients certified by their physician as terminally ill with a life expectancy of six months or less may elect to receive hospice care. Most private insurances now have hospice benefits, although coverage may vary.

Discharge from hospice occurs if prognosis improves or if the patient wishes to seek curative treatment.

A patient may be readmitted at any time, as long as the criteria for hospice are met.

See Appendix D, "Comparison between Palliative Care and Hospice," for a table outlying symptoms and conditions relative to palliative and hospice care settings. See Appendix E, "Medicare Hospice Benefit: Eligibility and Treatment Plan."

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### 13. Hospice Care Team Coordinates Palliative Care Plan with Primary Provider

Although the palliative care model encompasses hospice care (see the diagram in the Introduction in the guideline), it is beyond the scope of this guideline to include all aspects of care once the patient is admitted to hospice. See [Appendix D, "Comparison between Palliative Care and Hospice,"](#) for a table outlying symptoms and conditions relative to palliative and hospice care settings. See [Appendix E, "Medicare Hospice Benefit: Eligibility and Treatment Plan."](#)

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### 17. Remission or Resolution of Disease?

While palliative care is delivered across care settings and throughout the full course of illness, a patient may no longer require focused palliative care when:

- there is a remission of symptoms and the illness is no longer progressing,
- the disease process is resolved (cured), or
- death occurs.

If symptoms recur or the patient's condition deteriorates, a new evaluation of the patient's palliative care needs should be done.

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### 19. Death and Bereavement

Grief is the normal, expected emotional suffering caused by a significant loss, such as the death of a loved one, that includes both physiologic and psychological reactions (*McQuay, 1995*). Grief can be anticipatory, such as that experienced by the patient or a loved one prior to the expected death of the patient (*Hallenbeck, 2005*). Grief can also be complicated, leading to maladaptive behaviors associated with a distorted or prolonged grief period (*Ellifrit, 2003*). Grief following a death is called bereavement. However, bereavement interventions can begin prior to and in anticipation of the actual loss (*Chochinov, 1989*).

Clinicians play an important role in facilitating healthy grief and bereavement processes. Honesty at the end of life is essential. By avoiding mixed messages, patients may review their lives and assist loved ones in future plans. At this time it may be possible to identify bereavement needs of patients and their loved ones. By assessing the grief response prior to death, it is possible to identify risk of complicated grieving and to provide early intervention (*Ellifritt, 2003*).

Following the death of the patient, it is essential to allow the patient's loved ones to perform customs or rituals that are important to them, within the policy guidelines of the facility. Failure to do so may lead to complicated grieving (*Lebrocq, 2003*). Clinicians should be available to answer questions and offer support. This may be done informally or through a formal debriefing.

Contact by clinicians after the death of a patient can be comforting for the patient's loved ones (*Griffin, 2007*). Clinicians may wish to offer emotional support by sending a card expressing their condolences. Providers should also offer practical support by completing death certificates in a timely manner, filling out necessary forms or writing letters for the family as needed.

Several models defining grief are available, yet it is important to note that progress through grief is not predictable. Movement through grief varies from person to person, and the bereaved may vacillate between stages, or elements of stages may appear concurrently. **Grief is not on a linear continuum and does not follow a specific time frame.** In complicated grieving, the person may fail to progress through grief or may be "stuck" in one stage of the grief process.

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Several factors may predispose an individual to complicated grief. These include:

- Dependent or ambivalent relationship
- Multiple previous bereavements
- Previous psychiatric history, especially depression
- Sudden and unexpected death
- Death of a young person
- Stigmatized deaths such as suicide or AIDS
- Culpable deaths
- Inability to carry out valued religious rituals
- Lack of social support
- Survivor under age 45 whose partner died suddenly, or over 65 whose partner had illness of five years or more
- Multiple life crises
- Gender of bereaved person – e.g., elderly male widower

*(Sheldon, 1998; Chochinov, 1989)*

Others who are vulnerable to complicated grief include children, confused elders and those with learning disabilities. Many resources are available for children, including storybooks, workbooks and a regional camp for grieving children. For confused elders or survivors with learning disabilities, repeated explanations and participation in important events, such as the funeral, may decrease the repetitious questions about the deceased *(Sheldon, 1998)*.

In order to provide support through the first anniversary of the death, it is suggested that the length of follow-up with the bereaved is a minimum of thirteen months *(Nesbit, 1997; Buchanan, 1996; Moseley, 1989)*. Although it is not realistic for clinicians to personally provide bereavement services for the grieving loved ones of a patient, it is imperative that each clinician be aware of the needs of the bereaved, potential risk factors for complicated grieving and the services available within their area so that appropriate referrals can be made to promote healthy grieving. Possible community services include pastoral care, support groups, counseling services, grief groups, bereavement follow-up programs and communities of faith. A referral to social services or contacting a local hospice program may be appropriate for assistance in bereavement interventions.

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This section provides resources, strategies and measurement for use in closing the gap between current clinical practice and the recommendations set forth in the guideline.

The subdivisions of this section are:

- Aims and Measures
  - Measurement Specifications
- Implementation Recommendations
- Resources
- Resources Table

## Aims and Measures

1. Increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care. (*Annotations #1, 2*)

Measure for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have been screened for palliative care.

2. Improve the effectiveness and comfort level of the primary care clinician in communicating the necessity and benefits of palliative care with those patients with a serious illness. (*Annotation #2*)

Measures for accomplishing this aim:

- a. Percentage of clinicians who have had education and training regarding palliative care concepts.
- b. Percentage of clinicians who have training in the use of scripting for palliative care discussions.

3. Improve the assessment of the identified patient's palliative care needs utilizing the domains of palliative care. (*Annotations #3, 4-9*)

Measures for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have been assessed for the domains of palliative care.
- b. Percentage of adult patients with a serious illness who have a symptom assessment documented in the medical record.

4. Increase the percentage of patients in the early stages of a serious illness who have a care plan identified and documented. (*Annotations #3, 10*)

Measure for accomplishing this aim:

- a. Percentage of patients in the early stages of a serious illness who have the following identified/ documented:
  - A discussion of treatment options with risk and benefits to each option.
  - Patient goals such as needs, preferences, values, concerns and fears.
  - Plan of care follows the patient across the care continuum (palliative care program, inpatient, outpatient, home care/public health nursing, etc.).

5. Improve the ongoing reassessment and adjustment of the patient's plan of care as the condition warrants, utilizing the domains of care. (*Annotations #3, 4-9*)

Measures for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have a revised, documented care plan that addresses the domains of care.
- b. Percentage of adult patients with a serious illness who have a revised symptom assessment in the medical record.

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**Aims and Measures**

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6. Increase the completion, documentation and ongoing utilization of advance directives for patients with a serious illness. (*Annotations #3, 9*)

Measures for accomplishing this aim:

- a. Percentage of adult patients with a serious illness who have documentation in the medical record of a completed advance directive.
- b. Percentage of adult patients who have a completed POLST form documented in the medical record.

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## Implementation Recommendations

Prior to implementation, it is important to consider current organizational infrastructure that address the following:

- System and process design
- Training and education
- Culture and the need to shift values, beliefs and behaviors of the organization

The following system changes were identified by the guideline work group as key strategies for health care systems to incorporate in support of the implementation of this guideline.

1. Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice.
2. Develop a process that will allow clinicians to identify and assess patients who would benefit from palliative care services. This process should include the use of a screening tool that utilizes the domains of palliative care.
3. Develop scripts for clinicians that will assist them in initiating and discussing palliative care services.
4. Develop a process for timely referral to palliative care consultation for patients with a serious illness.

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## Resources

### Criteria for Selecting Resources

The following resources were selected by the guideline work group as additional resources for providers and/or patients. The following criteria were considered in selecting these resources.

- The site contains information specific to the topic of the guideline.
- The content is supported by evidence-based research.
- The content includes the source/author and contact information.
- The content clearly states revision dates or the date the information was published.
- The content is clear about potential biases, noting conflict of interest and/or disclaimers as appropriate.

### Resources Table to ICSI Members Only

ICSI has a wide variety of knowledge resources that are *only* available to ICSI members (these are indicated with an asterisk in far left-hand column of the Resources Table). In addition to the resources listed in the table, ICSI members have access to a broad range of materials including tool kits on CQI processes and Rapid Cycling that can be helpful. To obtain copies of these or other Resources, go to the [Education and Quality Improvement](#) page on the ICSI Web site. To access these materials on the Web site, you must be logged in as an ICSI member.

The resources in the table on the next page that are not reserved for ICSI members are available to the public free-of-charge.

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## Resources Table

*	Author/Organization	Title/Description	Audience	Web Sites/Order Information
	Aging with Dignity	"5 Wishes" and "My Wishes."  The documents address medical, personal, emotional, and spiritual needs that should be addressed when an adult or child is seriously ill and unable to speak for themselves.	Patients and Families	<a href="http://www.agingwithdignity.org">http://www.agingwithdignity.org</a>
	American Academy of Hospice and Palliative Medicine	A professional organization specializing in hospice and palliative care medicine.	Health Care Providers	<a href="http://www.aahpm.org">http://www.aahpm.org</a>
	American Academy of Hospice and Palliative Medicine	An excellent resource for clinicians to share with patients and families. It has been developed by the American Academy of Hospice and Palliative Medicine.	Health Care Providers	<a href="http://www.palliativedoctors.org">http://www.palliativedoctors.org</a>
	American Board of Hospice and Palliative Medicine (ABHPM)	ABHPM promotes excellence in the care of all patients with advanced, progressive illness through the development of standards for training and practice in palliative medicine. The board is an independent, non-profit organization whose certificate is recognized as signifying a high level of physician competence in the discipline of palliative medicine.	Health Care Providers	<a href="http://www.aahpm.org/certification/default/index.html">http://www.aahpm.org/certification/default/index.html</a>
	Caring Connections	Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.	Patients and Families	<a href="http://www.caringinfo.org">http://www.caringinfo.org</a>
	Center to Advance Palliative Care (CAPC) CAPC provides health care professionals with the tools and training necessary to start and sustain successful palliative care programs.	Tools for Palliative Care Programs.  A collection of tools assembled by CAPC to assist in designing, strengthening, maintaining and defending Palliative Care programs.	Health Care Provider	<a href="http://www.capc.org/tools-for-palliative-care-programs/">http://www.capc.org/tools-for-palliative-care-programs/</a>

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## Resources Table

*	Author/Organization	Title/Description	Audience	Web Sites/Order Information
	Center to Advance Palliative Care (CAPC)	CAPCconnect Forum: A free resource for health care professionals who want to share information, exchange ideas, and get advice from their colleagues on operational issues affecting their palliative care programs.	Health Care Provider	<a href="http://www.capc.org/forums/">http://www.capc.org/forums/</a>
	GetPalliativeCare.org The site is provided by the Center to Advance Palliative Care (CAPC)	The Web site provides clear, comprehensive palliative care information for people coping with serious, complex illness. Information includes description of what palliative care is, how it is different from hospice care, and information on advanced directives.	Patients and Families	<a href="http://www.getpalliativecare.org">http://www.getpalliativecare.org</a>
	Hank Dunn Hard Choices	Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness, Fourth Edition. Book: (ISBN 1-928560-30-2)	Patients and Families	To order: <a href="http://www.hardchoices.com">http://www.hardchoices.com</a> To download or read online: <a href="http://hardchoices.com/about_hc.html">http://hardchoices.com/about_hc.html</a>
	EPERC End of Life/Palliative Education Resource Center and the Medical College of Wisconsin	This Web site contains educational resource material for health care educators and providers. Materials include Fast Facts.	Health Care Provider	<a href="http://www.eperc.mcw.edu">http://www.eperc.mcw.edu</a>
	Honoring Choices Minnesota	A program with trained facilitators to help patients, along with their health care agents, articulate preferences in advanced care planning.	Health Care Providers; Patients and Families	<a href="http://www.metrodoctors.com">http://www.metrodoctors.com</a>
	Hospice Patients Alliance	Signs & Symptoms of Approaching Death The article describes the signs and symptoms of approaching death.	Health Care Professionals; Patients and Families	<a href="http://www.hospicepatients.org/hospic60.html">http://www.hospicepatients.org/hospic60.html</a>
*	ICSI	Summary Report: Palliative Care Patient Focus Group Report A summary of patient and caregiver focus groups.	Health Care Provider	<a href="http://www.icsi.org/improvement_resources/knowledge_resources/summary_reports/patient_focus_group_reports/">http://www.icsi.org/improvement_resources/knowledge_resources/summary_reports/patient_focus_group_reports/</a>
	Information Links for Brain Tumor	Preparing for Approaching Death The article discusses the dying process.	Patients and Families	<a href="http://www.virtualtrials.com/btlinks/death.cfm">http://www.virtualtrials.com/btlinks/death.cfm</a>

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*	Author/Organization	Title/Description	Audience	Web Sites/Order Information
*	ICSI Members	Toolkit: Palliative Care The toolkit includes: <ul style="list-style-type: none"> <li>• Palliative care screening tools</li> <li>• Palliative performance status scale</li> <li>• Palliative care overview handout</li> <li>• Scripting for conversations between primary care providers and patients about Fairview Palliative Care Clinic</li> <li>• Dictation template</li> </ul>	Health Care Provider	<a href="http://www.icsi.org">http://www.icsi.org</a>
	Barbara Karnes	Gone from My Sight; The Dying Experience	Patients and Families	Bookstores
	National Consensus Project	<b>Clinical Practice Guidelines for Quality Palliative Care</b> This is a revision of the original 2004 Clinical Guidelines with input from four major palliative care organizations: the American Hospice and Palliative Care Organization, Hospice and Palliative Nurses Association, National Hospice and Palliative Care Organization, and the Center to Advance Palliative Care. It includes updated references for each of the eight domains, exemplars illustrating implementation of the guidelines, and the relationship of the guideline domains with the National Quality Forum's Preferred Practices.	Health Care Provider	<a href="http://www.nationalconsensusproject.org">http://www.nationalconsensusproject.org</a>
	National Hospice and Palliative Care Organization	NHPCO is the largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people in America and their loved ones. This Web site provides information about end-of-life care, with resources, facts and figures, news briefs, patient advocacy, conferences and education.	Health Care Provider; Patients and Families	<a href="http://www.nhpc.org">http://www.nhpc.org</a>

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*	Author/Organization	Title/Description	Audience	Web Sites/Order Information
	National Palliative Care Research Center (NPCRC)	Web site provides measurement and evaluation tools for assessing pain and symptom management (i.e., Edmonton Symptom Assessment Scale [ESAS], Brief Pain Inventory), functional status (e.g., Karnofsky Performance Scale), psychosocial care, caregiver assessment, and quality of life.	Health Care Provider	<a href="http://www.npcrc.org/resources/">http://www.npcrc.org/resources/</a>
	Palliative.org (Regional Palliative Care Program in Edmonton Alberta)	The Web site provides clinical information to health care professionals regarding palliative care. The assessment tools include including various tools such as the Edmonton Symptom Assessment System (ESAS). The site also includes a link to the American Academy of Hospice and Palliative Medicine Fast Facts.	Health Care Provider	<a href="http://www.palliative.org/PC/ClinicalInfo/ClinicalIdx.html">http://www.palliative.org/PC/ClinicalInfo/ClinicalIdx.html</a>
	POLST.org is sponsored by the Center for Ethics in Health Care and Oregon Health & Science University	POLST (Physician Orders for Life-Sustaining Treatment) is designed to help health care professionals honor the end-of-life treatment desires of their patients. The form includes physician orders that follow patient wishes and treatment intentions, and enhances the appropriateness and quality of patient care.	Health Care Providers; Patients and Families	<a href="http://www.ohsu.edu/polst/">http://www.ohsu.edu/polst/</a>
	Put It In Writing, American Hospital Association	The Web site provides information about advanced directives, as well as provides educational resources to raise awareness regarding this issue.  Resources include Put It In Writing brochure, wallet ID, advertisements and links.	Patients and Families; Health Care Providers	<a href="http://www.putitinwriting.org">http://www.putitinwriting.org</a>

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- References
- Appendices

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Links are provided for those new references added to this edition (author name is highlighted in blue).

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## Appendix A – Myths About Palliative Care

**MYTH:** Palliative care teams take the patient away from the clinicians in charge.

**FACT:** Palliative care teams work with the attending clinicians to provide management of a patient's difficult physical and psychosocial symptoms. They can help coordinate challenging and time-consuming tasks such as arranging family conferences. By improving patient and family satisfaction, they can enhance the quality of the clinician-patient relationship.

**MYTH:** Palliative care teams try to convince the patients to stop treatment.

**FACT:** Palliative care teams work with patients and families to clarify goals of treatment, so that patients can make informed decisions about continuing treatments. Evidence shows that oncology patients served by a palliative care team have a higher likelihood of completing chemotherapy.

**MYTH:** When patients are referred to palliative care, he/she thinks his/her doctor is giving up on him/her.

**FACT:** Patients referred to palliative care teams actually have more satisfaction with their overall care, as well as with their clinicians. Patients want the treatment that palliative care provides pain and symptom relief, communication about their plan of care and coordinated care over the course of their illness.

**MYTH:** Palliative care is only for actively/imminently dying patients.

**FACT:** Palliative care is the aggressive management of symptoms in patients with complex or serious medical illness, at any stage of the illness.

**MYTH:** Palliative care is doing nothing – "nothing more can be done."

**FACT:** Palliative care is never futile. Even when the underlying condition cannot be cured, sophisticated medical technology can be used to control symptoms and improve a patient's quality of life. Palliative care is a very active approach to symptom management and family support.

**MYTH:** Palliative care starts when curative treatment stops.

**FACT:** Palliative care can be offered simultaneously with curative treatment, along the continuum of health care. Elements of palliative care and curative treatment can be combined. Specialized hospice care is implemented at the end of life and when curative treatment is no longer wanted or has become futile.

**MYTH:** Clinicians can suffer regulatory and legal consequences from prescribing opioids and sedation in the doses sometimes needed for palliative and end-of-life care.

**FACT:** Regulatory bodies at all levels recognize the importance of good pain control. Undertreatment of pain is considered to be as equally inappropriate as overtreatment, and successful actions have been brought against clinicians for failing to provide adequate relief of pain. The Minnesota Board of Medical Practice has adopted the Model Policy for the Use of Controlled Substances for the Treatment of Pain, initially adopted by the Federation of State Medical Boards of the United States in 2004. This document states, "Physicians should not fear disciplinary action from the Board for ordering, prescribing, dispensing or administering controlled substances, including opioid analgesics, for a legitimate medical purpose in the course of professional practice." Documentation of patient evaluation, objectives of treatment, periodic review, and consent serve to provide justification for appropriate use of analgesics.

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**Appendix A – Myths about Palliative Care**

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**MYTH:** Palliative sedation is considered euthanasia.

**FACT:** Palliative sedation is administered with the intent of relieving suffering from refractory physical symptoms. The intent is neither to hasten nor prolong death. Its use as a medical therapy has been noted by the United States Supreme Court. Euthanasia is the act of delivering medical treatments with the intent of causing death. Careful documentation of prior unsuccessful treatments, the goal of relieving suffering, discussion of risks and benefits with the patient and/or surrogate decision-makers, and careful dosing and monitoring of pharmacologic agents are important points to document.

**MYTH:** Once artificially administered nutrition and hydration therapy is initiated, it is illegal and/or immoral to discontinue it.

**FACT:** There is no legal or ethical distinction between withholding a treatment and withdrawing it. In most states, artificial nutrition and hydration are considered medical therapy and no distinction is made between withdrawal of artificial nutrition and hydration and any other medical therapy that is either not providing the desired effect or is increasing the distress of the patient.

**MYTH:** A formal legal opinion, or permission from a court of law, is required to withdraw treatment.

**FACT:** When clinicians and patients and/or families are in agreement about the goals of care and plan for withdrawal of treatment, there is no legal risk and no need for involvement of the courts.

*(Meisel, 2000)*

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## Appendix B – ICSI Shared Decision-Making Model

The technical aspects of Shared Decision-Making are widely discussed and understood. **Decisional conflict** occurs when a patient is presented with options where no single option satisfies all the patient's objectives, where there is an inherent difficulty in making a decision, or where external influencers act to make the choice more difficult. **Decision support** clarifies the decision that needs to be made, clarifies the patient's values and preferences, provides facts and probabilities, guides the deliberation and communication, and monitors the progress. **Decision aids** are evidence-based tools that outline the benefits, harms, probabilities and scientific uncertainties of specific health care options available to the patient.

However, before decision support and decision aids can be most advantageously utilized, **Collaborative Conversations™** should be engaged in between the provider and the patient to provide the supportive framework for Shared Decision-Making.

### **Collaborative Conversations™**

A collaborative approach toward decision-making is a fundamental tenet of Shared Decision-Making (SDM). Collaborative Conversations is an interprofessional approach that nurtures relationships, enhances patients' knowledge, skills and confidence as vital participants in their health, and encourages them to manage their health care. Within a collaborative conversation, the perspective is that the patient, rather than the provider, knows which course of action is most consistent with the patient's values and preferences.

Use of Collaborative Conversations elements and tools is even more necessary to support patient, care provider and team relationships when patients and families are dealing with high stakes or highly charged issues. A diagnosis of a life-limiting illness presents such a circumstance.

The overall framework for the Collaborative Conversations approach is to create an environment in which the patient, family and care team work collaboratively to reach and carry out a decision that is consistent with the patient's values and preferences. A rote script or a completed form or checklist does not constitute this approach. Rather it is a set of skills employed appropriately for the specific situation. These skills need to be used artfully to address all aspects involved in making a decision: cognitive, affective, social and spiritual.

**Key communication skills** help build the Collaborative Conversations approach. These skills include many elements, but in this appendix only the questioning skills will be described. (For complete instruction, see O'Connor, Jacobsen *Decisional Conflict: Supporting People Experiencing Uncertainty about Options Affecting Their Health* [2007], and Bunn H, O'Connor AM, Jacobsen MJ *Analyzing decision support and related communication* [1998,2003].)

#### **1. Listening skills:**

**Encourage** patient to talk by providing prompts to continue such as *go on, and then?, uh huh*, or by repeating the last thing a person said, It's confusing.

**Paraphrase content of messages shared by patient** to promote exploration, clarify content and to communicate that the person's unique perspective has been heard. The provider should use his/her own words rather than just parroting what he/she heard.

**Reflection of feelings** usually can be done effectively once trust has been established. Until the provider feels that trust has been established, short reflections at the same level of intensity expressed by the patient without omitting any of the message's meaning is appropriate. Reflection in this manner communicates that the provider understands the patient's feelings and may work as a catalyst for further problem solving. For example, the provider identifies what the person is feeling and responds back in his/her own words like this: *"So, you're unsure which choice is the best for you."*

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## Appendix B – ICSI Shared Decision-Making Model

**Summarize the person's key comments** and reflect them back to the patient. The provider should condense several key comments made by the patient and provide a summary of the situation. This assists the patient in gaining a broader understanding of the situations rather than getting mired down in the details. The most effective times to do this are midway through and at the end of the conversation. An example of this is "*You and your family have read the information together, discussed the pros and cons, but are having a hard time making a decision because of the risks.*"

**Perception checks** ensure that the provider accurately understands a patient or family member, and may be used as a summary or reflection. They are used to verify that the provider is interpreting the message correctly. The provider can say, "*So you are saying that you're not ready to make a decision at this time. Am I understanding you correctly?*"

### 2. Questioning Skills

**Open and closed questions** are both used, with the emphasis on open questions. Open questions ask for clarification or elaboration and cannot have a yes or no answer. An example would be "*What else would influence you to choose this?*" Closed questions are appropriate if specific information is required such as "*Does your daughter support your decision?*"

Other skills such as summarizing, paraphrasing and reflection of feeling can be used in the questioning process so that the patient doesn't feel pressured by questions.

Verbal tracking, referring back to a topic the patient mentioned earlier, is an important foundational skill (Ivey & Bradford-Ivey). An example of this is the provider saying, "*You mentioned earlier...*"

### 3. Information-Giving Skills

**Providing information** and **providing feedback** are two methods of information giving. The distinction between providing information and giving advice is important. Information giving allows a provider to supplement his/her knowledge and helps to keep the conversation patient centered. Giving advice, on the other hand, takes the attention away from the patient's unique goals and values and places it on those of the provider.

**Providing information** can be sharing facts or responding to questions. An example is, "*If we look at the evidence, the risk is...*" **Providing feedback** gives the patient the provider's view of the patient's reaction. For instance, the provider can say, "*You seem to understand the facts and value your daughter's advice.*"

## Additional Communication Components

Other elements that can impact the effectiveness of a Collaborative Conversation include:

- Eye contact
- Body language consistent with message
- Respect
- Empathy
- Partnerships

Self-examination by the provider involved in the Collaborative Conversation can be instructive. Some questions to ask oneself include:

- Do I have a clear understanding of the likely outcomes?
- Do I fully understand the patient's values?

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## **Appendix B – ICSI Shared Decision-Making Model**

- Have I framed the options in comprehensible ways?
- Have I helped the decision-makers recognize that preferences may change over time?
- Am I willing and able to assist the patient in reaching a decision based on his/her values, even when his/her values and ultimate decision may differ from my values and decisions in similar circumstances?

### **When to Initiate Collaborative Conversations**

Certain seminal events occur along the care continuum, creating especially opportune times for Collaborative Conversations. These opportunities occur both at the time of and several times after the diagnosis of a life-limiting illness. Use each opportunity along the care continuum to support patient preferences and values when dealing with life-limiting diagnoses.

### **Cues for the Care Team to Initiate a Collaborative Conversation:**

- **Life goal changes:** Patient's priorities change related to things the patient values such as activities, relationships, possessions, goals and hopes, or things that contribute to the patient's emotional and spiritual well-being.
- **Diagnosis/prognosis changes:** Additional diagnoses, improved or worsening prognosis.
- **Change or decline in health status:** Improving or worsening symptoms, change in performance status or psychological distress.
- **Change or lack of support:** Increase or decrease in caregiver support, change in caregiver, change in caregiver status, change in financial standing, difference between patient and family wishes
- **Disease progression:** Change in physical or psychological status as a result of the disease progression.
- **Provider/caregiver contact:** Each contact between the provider/ caregiver presents an opportunity to reaffirm with the patient that his/her care plan and the care he/she is receiving is consistent with his/her values.

### **Patient and Family Needs within Collaborative Conversations**

- **Request for support and information:** Decisional conflict is indicated by, among other things, the patient verbalizing uncertainty or concern about undesired outcomes, expressing concern about choice consistency with personal values, exhibiting behavior such as wavering, delay, preoccupation, distress or tension. Support resources may include health care professionals, family, friends, support groups, clergy and social workers. When patient expresses a need for information regarding options and their potential outcomes, the patient should understand the key facts about options, risks and benefits, and have realistic expectations. The method and pace with which this information is provided to the patient should be appropriate for the patient's capacity at that moment.
- **Advance Care Planning:** With the diagnosis of a life-limiting illness, conversations around advance care planning open up. This is an opportune time to expand the scope of the conversation to other types of decisions that will need to be made as a consequence of the diagnosis of a life-limiting illness.
- **Consideration of Values:** The personal importance a patient assigns potential outcomes must be respected. If the patient is unclear how to prioritize his/her preferences, value clarification can be achieved through the use of decision aids

Detailing the benefits and harms of potential outcomes in terms of how they will directly affect the patient, and through Collaborative Conversations with the provider.

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## Appendix B – ICSI Shared Decision-Making Model

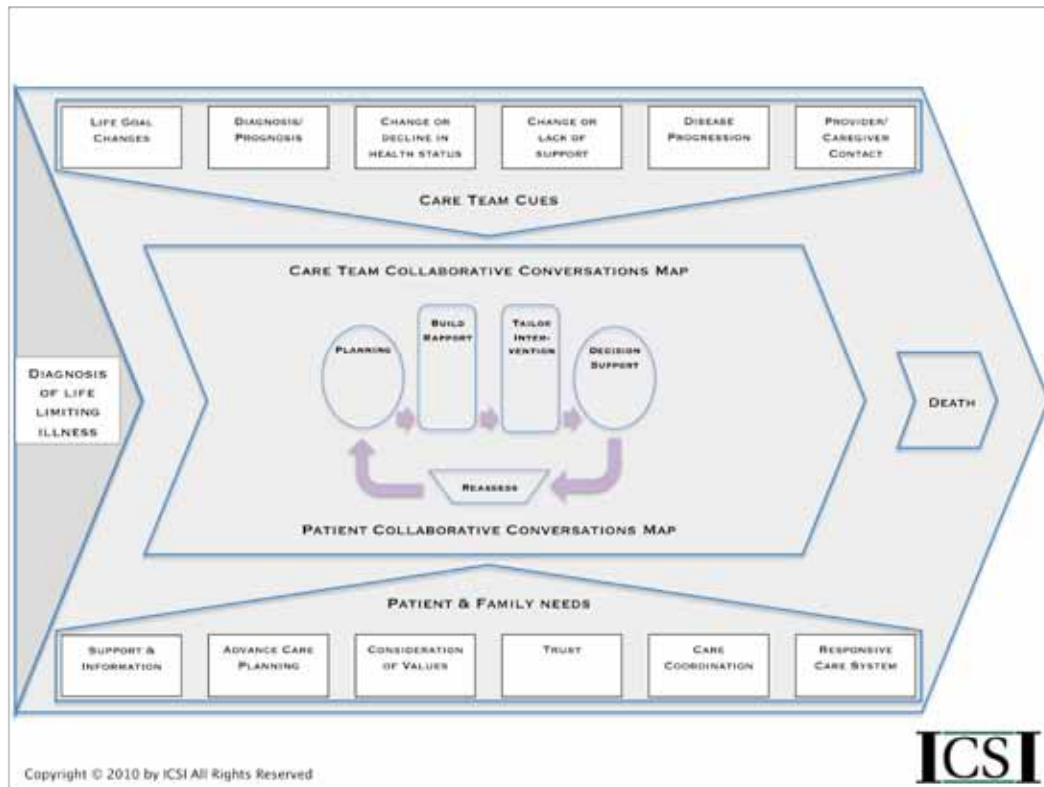
- Trust: the patient must feel confident that his/her preferences will be communicated and respected by all caregivers.
- Care Coordination: Should the patient require care coordination, this is an opportune time to discuss the other types of care-related decisions that need to be made. These decisions will most likely need to be revisited often. Further, the care delivery system must be capable of delivering coordinated care throughout the continuum of care.
- Responsive Care System: The care system needs to support the components of patient- and family-centered care so the patient's values and preferences are incorporated into the care he/she receives throughout the care continuum.

### Evaluating the Decision Quality

Adapted from O'Connor, Jacobsen Decisional Conflict: Supporting People Experiencing Uncertainty about Options Affecting Their Health [2007].

When the patient and family understand the key facts about the condition and their options, a good decision can be made. Additionally, the patient should have realistic expectations about the probable benefits and harms. A good indicator of the decision quality is whether or not the patient follows through with his/her chosen option. There may be implications of the decision on patient's emotional state such as regret or blame, and there may be utilization consequences.

Decision quality can be determined by the extent to which the patient's chosen option best matches his/her values and preferences as revealed through the collaborative conversation process.



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## Appendix C – Pediatrics

### Special Considerations for Pediatric Patients

- Children with a serious illness and their families benefit from pediatric-specific palliative care services.
- It is important to manage developmental level concerns, as well as symptoms needing to be addressed.
- There are specific ethical and legal concerns related to the pediatric population.

Great strides are being made to improve care for adults with serious, advancing illness. Unfortunately, there is growing evidence that health care has failed to meet the specialized needs of children with life-limiting and life-threatening conditions. Advances in pediatric programs, clinical education, and research have occurred in response to the Institute of Medicine's Report, "When Children Die: Improving Palliative Care for Children and their Families (2003)." The continuum of pediatric palliative care extends across settings, including perinatal and neonatal palliative care, as well as for children who are not expected to live to adulthood. Pediatric palliative care programs and organizations are available to provide additional resources. (See [Resources Table](#).)

Children and families are a special population that may also be confronted by a life-threatening illness. Many children undergo painful procedures and suffer from the symptoms of advancing disease without sufficient management of symptoms, despite the fact that modern medicine has the means to relieve their pain and discomfort, as well as improve most symptoms. Families may feel abandoned and overwhelmed, often suffering emotional as well as financial loss for years. Social supports to children and families before and after death are often inadequate, and health care professionals themselves are often left without emotional support for the difficult work they do. Many clinicians and nurses have received virtually no training to practice the skills necessary for communicating effectively with dying children and their families. Practicing health care professionals often lack assistance on how to manage the goals and values that can be conflicting, as well as the broad cultural and religious diversity represented in the U.S.

The Children's Institute for Palliative Care (CIPPC) provides training, continuing education, resources, consultation and technical assistance to health care clinicians who are interested in developing more opportunities for pediatric palliative care in their communities. The institute also develops and supports a network of clinicians in the Midwest region to ensure access to quality palliative care. The End of Life Nursing Education Consortium – Pediatric Palliative Care (ELNEC-PPC), a curriculum developed for pediatric nurses and other clinicians, includes 10 modules on pediatric palliative care. In addition, two pediatric Palliative Care Leadership Centers offer operational training on pediatric palliative care (<http://www.capc.org/pclc>).

The Initiative for Pediatric Palliative Care (IPPC) provides both an education and a quality improvement effort aimed at enhancing family-centered care for children living with life-threatening conditions. IPPC's comprehensive, interdisciplinary curriculum addresses knowledge, attitudes and skills that health care professionals need in order to better serve children and families. These include:

- **Engaging with children and families** – enhancing the ability of health care professionals to understand, support and engage effectively with children with life-threatening conditions, their parents and loved ones, reflecting on core principles in pediatric palliative care and discovering what matters most to families, by incorporating the perspectives of children and families in treatment.
- **Relieving pain and other symptoms** – by learning competent assessment, documentation, reassessment and the continuously monitoring of a pediatric patient's pain and other symptoms using developmentally appropriate pain assessment tools and strategies.

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**Appendix C – Pediatrics**

- **Analyzing ethical challenges in pediatric end-of-life decision-making** – learning methods to support families as they confront an array of difficult choices often encountered when a child is gravely ill and unlikely to recover. This includes ethical recommendations for guiding decisions regarding withholding or withdrawing of life support to allow natural death, and strategies for handling circumstances in which parents and clinicians may disagree about goals of care. It includes the degree of benefit and burden associated with different treatment (and not treating) options, the importance of honoring parental discretion in decision-making, especially when there are uncertain benefits associated with the continuation of life-prolonging treatments, the legitimacy of quality-of-life considerations in goal setting, how to handle conflicts, and the extent to which mature minors should be able to guide their own decisions. Other topics include the use or foregoing of artificial nutrition and hydration, as well as ethical issues relevant to the treatment of pain and suffering, such as those related to palliative sedation (*Diekema, 2009*).
- **Responding to suffering and bereavement** – enhances the ability of health care professionals to recognize, validate and respond to suffering in children, parents and family members by developing a perspective from which to understand and respond to the suffering and bereavement experience of children and families and how this interconnects with their own experience as professional caregivers. The potential contribution of palliative care to provide critical support to the dying child and grieving family members cannot be overstated.
- **Improving communication and strengthening relationships** – enhances health care professionals' communication and relational skills, specifically pertaining to what is known about working with children and families, including a cross-cultural undertaking in which the challenge is to understand and respond to the practices of the family.

*(Initiative for Pediatric Palliative Care, 2006)*

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## Appendix D – Comparison between Palliative Care and Hospice

	<b>Palliative Care</b>	<b>Hospice*</b>
<b>Debility/Failure to Thrive</b>	<ul style="list-style-type: none"> <li>• Greater than three chronic conditions in patient over 75 years old</li> <li>• Functional decline</li> <li>• Weight loss</li> <li>• Patient/family desire for low-yield therapy</li> <li>• Increasing frequency of outpatient visits, emergency department visits, hospitalizations</li> </ul>	<ul style="list-style-type: none"> <li>• Documentation of clinical progression of disease</li> <li>• ECOG three or more</li> <li>• No desire for aggressive treatment</li> <li>• Not a candidate for aggressive treatment</li> <li>• Frequent emergency room visits/frequent hospitalizations</li> </ul>
<b>Cancer</b>	<ul style="list-style-type: none"> <li>• Uncontrolled signs and symptoms due to cancer or treatment</li> <li>• Introduced at time of diagnosis – if disease terminal</li> <li>• Introduced when disease progresses despite therapy</li> </ul>	<ul style="list-style-type: none"> <li>• Any patient with metastatic or inoperable cancer</li> </ul>
<b>Heart Disease</b>	<ul style="list-style-type: none"> <li>• Stage III or IV heart failure despite optimal medical management</li> <li>• Angina refractory to medical or interventional management</li> <li>• Frequent emergency department visits or hospital admissions</li> <li>• Frequent discharges from implanted defibrillators despite optimal device and antiarrhythmic management</li> </ul>	<ul style="list-style-type: none"> <li>• Heart failure symptoms at rest</li> <li>• Ejection fraction less than 20%</li> <li>• New dysrhythmia</li> <li>• Cardiac arrest or syncope</li> <li>• Frequent emergency room visits for symptoms</li> </ul>
<b>Pulmonary Disease</b>	<ul style="list-style-type: none"> <li>• Oxygen-dependent, O<sub>2</sub> sats less than 88% on room air</li> <li>• Unintentional weight loss</li> <li>• Dyspnea with minimal to moderate exertion</li> <li>• Other pulmonary diagnoses, e.g., pulmonary fibrosis, pulmonary hypertension</li> </ul>	<ul style="list-style-type: none"> <li>• Dyspnea at rest</li> <li>• Signs or symptoms of right heart failure</li> <li>• O<sub>2</sub> sat or O<sub>2</sub> of less than 88%</li> <li>• PCO<sub>2</sub> greater than 50</li> <li>• Unintentional weight loss</li> </ul>
<b>Dementia</b>	<ul style="list-style-type: none"> <li>• Behavioral problems</li> <li>• Feeding problems – weight loss</li> <li>• Caregiver stress</li> <li>• Frequency of ED visits</li> <li>• Increased safety concerns</li> </ul>	<ul style="list-style-type: none"> <li>• Unable to walk, bathe or dress self without assistance</li> <li>• Incontinence</li> <li>• Less than six intelligible words</li> <li>• Frequent ER visits</li> </ul>
<b>Liver Disease</b>	<ul style="list-style-type: none"> <li>• Increased need for paracentesis for removal of ascitic fluid</li> <li>• Increased confusion (hepatic encephalopathy)</li> <li>• Increased safety concerns</li> <li>• Symptomatic disease</li> </ul>	<ul style="list-style-type: none"> <li>• INR greater than 5</li> <li>• Albumin less than 2.5</li> <li>• Refractory ascities</li> <li>• SBP</li> <li>• Jaundice</li> <li>• Malnutrition and muscle wasting</li> </ul>
<b>Renal Disease</b>	<ul style="list-style-type: none"> <li>• Dialysis</li> <li>• Stage IV or Stage V chronic kidney disease</li> </ul>	<ul style="list-style-type: none"> <li>• Not a candidate for dialysis</li> <li>• Creatinine clearance of less than 15 mL/minute</li> <li>• Serum creatinine greater than 6.0</li> </ul>
<b>Neurologic</b>	<ul style="list-style-type: none"> <li>• Stroke</li> <li>• Parkinson's</li> <li>• ALS – amyotrophic lateral sclerosis</li> <li>• MS – multiple sclerosis</li> </ul>	<ul style="list-style-type: none"> <li>• Frequent emergency room visits</li> <li>• Albumin less than 2.5</li> <li>• Unintentional weight loss</li> <li>• Decubitus ulcers</li> <li>• Homebound/bed confined</li> </ul>

\* Compiled from National Hospice and Palliative Care Organization, [www.nhpc.org](http://www.nhpc.org); Bailey, Amos, The Palliative Response, <http://www.hospice.va.gov>.

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## Appendix E – Medicare Hospice Benefit: Eligibility and Treatment Plan

In the United States, the Medicare Hospice Benefit (MHB) pays for the vast majority of all hospice care. Established in 1983, the MHB pays for medical, nursing, counseling and bereavement services for terminally ill patients and their families. The original goal of the MHB was to support families caring for their dying relative at home. Hospice services are not site specific; they can be provided in an acute care hospital, at home or in a long-term care facility. Referral for hospice care is appropriate when the overall plan of care is directed toward comfort rather than reversing the underlying disease process.

- Hospice services include medical equipment and supplies, medication for pain and symptom control, chemotherapy and radiation (if for palliation), grief counseling and bereavement support.
- Hospice benefits cover hospital services for short-term symptom control and temporary respite care to relieve family caregivers. They do not cover curative treatments or extensive evaluations inconsistent with the hospice approach.
- Patients, initially certified for two 90-day periods, may be recertified for an unlimited number of 60-day periods if the condition is still terminal with a life expectancy of less than six months if the disease runs its expected course.
- If a patient qualifies for MHB, Medicare and hospice benefits can be coordinated to cover the appropriate aspects of care.
- Under Medicare, DNR status cannot be used as a requirement for admission.

### Plan of Care (POC)

The hospice team and the patient's physician work together with the patient and family to maximize quality of life by jointly developing the Plan of Care. The POC is based on the patient's diagnosis, symptoms and goals of care. The hospice program and the patient's physician must together approve any proposed tests, treatments and services. In general, only those treatments that are necessary for palliation and/or management of the terminal illness will be approved.

### Physician Role

At the time of enrollment, the patient indicates the primary physician who will direct care; the patient may select a hospice physician for this role or may select his/her usual primary doctor. The primary physician is responsible for working with the hospice team to determine appropriate care.

### Places of Care

**Home.** The majority (95%) of hospice care takes place in the home. Hospice team members visit the patient and family on an intermittent basis, determined by the Plan of Care. Medicare rules do not require a primary caregiver in the home, but as death nears, it becomes increasingly difficult to provide care for a patient who does not have someone (family, friends, hired caregivers) who can be present 24 hours a day in the home.

**Long-term care facility.** 25% of patients in the U.S. die in nursing homes. Medicare recognizes that this can be the resident's home and that the patient's family frequently includes the nursing home staff. Hospice care under the MHB can be provided to residents in addition to usual care provided by the facility. Individual hospice programs must establish a contract with the facility to provide hospice care. The MHB does not pay for nursing home room and board charges.

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**Hospice inpatient unit.** Dedicated units, either freestanding or within other facilities, such as nursing homes or hospitals, are available in some areas. Permitted length of stay varies with the facility and its specific admission policies.

**General inpatient facility.** When pain or other symptoms related to the terminal illness cannot be managed at home, the patient may be admitted to a hospital or inpatient facility for more intensive management, still under the MHB. The inpatient facility must have a contract with the hospice program for acute care.

### **Emergency Department/Urgent Care**

Patients may seek medical care at EDs or urgent care centers when unable to manage their care independently at home. It is essential that any testing or treatment be coordinated with the hospice team.

*(Turner, 2006)*

For specific Medicare Hospice Benefit information, see <http://www.cms.hhs.gov/center/hospice.asp>.

### **Hospice Care Team Coordinates Palliative Care Plan with Primary Provider**

At the time of enrollment, the patient indicates the primary physician who will direct care. The patient usually selects the primary specialty care physician who is currently directing his/her care but may elect to have the hospice medical director as the primary physician in certain cases. The hospice team works with the primary physician and patient and family to determine appropriate care. (See [Annotation #11, "Does Patient Meet Hospice Criteria?"](#))

Discharge from hospice may occur for several reasons. These may include:

- an improved prognosis,
- the patient wishes to seek curative treatment, or
- an unrelated problem forces the patient to disenroll in hospice.

Patient may be readmitted to hospice at any time, as long as the criteria for admission are still met. (See [Annotation #11, "Does Patient Meet Hospice Criteria?"](#))

To determine whether a Medicare-approved hospice program is available in your area, contact the nearest Social Security Administration office, your state or local health department, or your state hospice organization (in Minnesota, Hospice Minnesota 800-214-9597), or call the National Hospice Organization Hospice Help Line (800) 658-8898.

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*The next scheduled revision will occur within 24 months.*

### Original Work Group Members

Dianne Brundage, Pharm D  
*Pharmacist*

**Park Nicollet-Methodist**

Howard Epstein, MD  
*Internal Medicine/Palliative  
Care, Work Group Leader*

**HealthPartners-Regions  
Hospital**

Mohamoud Hamud, Chaplain  
*Religious Counselor*

**Mayo Clinic**

Nancy Joyner, ACHPN  
*Family Medicine/Palliative Care*

**Altru Health System**

Ken Kephart, MD  
*Family Medicine/Geriatrics*

**University of MN Physicians**

Mark Leenay, MD  
*Palliative Care Content  
Consultant*

**Evercare Hospice and  
Palliative Care**

Martha McCusker, MD  
*Internal Medicine/Geriatrics*

**Hennepin County Medical  
Center**

Glenda Morris, CNP  
*Cardiology*

**St. Paul Heart Clinic**

Peter Nelson, MD  
*Anesthesiologist/Palliative  
Care*

**Winona Health**

Becky Nosan, CNP  
*Family Medicine/Geriatrics*

**Park Nicollet-Methodist**

Janet Jorgenson-Rathke, PT  
*Measurement/Implementation  
Advisor*

**ICSI**

Mabel Rohr, CNP  
*Family Medicine/Geriatrics*

**HealthPartners Medical  
Group**

Kristina Schlecht, MD  
*Family Medicine*

**Dakota Clinic**

Linda Setterlund, MA  
*Facilitator*

**ICSI**

Sara Shorter, MD  
*Family Medicine/Palliative  
Care*

**Hutchinson Medical Center**

Sheila Skeels, LICSW  
*Social Worker*

**Winona Health**

Cally Vinz, RN  
*Facilitator*

**ICSI**

[Return to Table of Contents](#)

**Contact ICSI at:**

8009 34th Avenue South, Suite 1200; Bloomington, MN 55425; (952) 814-7060; (952) 858-9675 (fax)

Online at <http://www.ICSI.org>

## Document History

The original guideline document was drafted in 2006 by a committee of 14 clinicians. It was approved for release early in 2007. In that year a subgroup of the committee was commissioned to develop an order set for symptom management for patients with a life-limiting, progressive illness. This order set was approved and released in December 2007. It contained numerous symptoms – both physical and psychological. Many options for treatment were described incorporating pharmacological, non-pharmacological and complementary/supportive therapies.

Controlling physical and psychological symptoms for patients with a serious illness is core to palliative care. Therapy should be individualized for each patient's unique circumstances. In 2011 the work group made the decision to discontinue revision of the order set. It recognizes that there is not a single order set that covers all symptoms and possible therapies. The guideline contains some resources that are available to assist the clinician in symptom management.

In 2009, ICSI formed a strategic initiative to integrate palliative care into routine care delivery, recognizing that a palliative care specialty may not be available in all health care settings. This initiative was designed to create a more efficient model for the delivery of pain and symptom management, care coordination and shared decision-making from the moment the patient was diagnosed with a serious illness.

A palliative care model and a communication plan were developed for introducing elements of palliative care at the time a patient was identified with a life-limiting illness. Goals included identifying metrics to evaluate the model and creating a plan to ensure the model's financial sustainability. The design team identified what palliative care might look like in primary care, long-term care, home care and specialty care settings by applying the agreed-upon elements of palliative care. In 2011 the specific work on the initiative was halted. Instead, the elements plus other principles learned through the effort were incorporated into other health care redesign efforts, such as Health Care Home, Reducing Avoidable Readmissions to hospitals, and Shared Decision-Making.

The GRADE system as a method of assessing evidence and writing recommendations was implemented in 2011.

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## **ICSI Document Development and Revision Process**

### **Overview**

Since 1993, the Institute for Clinical Systems Improvement (ICSI) has developed more than 60 evidence-based health care documents that support best practices for the prevention, diagnosis, treatment or management of a given symptom, disease or condition for patients.

### **Document Development and Revision Process**

The development process is based on a number of long-proven approaches. ICSI staff first conducts a literature search to identify pertinent clinical trials, meta-analysis, systematic reviews, regulatory statements and other professional guidelines. The literature is reviewed and graded based on the ICSI Evidence Grading System.

ICSI facilitators identify gaps between current and optimal practices. The work group uses this information to develop or revise the clinical flow and algorithm, drafting of annotations and identification of the literature citations. ICSI staff reviews existing regulatory and standard measures and drafts outcome and process measures for work group consideration. The work group gives consideration to the importance of changing systems and physician behavior so that outcomes such as health status, patient and provider satisfaction, and cost/utilization are maximized.

Medical groups that are members of ICSI, review each guideline as part of the revision process. The medical groups provide feedback on new literature, identify areas needing clarification, offer recommended changes, outline successful implementation strategies and list barriers to implementation. A summary of the feedback from all medical groups is provided to the guideline work group for use in the revision of the guideline.

### **Implementation Recommendations and Measures**

Each guideline includes implementation strategies related to key clinical recommendations. In addition, ICSI offers guideline-derived measures. Assisted by measurement consultants on the guideline development work group, ICSI's measures flow from each guideline's clinical recommendations and implementation strategies. Most regulatory and publicly reported measures are included but, more importantly, measures are recommended to assist medical groups with implementation; thus, both process and outcomes measures are offered.

### **Document Revision Cycle**

Scientific documents are revised every 12-24 months as indicated by changes in clinical practice and literature. Each ICSI staff monitors major peer-reviewed journals every month for the guidelines for which they are responsible. Work group members are also asked to provide any pertinent literature through check-ins with the work group mid-cycle and annually to determine if there have been changes in the evidence significant enough to warrant document revision earlier than scheduled. This process complements the exhaustive literature search that is done on the subject prior to development of the first version of a guideline.

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