LTC Information Series

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Dedicated To Long Term Care Medicine

Palliative Care

in the Long-Term Care Setting

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American Medical Directors Association (AMDA)

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TABLE OF CONTENTS

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1 SECTION 1: INTRODUCTION

> "My own notion is that palliative care is a concept of care that should be given to all nursing home residents, regardless of their status as 'terminally ill' or not….All residents need alleviation of symptoms, pain management, psychosocial intervention, and spiritual care…" Jacob Dimant.[1]

Professionals caring for frail older adults understand that the percentage of patients dying in hospitals is decreasing while the percentage of patients dying at home or in long-term care facilities is increasing. Patients may experience physical, emotional, and spiritual suffering for months or even years before they enter the active phase of dying from their illness. To ensure that long-term care patients with chronic and progressive illnesses receive optimal care, all members of the interdisciplinary team should be proficient in the assessment and relief of suffering. Such a "whole-person" approach to the care of patients whose diseases are not responsive to curative treatment is called palliative care.

This toolkit aims to provide helpful and practical guidance to long-term care professionals who are motivated to improve palliative and end-of-life care by providing organizational leadership, promoting education, developing best-practice guidelines, and implementing quality assurance and improvement procedures in palliative and end-of-life care.

DEFINITIONS

Palliative Care

Palliative care is best understood as a system of care based on a patient-centered, quality-of-life model that values patient autonomy and focuses on anticipating, preventing, and treating the suffering of patients and families regardless of diagnosis or stage of illness. Although the palliative paradigm differs from the more traditional illness-centered, curative model, palliative care can be integrated into curative and restorative treatment plans. Thus, no specific therapy should be excluded from consideration as a palliative treatment if it can enhance comfort or improve the patient's quality of life.

Palliative care is usually delivered by an interdisciplinary team. Multiple disciplines are needed to address medical, nursing, and other therapeutic aspects of care and to meet the patient's or family's needs for social, emotional, and spiritual support.

Hospice

Hospice is one system for delivering palliative care. Hospice care has traditionally focused on caring for patients who have a limited (i.e., 6 months or less) life expectancy or who are in the terminal phase of their illness. In addition to providing all elements of interdisciplinary palliative care, hospice care also provides bereavement support for families after a patient's death.

Medicare Hospice Benefit

The Medicare Hospice Benefit is designed to support the provision of interdisciplinary, comprehensive, palliative, and end-of-life care to patients with anticipated life expectancies of 6 months or less.

SCOPE OF THE PROBLEM

> "The key to caring well for people who will die in the (relatively) near future is to understand how they may die and then plan appropriately."[2]

Approximately 20 percent of nursing home residents die each year in nursing homes or shortly after a transfer from a nursing home to an acute care setting.[3]

Despite the relatively high likelihood that patients who are admitted to a long-term care facility for the care of an advanced chronic illness will suffer further decline in function and will die within a relatively short period of time, the long-term care regulatory environment emphasizes rehabilitation and optimization of function. This focus may have the unintended consequence of minimizing the importance of the patient's palliative care needs.

- Studies show that dying residents with daily pain do not receive adequate pain management or receive pain management that is inconsistent with expert guidelines.[4]
- Residents' family members report that the addition of hospice care improves the quality of symptom management for their relatives at the end of life.[3]
- Few long-term care facilities have organized bereavement services for family members.[3]

Despite the potential benefits of palliative and hospice care in long-term care facilities, only one in four Medicare-eligible residents of a long-term care facility uses hospice care before death.[3] Of 12,000 residents of long-term care facilities who used the Medicare Hospice Benefit in 1996, 32% had hospice stays of 14 days or less and 20% had hospice stays of 1 week or less, which is considerably shorter than the national median length of stay for all hospice patients.

PALLIATIVE CARE IN THE LONG-TERM CARE SETTING: UNDERLYING PRINCIPLES

The principles underlying this Toolkit are as follows:

1. High-quality palliative care is essential in long-term care facilities.

Long-term care patients have multiple chronic illnesses (e.g., dementia, heart disease, pulmonary disease, arthritis) that generally result in progressive loss of function and the emergence of distressing symptoms that often cause physical, emotional, and spiritual suffering. Understanding the needs of a person with a chronic illness involves consideration of the disease's impact not only on physical and cognitive function but also on quality of life. Although chronic illnesses cannot be cured, they may respond to treatments that slow disease progression or alleviate the severity of symptoms. Relief of suffering usually involves a multimodal program of medication, restorative therapies, activities, and emotional or spiritual support.

2. Palliative care requires understanding and communicating with the person with the illness and with the person's surrogate or family.

Ideally, care is individualized on the basis of the patient's values, preferences, and negotiated goals of care. It is the responsibility of the long-term care attending physician to discuss with the patient and family the patient's diagnoses, prognosis, treatment options, and goals of care.

3. A patient's goals of care may be multiple and overlapping.

For example, although congestive heart failure cannot be cured, the patient may simultaneously choose palliative care for relief of symptoms of breathlessness due to heart failure, rehabilitative and restorative therapy to optimize mobility, and curative treatment for an acute illness such as pneumonia.

4. The palliative care plan is dynamic.

The relative amounts and types of curative, restorative, and palliative care deemed appropriate for a patient will depend on the individual's goals of care and informed choices. An informed choice should reflect the patient's values, diagnosis, prognosis, and assessment of the relative benefits and burdens of various curative, restorative, and palliative treatment choices. Treatment choices and goals of care may change as the patient's condition responds positively to treatments or declines as the result of an acute illness or disease exacerbation. The diagnostic and therapeutic responses to changes in the patient's condition should take into consideration both the circumstances leading to the change in status and the benefits, burdens, and goals of care.

5. Although the specific mission of hospice organizations is to deliver palliative and end-of-life care, hospices cannot and should not be the sole providers of palliative care in long-term care facilities.

The Medicare Hospice Benefit exists to deliver coordinated, comprehensive palliative care for terminally ill patients (i.e., those with a life expectancy of approximately 6 months or less) and their families. Hospice care may not be appropriate for all long-term care patients, but most long-term care patients need palliative care for months or even years before they progress to the terminal phase of their illnesses. For example, many long-term care patients have moderate to severe pain due to osteoarthritis and other painful, nonfatal conditions. If their pain is recognized and treated, these patients may be able to postpone functional decline and avoid the emotional and spiritual suffering associated with unrelieved pain.

Even when a hospice organization supplements the care a patient receives in a long-term care facility, the hospice staff cannot be present at all times. Because the staff of the long-term care facility provides most of the patient's care, including palliative and end-of-life care, they must have the necessary knowledge, attitudes, skills, and support to optimize end-of-life care.

6. Collaborative care that involves the staff of a long-term care facility and a hospice organization can both provide benefits and pose challenges for the attending physician and medical director.

When a hospice care team enters the long-term care facility to collaborate with the facility's staff and provide comprehensive palliative care, the facility medical director must deal with an added layer of complexity. The care of patients receiving hospice care in a long-term care facility is subject both to the regulations governing the hospice program and to the regulations, surveys, and quality indicators aimed at achieving the highest practical level of function for long-term care patients. A care plan designed to achieve the highest practical level of function may be perceived as conflicting with one that focuses on the patient's comfort.

7. When the end of life (i.e., the active phase of decline and dying) approaches, the ultimate goal of care is to provide the dying patient with a "good death."

A good death may be thought of as one that[5]:

- Provides relief from distressing symptoms,
- Addresses psychosocial and spiritual needs,
- Provides a chance for patients and families to face the inevitable without additional fear or misinformation, and
- Produces a sense of autonomy and reduced powerlessness in the face of death.

8. The medical director, attending physicians, nursing leadership, and administration should continually strive to develop a culture within the long-term care facility that effectively supports the implementation of palliative principles and practices.

The attending physician and the medical director can make valuable contributions to the interdisciplinary teams providing palliative and hospice care. Facilities benefit when attending physicians and medical directors encourage the development and implementation of policies, processes, and quality improvement activities that address palliative and end-of-life care.

The tasks involved in providing optimal end-of-life care in long-term care facilities can generally be categorized into five areas:

- Explicit recognition that an individual resident has a limited life expectancy, with no reasonable expectation of a change in this prognosis.
- Identification of the person authorized to make decisions about what, when, and how end-of-life care can best be delivered to reflect the individual's needs. Sometimes this person is the resident himself or herself. When the resident is unable to make his or her own decisions, an agent, proxy, or valid set of instructions should be identified.
- Care planning that specifically includes end-of-life issues.
- Implementation of the care plan, with monitoring to ensure that the resident receives appropriate end-of-life care.
- Promotion or maintenance of the dignity of the patient.

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2 SECTION 2: PROGNOSIS

> "The key to caring well for people who will die in the (relatively) near future is to understand how they may die and then plan appropriately."[1]

In the long-term care facility setting, prognostication is important for appropriate care planning and timely use of available resources. Prognostication is not a guarantee of future events but rather an estimate of what can reasonably be expected. Ideally, an accurate prognostic model would allow one to determine whether a person could expect to live 6 months or less and thus be considered terminally ill. Such a person might then decide to forego certain life-prolonging treatments, pursue a more palliative course, or elect hospice care.

Several studies have shown a high mortality rate among populations living in long-term care facilities:

- One-third to one-half of individuals admitted to a nursing home died within 12 months of admission.[2]
- Median duration of life following admission to long-term care was 2.75 years.[3]
- Among Dutch patients with dementia who were admitted to long-term care, the 2-year survival rate was 43%.[4]

Yet even among patients with a high mortality rate, physicians have difficulty predicting short-term survival.

- Although nearly three-quarters of patients with advanced dementia who are admitted to a nursing home have a life expectancy of less than 6 months, as few as 1% will be perceived as having such a life expectancy at the time of admission. Even at the last Minimum Data Set assessment before death, only 4% of these patients were perceived as having a prognosis of less than 6 months.[5]
- When patients are admitted to hospice programs, their attending physicians accurately predict their length of survival only 20% of the time. Most of the time, attending physicians are overoptimistic, estimating that their patients will live five times as long as they actually do after admission to hospice care. Only 17% of attending physicians thought their patients would die sooner than they did after enrollment in the hospice program.[6]

Several factors may account for practitioners' imprecise predictions about life expectancy. Practitioners may unconsciously be biased toward optimism or denial of death. Additionally, prognosis in advanced nonmalignant diseases (the commonest cause of death among the elderly) is complicated because these patients begin with a low functional status and experience unpredictable and episodic exacerbations that cause marked declines in function. Following these acute functional declines, whether an individual returns to baseline function or declines further is unpredictable.[7] For example, practitioners have had the experience of seeing severe functional impairments or organ dysfunctions in a wide range of potentially fatal conditions, but the impairment was completely or partially reversible or manageable, making prognostication about 6-month survival very difficult.[8]

Moreover, predicting the average life span of a group of patients with given characteristics (e.g., age, disease, functional status)—which can be done with great precision—is different from predicting the life span of an individual. This difference represents perhaps the greatest barrier to modern prognostication. For example, few 85-year-old men with advanced Alzheimer's disease who are bed-bound, doubly incontinent, and able to speak less than one word per day would be expected to live longer than 6 months. However, some individuals who fit this description do live for a longer time. It is impossible to predict with complete accuracy which individuals will die within 6 months and which will not. This uncertainty causes many practitioners to avoid prognostication altogether.

Researchers have developed predictive models to guide practitioners as they try to determine whether death is imminent for a specific individual. Several of these disease or condition-specific prediction models are discussed below.

Prediction Models Based on Function in Community-Dwelling Elders

One study of 917 community-based elderly patients eligible for nursing home care could not detect a state of functional or cognitive decline that marked an obvious trajectory toward the end of life.[9]

A large study of elderly patients attempted to construct a prognostic model to describe variables predicting 1-month and 6-month mortality. On average, patients who died were dependent in 3 activities of daily living (ADLs) 12 months before death, dependent in 4 ADLs 5 months before death, and may have been dependent in 5 ADLs 1 to 2 months before death. The investigators could not find an accurate predictor of 1-month or 6-month mortality. They concluded that good end-of-life care cannot be dependent upon the ability to predict imminent demise or 6-month mortality.[10]

Long-Term Care Prediction Models

One prediction model[11] estimates 1-year mortality in long-term care (Table 2.1). The author of the scale points out that a potential limitation of this prognostic index is that most factors in the predictive model are modifiable. It is unknown whether intervention to modify these factors changes the 1-year mortality hazard ratio.[11] Another group has modified this scale, using a score of 7 (indicating 50% 1-year mortality) as a trigger to update advance care planning and consider a hospice or palliative care consultation (Table 2.2).[12,13]

Alzheimer's Prognostic Instruments

Alzheimer's disease is a progressive, ultimately fatal illness with a median survival from the time of diagnosis of 4.2 years for men and 5.7 years for women.[14] To determine hospice eligibility for patients with Alzheimer's disease, the National Hospice and Palliative Care Organization (NHPCO) has recommended using the Functional Assessment Stage (FAST) criteria (Table 2.3).[15] Hospices often recommend enrollment when the patient reaches FAST stage 7(c). Unfortunately, the FAST criteria do not accurately predict 6-month survival, a key criterion for hospice enrollment. FAST is therefore a problematic tool for this purpose. In addition, many patients cannot be staged by FAST criteria because their disease does not progress in the ordinal sequence of the scale.[16] Finally, only a minority of long-term care patients who die from dementia meet the criteria for FAST stage 7(c).[17] Among long-term care dementia patients who do reach this stage, less than one-half died within 6 months and two-thirds died within 1 year.[4]

Mitchell et al[17] derived a predictive scale using 12 variables from the Minimum Data Set (MDS) that performed better than FAST stage 7(c) at predicting 6-month mortality in long-term care patients with severe dementia (Table 2.4). However, this prognostic model also had its limitations: A cut-off score of 6 or higher would fail to enroll 28% of residents with advanced dementia who died. Furthermore, of those with a score of 6 or higher, 53% would still be alive after 6 months.

Other Prognostic Tools

Illness trajectory models of prognosis may use different combinations of functional status, lab values, signs, symptoms, and diagnoses to determine how close a person is to death. However, illnesses often do not follow a given trajectory, patients may have multiple progressive illnesses with multiple trajectories that may be additive or independent, and the trajectory of certain illnesses depends on the number and severity of recurrences or exacerbations. A further limitation of prognostic indices and illness trajectory models is that they do not address the trajectory of spiritual, psychological, or social distress as an illness progresses.[1] Ultimately, the imprecision of current prognostic models argues against their use as a basis for initiating advance care planning discussions or delivering palliative care services.[7]

Other authors have suggested using relatively nonspecific general indicators of decline such as:

- Karnofsky Performance Status (Table 2.5)[18]
- The Palliative Prognosis Score (PaP) to determine short-term prognosis in nonmalignant disease (Table 2.6).[19]
- A 10% loss of body weight over a 6-month period as a predictor of mortality in the next 6 months.[20]
- Core and disease-specific end-stage indicators (Table 2.7)[21]
- Debility, which identified hospice patients with nonmalignant illness with a mortality rate similar to patients with a 6-month prognosis based on organ- or disease-specific survival criteria (Table 2.8).[22]

In summary, both practitioners' judgment and predictive tools are fraught with inaccuracy when trying to predict the likelihood of an individual patient's dying within a 6-month period, the current prognostic criterion for hospice eligibility. This difficulty should not lead to therapeutic nihilism, but rather should affirm the importance of having policies and procedures in place to anticipate, assess, and treat distressing symptoms associated with chronic medical conditions regardless of a patient's appropriateness for hospice enrollment.

It is possible to have meaningful prognostic discussions that provide essential information and anticipatory guidance to patients, families, and caregivers even if practitioners cannot predict the exact timing of critical events or the active phase of dying. Such conversations can begin with acknowledgment of the presence of chronic progressive illnesses (e.g., congestive heart failure, dementia) and a frank discussion of the likely sequence of events that signals progression of the illness. For example, as dementia becomes more severe, patients may become bed bound and may suffer one or more of the predictable consequences of immobility (i.e., falls, pneumonia, skin breakdown). These conversations are essential to meaningful advance care planning, effective palliation, and good end-of-life care.

The End of Life/Palliative Education Resource Center (www.eperc.mcw.edu) is a useful resource for prognostication tools.

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TABLE 2.1. PREDICTING 1-YEAR SURVIVAL IN LONG-TERM CARE RESIDENTS

A. NEWLY ADMITTED RESIDENTS

Proportional Hazards Regression Analysis Examining the Association Between Major Mortality-Related Factors and 1-Year Mortality in Newly Admitted Residents

Clinical Variable	Hazard Ratio
Cancer	2.48
Shortness of breath	2.24
Congestive heart failure	1.65
Bedfast	1.92
Male	1.52
Unstable conditions	1.87
>25% of food uneaten	1.80
Low functional ability score	1.76
Swallowing problem	1.53
Bowel incontinence	1.39
Body mass index <23 kg/m^2	1.29

B. LONG STAY RESIDENTS

Proportional Hazards Regression Analysis Examining the Association Between Major Mortality-Related Factors and 1-Year Development and Validation Cohorts for Long-Stay Residents

Clinical Variable	Hazard Ratio
Shortness of breath	2.69
Feeding tube	2.09
Unstable conditions	2.16
Male gender	1.59
>25% of food uneaten	1.86
Congestive heart failure	1.58
Low functional ability score	1.99
Weight loss	2.04
Body mass index <23 kg/m^2	1.47
Diabetes mellitus	1.32
Age ≥ 84	1.24

C. PERCENT 1-YEAR MORTALITY BY MORTALITY RISK INDEX SCORE

	Newly Admitted Residents	Long-Stay Residents
Score		
0–1	11.8	8.1
2–3	20.7	12.5
4–5	1.3	20.9
6–7	43.4	31.0
8–9	56.6	44.6
10–11	70.6	51.6
12–13	80.6	69.6
14–15	92.7	76.3
16–17	95.4	80.0
18–19	100.0	100.0

Determination of Mortality Risk Index Score
To stratify residents into different levels of risk for 1-year mortality, first determine if they are Newly Admitted Residents or Long Stay Residents.

Next, determine the presence or absence of the clinical variables in the appropriate table (Newly Admitted or Long-Stay Resident).

Then sum the Hazard Ratios associated with the clinical variables to determine the Mortality Risk Index Score (MRIS). This sum is rounded to the nearest integer, and values of 0.5 are rounded up to the next highest integer. Residents who had none of the risk factors are given an MRIS of 0, representing no risk.

Determining presence of variables

- **Weight loss** is defined by the Minimum Data Set (MDS) as a loss of 5 or more pounds in the past 30 days or 10 or more pounds in the past 6 months.
- **Unstable conditions** are defined as conditions or diseases that make residents' cognitive, activity of daily living (ADL), or behavior status unstable, fluctuating, or deteriorating.

Simple yes/no variables regarding the presence of many morbid symptoms included (more than 25% of food uneaten, swallowing problem, shortness of breath, bedfast).

Congestive heart failure, diabetes mellitus are indicated on the MDS if they *bear a relationship to current function, cognition, mood, treatments, or risk of death.*

Low functional ability score is derived from the MDS ADL long form measuring functional performance (Section G1) during the 7 days before the completion of the MDS. A score $\geq$ 5 on this scale is considered low functional ability.

Source: Flacker and Kiely, 2003.[11] Reprinted with permission.

TABLE 2.2. FLACKER MORTALITY SCORE WORKSHEET

Resident: ______________________________ Date: ____________

Resident Characteristic	Information Location	Scoring Chart	Score
Functional ability score	MDS Section G1 See chart below	If summary functional ability score >4, score **2.50**.	
Weight loss	Weight sheet	If lost ≥5 pounds in past 30 days or >10 pounds in past 180 days, score **2.26**.	
Shortness of breath	MDS Section **J1l**	If yes, score **2.08**.	
Swallowing problems	MDS Section **K1b**, **K5c**, also see diet order for special texture	If yes, score **1.81**.	
Male	MDS Section **AA 2**	If male, score **1.76**.	
Body mass index	MDS Section **K2**, Use chart on next page	If BMI is <22 kg/m^2, score **1.75**.	
Congestive heart failure	MDS Section **I1f**	If yes, score **1.57**.	
Age >88 years	DOB- MDS Section **AA3** or face sheet	If yes, score **1.48**.	
		Total score	

If total score is:	**Probability of dying within 1 year is approximately:**
0-2	7%
3-6	19%
7-10	50%
11+	86%

Functional ability score
To derive functional ability score, use MDS Section G1 data for the following 7 items. Each item is scored on a scale of 0 (no impairment) to 4 (high impairment), for a total score ranging from 0-28.

Bed mobility ________________
Transferring ________________
Eating ________________
Toileting ________________
Hygiene ________________
Locomotion on unit ________________
Dressing ________________
TOTAL ________________

DOB: date of birth; MDS: Minimum Data Set.

Source: Derived from Flacker and Kiely, 1998.[12] Worksheet developed by Cari R. Levy,[13] MD, CMD, Aurora, CO 80011. Reprinted with permission.

TABLE 2.3. FUNCTIONAL ASSESSMENT STAGING (FAST)

FAST Stage and Characteristics	**Clinical Diagnosis**	**Duration of Stage***
1. No functional decrement	Normal adult	50 years
2. Subjective word difficulties	Normal aged adult	15 years
3. Decreased function in demanding employment settings	Compatible with possible incipient Alzheimer's disease in minority of cases	7 years
4. Decreased ability to handle complex tasks such as finances or planning dinner for guests	Mild Alzheimer's disease	2 years
5. Requires assistance in choosing proper clothing	Moderate Alzheimer's disease	18 months
6. (a) Difficulty dressing properly (b) Requires assistance bathing (c) Inability to handle mechanics of toileting (d) Urinary incontinence (e) Fecal incontinence	Moderately severe Alzheimer's disease	5 months 5 months 5 months 4 months 10 months
7. (a) Ability to speak limited to about six words (b) Intelligible vocabulary limited to single word (c) Ambulatory ability lost (d) Ability to sit up lost (e) Ability to smile lost (f) Ability to hold head up lost	Severe Alzheimer's disease	12 months 18 months 12 months 12 months 18 months Not applicable

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* Duration of stage in those entering the stage who progress into the next stage; not all patients progress.

Source: Reisberg, B. Functional Assessment Staging (FAST). *Psychopharmacology Bulletin,* 1988; 24:653-659.

TABLE 2.4. MORTALITY RISK INDEX SCORE FOR STRATIFICATION OF RESIDENTS INTO LEVELS OF RISK FOR 6-MONTH MORTALITY

Score Sheet to Estimate 6-Month Prognosis in Nursing Home Residents With Advanced Dementia

Risk Factor From Minimum Data Set	**Points**	**Score**
Activities of daily living scale= 28*	1.9	_____
Male	1.9	_____
Cancer	1.7	_____
Congestive heart failure	1.6	_____
Oxygen therapy needed in prior 14 days	1.6	_____
Shortness of breath	1.5	_____
<25% of food eaten at most meals	1.5	_____
Unstable medical condition	1.5	_____
Bowel incontinence	1.5	_____
Bedfast	1.5	_____
Age >83 y	1.4	_____
Not awake most of the day	1.4	_____

Total risk score, rounded to nearest integer
Possible range, 0-19

*The Activities of Daily Living Scale is obtained by summing the resident's self-performance ratings on the Minimum Data Set for the following 7 functional activities: bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. In the Minimum Data Set, functional ability is rated on 5-point scale for each activity (0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence). A total score of 28 represents complete functional dependence.

If Total Risk Score is…	**Estimated Risk of Death Within 6 Months (%)**
0	8.9
1 or 2	10.8
3, 4, or 5	23.2
6, 7, or 8	40.4
9, 10, or 11	57.0
≥ 12	70.0

Source: Mitchell et al, 2004.[17] Reprinted with permission.

TABLE 2.5. KARNOFSKY PERFORMANCE STATUS

Score	**Function**
100%	Normal, no evidence of disease
90%	Able to perform normal activity with only minor symptoms
80%	Normal activity with effort, some symptoms
70%	Able to care for self but unable to do normal activities
60%	Requires occasional assistance, cares for most needs
50%	Requires considerable assistance
40%	Disabled, requires special assistance
30%	Severely disabled
20%	Very sick, requires active supportive treatment
10%	Moribund (fatal processes are progressing rapidly)
0%	Dead

Source: Karnofsky et al, 1948.[18] Reprinted with permission.

TABLE 2.6. PALLIATIVE PROGNOSIS SCORE

Clinical Factor	Points
Dyspnea present	1
Anorexia present	1.5
Karnofsky Performance Scale (KPS) score of 10-20*	2.5
Clinical prediction of survival (weeks)	
>12	0
11-12	2
7-10	2.5
5-6	4.5
3-4	6
1-2	8.5
Total white blood cell count	
≥8,500 cells/mm^3 (8.5 x10^9 cells/L)	0
8,501-11,000 cells/mm^3 (8.5 to 11 x10^9 cells/L)	1
>11,000 cells/mm^3	2.5
Lymphocyte percentage	
≥20	0
12.0-19.9	1
<12	2.5
Total points	

Score	Risk Group	Median Survival (days) (95% CI)	Probability of 30-day Survival (%)
0-5.5	Low	76 (67-87)	87
5.6-11.0	Moderate	32 (28-39)	52
11.1-17.5	High	14 (11-18)	17

*A patient with a KPS score of 10 to 20 is very sick (i.e., hospitalization is necessary, active supportive treatment is necessary, or patient is moribund).

Source: Glare et al, 2003[19] (adapted from Maltoni et al, 1999[20]). Reprinted with permission.

TABLE 2.7. CORE AND DISEASE-SPECIFIC END-STAGE INDICATORS

Core End-Stage Indicators
Physical decline
Weight loss
Multiple comorbidities
Serum albumin level <2.5 g/dL
Dependence on assistance with most activities of daily living
Karnofsky Performance Status score of <50%

Select Disease-Specific Indicators

Dementia
Inability to walk or dress without assistance
Urinary and fecal incontinence
Absence of consistently meaningful verbal communication
Plus any one of the following:

- 10% weight loss in previous 6 months
- Serum albumin level <2.5 g/dL
- Recurrent fevers
- Aspiration pneumonia
- Pyelonephritis or upper-tract urinary infection
- Multiple stage III or stage IV pressure ulcers

Heart disease - Congestive heart failure
New York Heart Association class IV disease
Symptomatic at rest despite optimal diuretic-vasodilator therapy
Patient is not a candidate for or declines revascularization

Liver disease
Prothrombin time >5 sec above control or international normalized ratio >1.5
Serum albumin level <2.5 g/dL
Plus any one of the following:

- Refractory ascites
- Spontaneous bacterial peritonitis
- Hepatorenal syndrome
- Encephalopathy with asterixis, somnolence, or coma
- Recurrent variceal bleeding

HIV or AIDS
CD4+ cell count <25 cells/mm^3 or persistent viral load >100,000 copies/mL
Antiretroviral therapy no longer effective or desired
Plus any one of the following:

- Wasting syndrome
- Progressive multifocal leukoencephalopathy
- Cryptosporidiosis
- *Mycobacterium avium* complex, unresponsive to treatment
- Visceral Kaposi sarcoma, unresponsive to treatment
- Toxoplasmosis, unresponsive to treatment

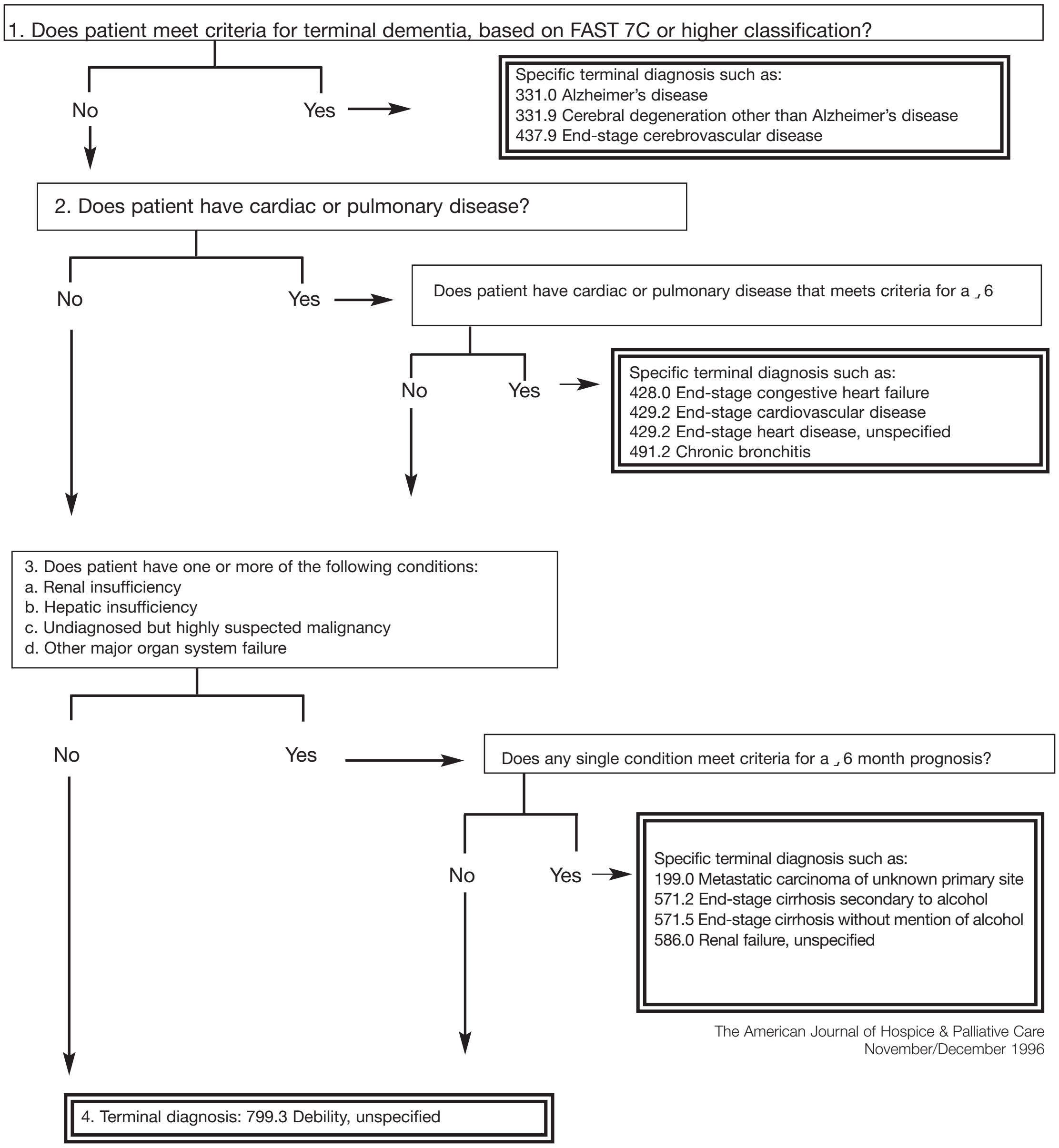
Source: Adapted from Matzo, 2004.[21]

TABLE 2.8

Decision Tree
Diagnosis: Debility, unspecified (799.3)

Figure 3. Decision tree for assigning the diagnosis of ‘‘debility, unspecified” (ICD-9 code 799.3). The tree permits the physician to eliminate other defined diseases of specific organ systems as the cause of terminality. If no anatomic disease is sufficient by itself to warrant a terminal diagnosis, and if cumulative comorbidities exist, then the diagnosis of debility, unspecified is warranted.

Prognosis: ¸6 months: Severe ADL Deficits; CNS Disease



The American Journal of Hospice & Palliative Care
November/December 1996

Source: Kinzbrunner et al, 1996.[22] Reprinted with permission.

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3 SECTION 3: COMMUNICATION

> "Timely, sensitive discussions with seriously ill patients regarding medical, psychosocial, and spiritual needs at the end of life are both an obligation of and privilege for every physician….When physicians provide their patients with the honesty, expertise, advocacy, compassion, and commitment they would want for themselves and their families, they provide the highest quality of medical care possible….Failure to provide appropriate information about palliative care and prognosis can contribute to unnecessary pain and suffering."[1]

Communication is *the* essential skill needed for palliative and end-of-life care. It is clear from the high burden of suffering and the high mortality rate of long-term care residents that palliative and end-of-life care should be discussed with most of these residents at the time of admission to a long-term care facility.

Patients and families desire and need professionals to listen to their hopes, fears, goals, and treatment preferences. Practitioners must be able to discuss in a direct, truthful, and compassionate manner the patient's diagnoses and prognosis and describe the benefits and burdens of his or her treatment options. Forthright communication strengthens the patient-practitioner relationship and empowers the patient to collaborate with health care providers to create the most appropriate plan of care. Knowing what to expect enables patients and families to make needed plans and prepare for possible future outcomes, rather than react to an unforeseen crisis.

Patients with a terminal diagnosis appreciate communication that:[2]

- Is honest, especially about uncertainty.
- Uses clear and straightforward language and avoids jargon and euphemisms when discussing diagnosis, prognosis, and treatment options (e.g., say "cancer," not "a spot on your scan," "a mass," or "a malignancy"). If a patient is dying, avoid euphemisms like "he or she may not do well."
- Is delivered in a personal and involved communication style that encourages questions and conveys a willingness to talk about dying.

In long-term care, certain conditions (e.g., dysphagia with recurrent pneumonia, frailty, immobility, pressure ulcers, unintended weight loss) and advanced stages of certain illnesses (e.g., Alzheimer's disease, atherosclerosis, chronic obstructive pulmonary disease, congestive heart failure, Parkinson's disease) are harbingers of further decline and death. It is appropriate to review the prognostic pathways associated with these conditions, including the situations, signs, and symptoms that can signal the last weeks and months of life. Such anticipatory guidance can help patients and families cope with difficult end-of-life realities.

Most people want the opportunity to prepare for death. Preparation requires a trusting and open relationship with caregivers. It means knowing what to expect about one's physical condition, believing one's family is ready for one's death, and having financial affairs in order. In addition, people want to be able to bring a sense of completion to life by reflecting on personal accomplishments, saying good-bye to important people, and resolving unfinished business. At the end of life people are concerned about maintaining dignity, having close friends and family near, and not dying alone. People worry that death will bring discomfort, so they need reassurance that pain, dyspnea, and anxiety will be managed.[3]

Many potential barriers exist to end-of-life discussions. Time constraints and prognostic uncertainty may hinder timely discussions. In addition, both practitioners and patients may be inclined to avoid these difficult discussions for various reasons. These discussions are never easy because they address such weighty issues and are often emotionally charged. Practitioners must be aware that some patients, sensing that further treatment may be futile or that they are approaching death, will avoid asking for precise prognostic information.[4]

Table 3.1 offers a stepwise approach to conducting a discussion with a patient or family about palliative care and end-of-life issues. Not all steps are appropriate or necessary to every discussion; the practitioner may choose those that are appropriate to a specific situation. The talking points are suggested wording for broaching potentially emotional topics in conversation.

TABLE 3.1. A STEPWISE APPROACH TO A DISCUSSION OF END-OF-LIFE ISSUES WITH A PATIENT OR FAMILY

Step	Talking Points
Prepare for the discussion • To the extent possible, before scheduling or beginning a discussion of treatment options and goals of care, review relevant information about the patient's diagnosis, course of illness, current condition, prognosis, treatment options, and opinions of relevant consultants and allied health professionals. • Confirm that all relevant family members and friends have been invited to attend the meeting. • Prepare and review a brief timeline of the patient's illness. The purpose of this review is to make sense of a series of complex and seemingly unconnected symptoms, tests, consultations, and treatments. • Prepare an "agenda" based on the steps that follow to ensure that the discussion covers all relevant topics.	
Arrange an appropriate environment The discussion should take place in a comfortable setting that is private and uninterrupted by phones, pagers, or other distractions. Ideally, the practitioner should sit at eye level and within reach of the patient.	
Identify participants and their readiness to proceed • All participants should identify themselves and state their relationship to the patient. • Because the patient or family members may be ill, tired, or overwhelmed, the practitioner should determine if they are ready for the discussion or would rather reschedule for a later date.	"Before we start, I want to make sure we all know each other and understand our relationship to each other." "We planned to discuss your condition, answer questions you might have, go over what to expect in the future, and hopefully decide on the best treatment plan for you. This kind of thing can be tiring and sometimes upsetting. Are you feeling up to this now?"
Identify any pressing concerns or questions Identifying a patient or family's questions and concerns gives them permission to set the agenda and name the most important elements of the discussion. It is helpful to write each concern down. Make every attempt to address each of them.	"Before we start talking, what concerns or questions do you have at this time?"
Seek to understand the current situation in the context of the patient's life and recent past	"We've just met and there is so much going on with you right now. To help me get to know you better, can you tell me about your life outside of the hospital?" "It would help me to understand how things were before this illness; can you describe what a typical day was like six months or a year ago?" "Can you tell me how things have changed for you?"
Establish what the patient and family know	"Please tell me what you know about your situation. For instance, what is your sense of whether you can return to good health, and if not, what do you think is likely to happen? What do you know about your treatment choices, and what do you think about those choices?" "Tell me what you understand about your illness." When the patient is unable to participate: "Can you please help me to understand what I need to know about [the patient's] beliefs and practices to take the best care of [the patient]?" "Our goal is not so much to think about what you would want or not want but to use your knowledge of [the patient] to understand what he or she would want in this situation."

TABLE 3.1. A STEPWISE APPROACH TO A DISCUSSION OF END-OF-LIFE ISSUES WITH A PATIENT OR FAMILY (CONTINUED)

Step	Talking Points
	"Has [the patient] ever discussed what he or she would want or not want in this kind of a situation?"
"Titrate" the rate and amount of information to suit the patient's condition	"Some people want to know everything possible about their illness and others prefer to know very little. How much about your illness do you want to know from me today?"
Deliver the information • Use clear and straightforward language, avoiding jargon and euphemisms. • Review the prognostic pathways associated with the patient's conditions, including the situations, signs, and symptoms that can signal the last weeks and months of life. • Review the risks and benefits of aggressive, curative care versus palliative care.	"Your mother is in an advanced state of her illness." "She continues to get weaker and lose weight despite all efforts to get her stronger and improve her intake. As this trend continues, her body will get so weak that certain things are likely to happen." "If she cannot drink enough water to say healthy, she will get weaker, sleep more and more, and her systems will shut down and she will lapse into a peaceful coma." "As she becomes more malnourished, she may get one bout of pneumonia after another until she is not strong enough to fight the infection, and it will cause her death." "If she gets malnourished and spends more and more time in a bed or chair, she could develop pressure ulcers that the body will be too weak to heal." "As her weakness worsens, she may have repeated falls and get injured." "Because we cannot reverse the progressive decline, we need to think about the best way to respond to each of these potential end-stage conditions."
Anticipate and respond to emotional outbursts • Patients and families may react with sadness, anger, extreme grief, or complete disengagement, shock, and disbelief. • When emotional reactions occur, consider just being present and silent for a minute or so to allow the reaction to run its course. Rather than trying to "fix" and stop the emotional distress, it can be helpful to reflect the words to demonstrate they were heard, describe your sense of their distress, and ask the speaker to elaborate on his or her feelings.	"I can tell how very difficult it is for you to hear this bad news." "You seem upset. Can you tell me what you are feeling right now?" "You've just mentioned feeling scared. Can you tell me more about what scares you?" "Is talking about these issues too difficult for you?" "Making these decisions is not easy. I wonder if it sometimes feels overwhelming?"
Establish goals for care and treatment priorities • Even if cure or recovery is not possible, some positive goals may be achievable. Goals of palliative care include: – Improving quality of life – Relieving suffering – Giving the patient as much control as possible over things like diet, meaningful activities, and therapies • Other important goals may include: – Getting financial and personal affairs in order – Addressing spiritual issues – Bringing closure to unfinished business • In some circumstances, it may be possible to maintain or improve function or prolong life. • Ask open-ended questions (i.e., questions that cannot be answered "yes" or "no").	"What is the most important thing from here on out?" "What are the things we should be making sure we take care of?" "We've been talking about some treatments that are really not going to be effective and that we don't recommend you use. But there are a lot of things we can still do to help you – let's focus on those." "What sorts of things are left undone for you? Let's talk about how we might be able to make these happen." "What do you consider your quality of life to be like now?" "Would there be any circumstances under which you would find life not worth living?" "How do you think about balancing quality of life with length of life?"
Establish specific treatment preferences • Clarify vague answers about goals (e.g., "It's all in my living will," "I don't want any machines," "I don't want to be a vegetable," "I don't want to be a burden"). • Discuss specific treatment preferences for life-sustaining treatments (e.g., CPR, mechanical ventilation, tube feeding) as appropriate to the patient's situation.	"You say you don't want any machines, but I need to be sure I understand exactly what you mean by that." **CPR:** "If you were to die suddenly—that is, if you stopped breathing or your heart stopped—we could try to revive you by using cardiopulmonary resuscitation, or CPR. Are you familiar with CPR? Have you thought about whether you would want it? Given the severity of your illness, CPR would in all likelihood be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?" **Feeding Tube, Artificial Nutrition, and Hydration:** "One option to consider when people cannot swallow safely or do not take enough water or food to stay healthy is to use a feeding tube. Are you familiar with feeding tubes? For people with advanced illness, like yours, feeding tubes do not usually improve the quality of life; people may live weeks or months longer but they do not usually 'do better' or regain prior functions. Given the severity of your illness, tube feeding would in all likelihood be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?" **Mechanical Ventilation:** "When people have severe lung or heart disease and cannot get enough oxygen into their system, one treatment that can be used is mechanical ventilation, also known as a 'breathing machine.' In advanced illness, many people sick enough to need a breathing machine will not survive the treatment. Some people can be kept alive for days or weeks with a breathing machine, but may be too weak to be able to ever return to normal function. For people with advanced illness, like yours, breathing machines do not usually improve survival or the quality of life. Any suffering caused by difficulty breathing can be controlled with medications. Given the severity of your illness, I would recommend that you choose not to have mechanical ventilation. What do you think?"
Find out if the patient or family wants your opinion or recommendation	"Of course, only you know what is best for you. If you want my opinion or my experiences with what other people tend to do in these situations, I will share that with you."
Establish a plan • Ask for clarification as you summarize the discussion so far. This gives the patient or family an opportunity to confirm mutual understanding. • Review key elements of the discussion, focusing on: – Symptom control – Social and emotional issues – Access to support services • Review any decisions about limiting testing or precluding certain treatments (e.g., CPR, mechanical ventilation, tube feeding). • Close with a question that again gives the patient or family an opportunity to confirm mutual understanding.	"Let me see if I've gotten this right…." "Does that sound like I got it right?" "Anything I forgot to mention?"

TABLE 3.1. A STEPWISE APPROACH TO A DISCUSSION OF END-OF-LIFE ISSUES WITH A PATIENT OR FAMILY (CONTINUED)

Step	Talking Points
Finish with communication of hope and commitment	"I want you to know that whatever happens, we will face it and deal with it together." "We will make ourselves available so you and your family know what is going on and can be prepared for what will happen." "Even if/though your condition cannot be cured, there is always something we can do to help you deal with this and make the best of a tough situation." "What we can do now is concentrate on doing things to make sure you are comfortable." "Sometimes having a plan that prepares you for the worst makes it easier to focus on what you hope for the most."
Plan for follow-up Give the patient and family the opportunity to meet with you again or contact you to review any unresolved or unclear issues.	

CPR: cardiopulmonary resuscitation.

Sources: Adapted from Belfi, 2006;[5] Belfi, 2006;[6] Boockvar and Meier, 2006;[7] Tulsky, 2005;[8] Rabow et al, 2004;[9] Lamont and Christakis, 2003;[10] von Gunten et al, 2000.[11]

Special Circumstances in End-of-Life Communication

Special circumstances may present particular challenges for end-of-life communication. These circumstances may include:

- Language barriers;
- Requests to "protect" patients or families from the truth about a patient's condition;
- Discussion of cultural, religious, and spiritual issues that are important to the patient and family; and
- Conflict within families, within the care team, or between the care team and the family. (Guides to conflict resolution can be found in Section 5, Ethical and Legal Concerns.)

Language Barriers

If the patient's primary language is not English, consider using a skilled translator who is familiar with medical terminology and is comfortable translating emotionally difficult information. When using a translator, it is important to face and address your comments to the patient, not the translator. If the translator cannot be present in person, it may be possible to arrange for telephone translation services. In general, avoid asking a family member to act as the translator. This can cause confusion about family roles, may result in miscommunication about medical concepts, and may result in the translator changing the practitioner's words to "protect" the patient.

Requests to Protect Patients or Families From the Truth

Patients or families may ask the practitioner not to disclose the truth about a patient's condition to the patient or to other family members. They may shy away from a frank discussion because of past experiences, concerns about adverse emotional or physical effects on an individual, or other family, religious, or cultural issues.

Current medical and ethical practice encourages full disclosure and informed decision making by an autonomous patient. It may help to talk about the potential benefits of full disclosure for patients or family members and then to strategize about the best way to do this.[12] Table 3.2 suggests ways of approaching this discussion.

TABLE 3.2. “PLEASE DON’T TELL HIM (OR HER) THE TRUTH”: TALKING POINTS

“I realize you and your mother are facing a very intense and personal time right now, and that different people have different ways in which they would like things to be handled. Thank you for telling me about your preferences.”

“Is there a specific situation you fear might occur if I were to speak directly to your mother about her condition?”

“How has your mother dealt with other family members’ or her own health issues in the past?” Have you previously discussed with your mother the issue of telling people bad news about their health?”

“It is customary to let clear-thinking patients make their own informed choices. If my mother were in this situation, I believe she would prefer to be fully informed and make her own decisions.”

“Maybe we could go together and ask (the person of concern) whether she wants to discuss things in detail and make the important decisions, or whether she wants to know less and leave important decisions to someone else.”

“I have been told by your son that medical information and decision making in your family is generally handled by a patient’s relatives rather than by the patient. Is this how you want to proceed in your case, or would you prefer to be more involved?”

“Some people want to know the details about their condition so they can make choices about treatment and make necessary plans for the future. Others want family members to get the details and make the decisions. Which way of handling things do you think is best for you?”

Source: Adapted from Cochella and Pedersen, 2003.[12]

Cultural, Religious, and Spiritual Issues

Conflicts may result from cultural misunderstandings.[3] Discussion of cultural, religious, and spiritual issues can be an important part of the conversation about palliative and end-of-life care and can assist with goal setting and values clarification.

Be sensitive to the terminology used when discussing end-of-life issues. For example, certain cultural groups may prefer the use of the term “palliative care” to the term “hospice”.

Practitioners should never make assumptions based on what they think they know about the patient’s culture, ethnicity, or religious background. Rather, begin the discussion with an open-ended question such as, “Is there anything that I or other members of your treatment team need to know about in order to provide the best care and to be sensitive to your specific cultural needs?”

A series of communication techniques can be used to explore issues influenced by culture that are important in end-of-life care (Table 3.3). In addition, the ABCDE technique (Table 3.4) can be used to begin a dialogue about the influence of culture on the patient’s and family’s approach to end-of-life care. Table 3.5 offers further suggestions for approaching the discussion of these potentially sensitive issues.

TABLE 3.3. TECHNIQUES FOR NEGOTIATING ISSUES INFLUENCED BY CULTURE THAT ARE IMPORTANT IN END-OF-LIFE CARE

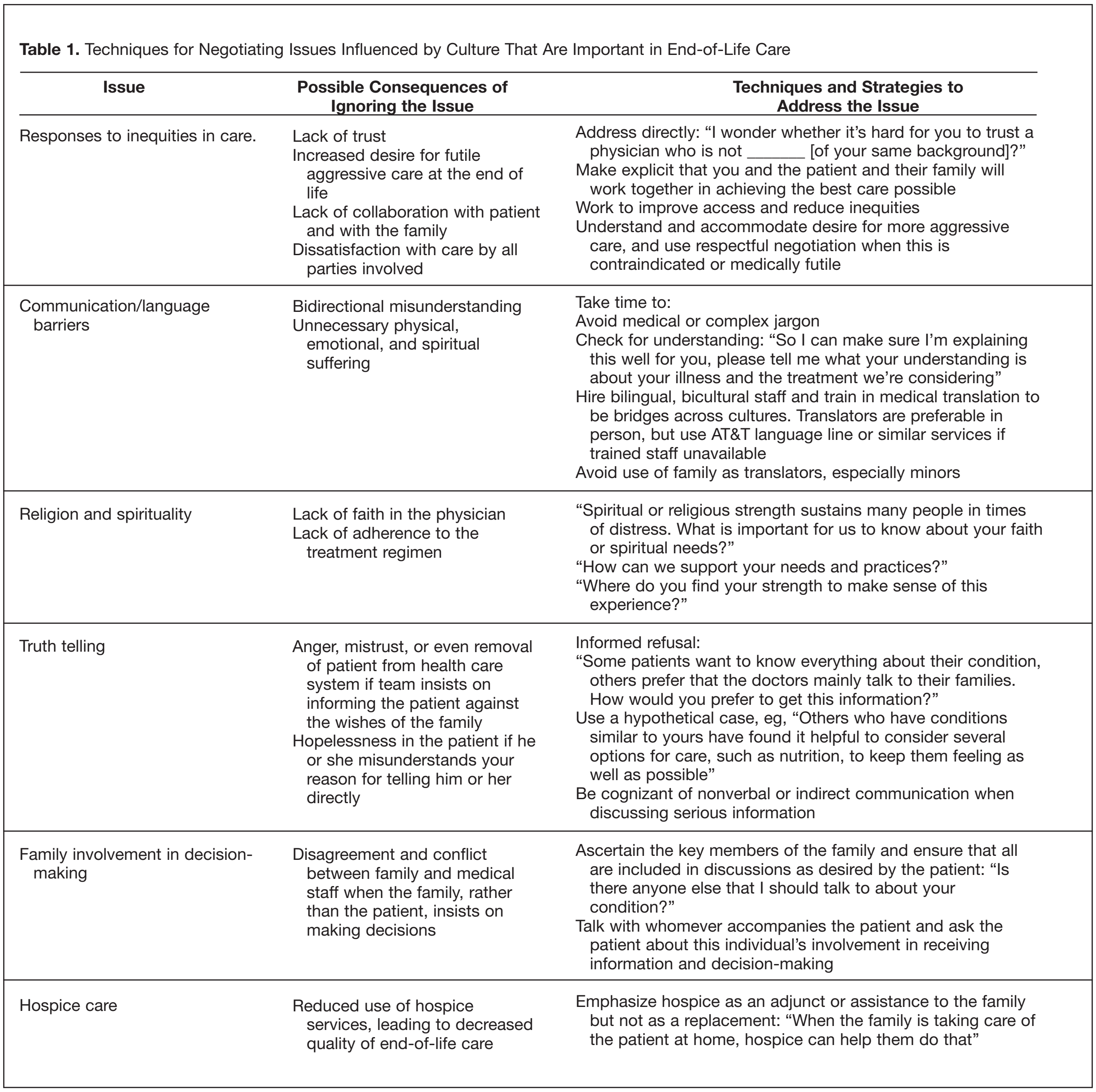

Table 1. Techniques for Negotiating Issues Influenced by Culture That Are Important in End-of-Life Care

Issue	Possible Consequences of Ignoring the Issue	Techniques and Strategies to Address the Issue
Responses to inequities in care.	Lack of trust Increased desire for futile aggressive care at the end of life Lack of collaboration with patient and with the family Dissatisfaction with care by all parties involved	Address directly: "I wonder whether it's hard for you to trust a physician who is not _______ [of your same background]?" Make explicit that you and the patient and their family will work together in achieving the best care possible Work to improve access and reduce inequities Understand and accommodate desire for more aggressive care, and use respectful negotiation when this is contraindicated or medically futile
Communication/language barriers	Bidirectional misunderstanding Unnecessary physical, emotional, and spiritual suffering	Take time to: Avoid medical or complex jargon Check for understanding: "So I can make sure I'm explaining this well for you, please tell me what your understanding is about your illness and the treatment we're considering" Hire bilingual, bicultural staff and train in medical translation to be bridges across cultures. Translators are preferable in person, but use AT&T language line or similar services if trained staff unavailable Avoid use of family as translators, especially minors
Religion and spirituality	Lack of faith in the physician Lack of adherence to the treatment regimen	"Spiritual or religious strength sustains many people in times of distress. What is important for us to know about your faith or spiritual needs?" "How can we support your needs and practices?" "Where do you find your strength to make sense of this experience?"
Truth telling	Anger, mistrust, or even removal of patient from health care system if team insists on informing the patient against the wishes of the family Hopelessness in the patient if he or she misunderstands your reason for telling him or her directly	Informed refusal: "Some patients want to know everything about their condition, others prefer that the doctors mainly talk to their families. How would you prefer to get this information?" Use a hypothetical case, eg, "Others who have conditions similar to yours have found it helpful to consider several options for care, such as nutrition, to keep them feeling as well as possible" Be cognizant of nonverbal or indirect communication when discussing serious information
Family involvement in decision-making	Disagreement and conflict between family and medical staff when the family, rather than the patient, insists on making decisions	Ascertain the key members of the family and ensure that all are included in discussions as desired by the patient: "Is there anyone else that I should talk to about your condition?" Talk with whomever accompanies the patient and ask the patient about this individual's involvement in receiving information and decision-making
Hospice care	Reduced use of hospice services, leading to decreased quality of end-of-life care	Emphasize hospice as an adjunct or assistance to the family but not as a replacement: "When the family is taking care of the patient at home, hospice can help them do that"

Source: Kagawa-Singer and Blackhall, 2001.[13] Reprinted with permission.

TABLE 3.4. ASSESS ABCDE TO ASCERTAIN LEVEL OF CULTURAL INFLUENCE

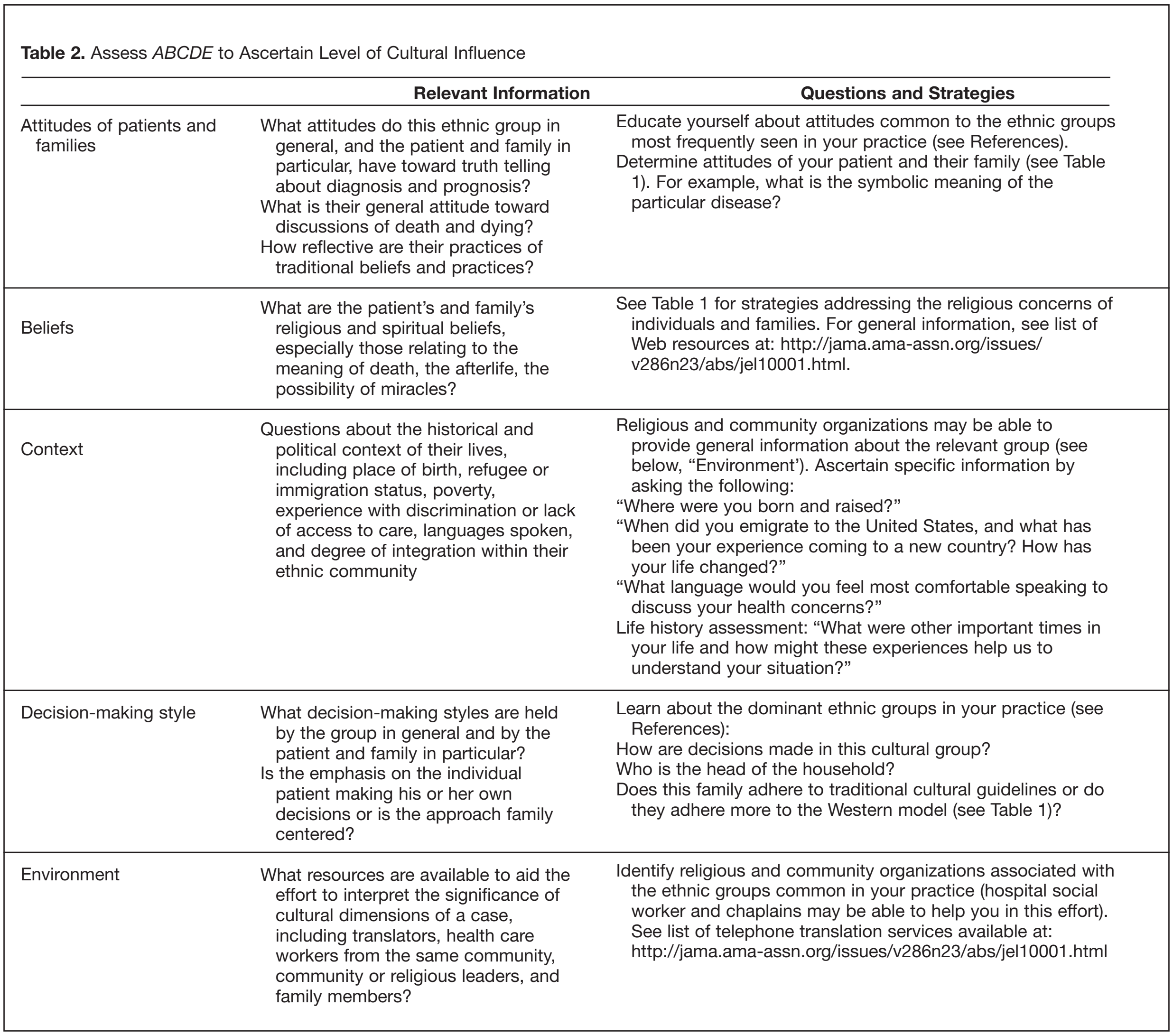

Table 2. Assess *ABCDE* to Ascertain Level of Cultural Influence

	Relevant Information	Questions and Strategies
Attitudes of patients and families	What attitudes do this ethnic group in general, and the patient and family in particular, have toward truth telling about diagnosis and prognosis? What is their general attitude toward discussions of death and dying? How reflective are their practices of traditional beliefs and practices?	Educate yourself about attitudes common to the ethnic groups most frequently seen in your practice (see References). Determine attitudes of your patient and their family (see Table 1). For example, what is the symbolic meaning of the particular disease?
Beliefs	What are the patient's and family's religious and spiritual beliefs, especially those relating to the meaning of death, the afterlife, the possibility of miracles?	See Table 1 for strategies addressing the religious concerns of individuals and families. For general information, see list of Web resources at: http://jama.ama-assn.org/issues/v286n23/abs/jel10001.html.
Context	Questions about the historical and political context of their lives, including place of birth, refugee or immigration status, poverty, experience with discrimination or lack of access to care, languages spoken, and degree of integration within their ethnic community	Religious and community organizations may be able to provide general information about the relevant group (see below, "Environment'). Ascertain specific information by asking the following: "Where were you born and raised?" "When did you emigrate to the United States, and what has been your experience coming to a new country? How has your life changed?" "What language would you feel most comfortable speaking to discuss your health concerns?" Life history assessment: "What were other important times in your life and how might these experiences help us to understand your situation?"
Decision-making style	What decision-making styles are held by the group in general and by the patient and family in particular? Is the emphasis on the individual patient making his or her own decisions or is the approach family centered?	Learn about the dominant ethnic groups in your practice (see References): How are decisions made in this cultural group? Who is the head of the household? Does this family adhere to traditional cultural guidelines or do they adhere more to the Western model (see Table 1)?
Environment	What resources are available to aid the effort to interpret the significance of cultural dimensions of a case, including translators, health care workers from the same community, community or religious leaders, and family members?	Identify religious and community organizations associated with the ethnic groups common in your practice (hospital social worker and chaplains may be able to help you in this effort). See list of telephone translation services available at: http://jama.ama-assn.org/issues/v286n23/abs/jel10001.html

Source: Kagawa-Singer and Blackhall, 2001[13] (adapted from work by Koenig and Gates-Williams, 1995[14]). Reprinted with permission.

TABLE 3.5. DISCUSSING RELIGIOUS AND SPIRITUAL ISSUES AT THE END OF LIFE: A PRACTICAL GUIDE FOR PHYSICIANS

<table>
<tr><th>Eliciting the Patient's Concerns</th><th>Talking Points</th></tr>
<tr><td>Ask open-ended questions</td><td>“Does your trust in God lead you to think about CPR in a particular way?”
“Do you have any thoughts about why this is happening?”</td></tr>
<tr><td>Ask for elaboration</td><td>“Tell me more about that.”
“Can you tell me how you think she is suffering?”</td></tr>
<tr><td>Acknowledge and normalize the patient's concerns</td><td>“Many patients ask such questions.”</td></tr>
<tr><td>Make empathic comments</td><td>“I imagine I would feel pretty puzzled to not know.“
“That sounds like a painful situation.”</td></tr>
<tr><td>Ask about emotions</td><td>“How do you feel about . . .?”
“How has it been for you with your wife in the intensive care unit for so long?”</td></tr>
<tr><td colspan="2">Potential Pitfalls
• Trying to solve the patient's problems or resolve unanswerable questions.
• Going beyond the physician's expertise and role, or imposing the physician's religious beliefs on the patient.
• Providing premature reassurance.</td></tr>
<tr><td colspan="2">Goals for Physicians
• Clarify the patient's concerns, beliefs, and needs and follow hints about spiritual or religious issues.
• Make a connection with the patient by listening carefully, acknowledging the patient's concerns, exploring emotions, making empathic statements, and using wish statements.
• Identify common goals for care and reach agreement on clinical decisions.
• Mobilize sources of support for the patient.</td></tr>
</table>

CPR: cardiopulmonary resuscitation.

Source: Lo et al, 2002.[15] Reprinted with permission.

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4

SECTION 4: SYMPTOM CONTROL

"Relief of suffering is the business of every discipline."[1]

"As physicians, we can be the primary cause of suffering in their last week of life, or the primary cause of its relief."[2]

"As sickness progresses toward death, measures to minimize suffering should be intensified. Dying patients require palliative care of an intensity that rivals even that of curative efforts…."[3]

Pain and other symptoms occur with many chronic illnesses and at the end of life. Table 4.1 lists the symptoms that commonly require palliation in long-term care patients.

To improve the quality of symptom control, the long-term care practitioner should:

- Anticipate and when possible prevent the likely symptoms of chronic illness and the dying process;
- Know the generally accepted standards and the supporting evidence for symptom recognition, assessment, management, and monitoring and the indications for specialty referral;
- Support staff training and policies and procedures on symptom control that are based on standards and evidence;
- Undertake ongoing assessment and quality improvement of symptom control practice;
- Collaborate with nursing staff, social service staff, chaplains, the hospice team, and others involved in providing palliative care to set reasonable expectations for each team member regarding roles, responsibilities, and appropriate communication about symptom control; and
- Optimize the patient's and family's understanding and sense of control by educating them about likely signs and symptoms, the significance of symptoms, and plans to monitor and relieve symptoms when they occur.

When assessing signs and symptoms in palliative and end-of-life care, ideally the practitioner should describe:

- Severity, duration, time of onset, and quality;
- Aggravating and relieving factors;
- Effects of previous treatments; and
- Impact on function, appetite, activity, mood, sleep, and family.

Rather than treating a sign or symptom reflexively, be aware of its differential diagnosis. Consider whether it is appropriate to perform an assessment to determine the likely cause of the sign or symptom. Unlike acute care medicine, in palliative and end-of-life care, it is wise to temper the intensity of the diagnostic evaluation on the basis of not only the benefits and burdens of laboratory evaluation and interventions but also the stage of the illness, the patient's preferences, and the goals of care. For example, it may be appropriate to obtain X-rays and laboratory tests for an ambulatory patient with moderate dementia and heart failure but not for a patient who is bedbound and in the final stages of advanced illness.

Caregiver and family education and reassurance are the foundations of a symptom control regimen. It is also important to ask what the patient and family think the symptom means. In many cases, the patient can obtain much relief from nonpharmacologic interventions (Table 4.2), and families can be empowered to provide many of these interventions.

Because the terminal phase of an illness is a dynamic process and because medications can have adverse effects in frail elderly people, treatment plans should include regular, diligent monitoring of both pharmacologic and nonpharmacologic interventions for both efficacy and side effects.

To reinforce the concept that much can be done to relieve suffering when "there is nothing left to do," it may be helpful to follow the mnemonic AGGRESSIVE to create a comprehensive palliative care plan for nonpain symptoms (Appendix 4.1). In addition, the following appendixes may help to guide assessment, treatment, and monitoring of patients receiving palliative care:

- Appendix 4.2 (sample doctor's order sheet for palliative care)
- Appendix 4.3 (sample daily flow sheet for patient receiving palliative care)
- Appendix 4.4 (sample palliative care plan)

TABLE 4.1. SYMPTOMS THAT COMMONLY REQUIRE PALLIATION IN LONG-TERM CARE PATIENTS

Most common end-of-life symptoms

Dyspnea (suffered by 62% of dying patients in one study in the long-term care setting)[5]
Noisy breathing (death rattle) (25-50%)[4,5]
Pain (44%)[5]
Delirium, restlessness (29%)[5]
Fever (24%)[5]
Myoclonus (18%)[5]

Other end-of-life symptoms that may benefit from palliation

Dry mouth
Nausea and vomiting
Nonhealing wounds

TABLE 4.2. GENERAL NONPHARMACOLOGIC INTERVENTIONS FOR SYMPTOM CONTROL

Nurses and family members may apply general nonpharmacologic interventions such as the following as needed to control symptoms and provide comfort:

- Specialized (pressure-reducing) mattress
- Position changes every 1-2 h as tolerated
- Pillows and protectors for positioning
- Lamb's wool for pressure relief
- Gentle massage of extremities as tolerated
- Soothing bath as tolerated
- Lotion to extremities as tolerated
- Mouth care q 1-2 h and PRN as tolerated
- Lip balm topically PRN as tolerated
- Fan to blow gently across resident's face as tolerated
- Offer foods, fluids, or ice chips as tolerated
- Activity as tolerated
- Music in room
- Reassuring touch (e.g., hand holding)

PRN: as needed.

Dyspnea

Dyspnea (air hunger, shortness of breath) is a subjective sensation of uncomfortable breathing. It is among the most distressing nonpain symptoms, often producing anxiety in both patients and caregivers. Dyspnea often limits activities of daily living, including the ability to converse or eat normally, and thus adversely affects quality of life.

Dyspnea is common in patients with cardiac and pulmonary disease and is a frequent symptom during the end stages of many illnesses. In general, the sensation of dyspnea will not be explained by measurements of blood gases, respiratory rate, or oxygen saturation. Apparently, multiple factors associated with the work of breathing contribute to the sensation.

Nonpharmacologic approaches such as the following may relieve the patient's discomfort:

- Energy conservation, positioning, fan (works via V2 branch of 5th cranial nerve), open window, relaxation techniques.
- Trial of oxygen therapy (4-6 liters/min by nasal cannula). Continue therapy if it relieves the patient's dyspnea; otherwise, discontinue it.

Suctioning is to be avoided in most patients with dyspnea because it can cause distress.

When a patient is experiencing dyspnea, first consider the cause of the problem. If an intervention is available that will directly affect the primary cause of the patient's dyspnea (e.g., bronchodilators or steroids for chronic obstructive pulmonary disease, diuretics for congestive heart failure), this should be the treatment of first choice. If such treatment is unsuccessful or has been attempted unsuccessfully in the past, opioids should be the next treatment of choice. Morphine is the most studied and versatile of the opioids for treatment of dyspnea.

An opioid equianalgesic dosing table (Table 4.3) is a useful guide when switching from one opioid to another. When using this table, be aware that the effect of a new opioid is somewhat unpredictable because of incomplete cross tolerance, differences in metabolism and mechanisms of action, and idiosyncratic patient factors. For this reason, after calculating an equianalgesic dose, it is best to decrease the total daily dose of the new opioid by 25% to 33%. An excellent online source for calculating equianalgesic opioid doses and adjusting for incomplete cross tolerance is *The Clinician's Ultimate Reference* (http://www.globalrph.com/narcoticonv.htm). Appendixes 4.5 and 4.6 provide guidance on opioid titration to gain rapid control of symptoms such as dyspnea and pain.

TABLE 4.3. EQUIANALGESIC STARTING DOSES OF OPIOIDS FOR RELIEF OF PAIN AND DYSPNEA

Opioid-Naïve Frail Elderly Patient

The practitioner may choose from the following suggested starting doses:

Morphine 2 mg PO or SL	0.1 mL morphine 20 mg/mL (Roxanol®)
Oxycodone liquid 2 mg PO or SL	0.1 mL oxycodone 20 mg/mL (Oxyfast®)
Oxycodone 2.5 mg	• 1/2 of a 5 mg oxycodone tablet • 1/2 of an oxycodone 5 mg/acetaminophen 325 mg (Percocet®)
Hydromorphone 0.5 mg	0.5 mL hydromorphone 1 mg/mL (Dilaudid®)
Hydrocodone 2.5 mg	1/2 of a hydrocodone 5 mg/acetaminophen 500 mg (Vicodin®)

NOTE: Although propoxyphene is ***not*** recommended in the elderly, it is still frequently prescribed. Prescribers may find it helpful to know that the above-listed doses are equivalent to propoxyphene 50 mg, Darvon® 65, or Darvocet® N-50.

TABLE 4.3. EQUIANALGESIC STARTING DOSES OF OPIOIDS FOR RELIEF OF PAIN AND DYSPNEA (CONTINUED)

Opioid-Naïve Adult Patient
The practitioner may choose from the following suggested starting doses:

Morphine 5 mg PO or SL	0.25 mL morphine 20 mg/mL (Roxanol®)
Oxycodone liquid 5 mg PO or SL	0.25 mL oxycodone 20 mg/mL (Oxyfast®)
Oxycodone 5 mg	• 5 mg oxycodone tablet • Oxycodone 5 mg/acetaminophen 325mg (Percocet®)
Hydromorphone 1 mg	1/2 of a 2 mg tablet PO (Dilaudid®) 1 mL of hydromorphone 1 mg/mL SL
Hydrocodone 5 mg	Hydrocodone 5 mg/acetaminophen 500 mg (Vicodin®)

- For patients already taking opioids, increase total daily dose by 25% to 50%
- PRN opioid use may be acceptable for intermittent dyspnea

Other medications to consider for dyspnea:
- Benzodiazepines for anxiety (lorazepam PO/SL/IV 0.5-1 mg q 4 h)
- Bronchodilators for wheezing
- Chlorpromazine 10-25 mg IM or IV q 4-6 h (may work synergistically with morphine)*
- Steroids, diuretics, anticoagulation, erythropoietin in appropriate settings

Other medications to consider for pain:
- For opioid-naïve frail elderly patient: tramadol (Ultram®) 25 mg (1/2 of a 50 mg tablet)
- For opioid-naïve adult patient; tramadol 50 mg

IM: intramuscular; IV: intravenous; PO: by mouth; PRN: as needed; SL: sublingual.
*Chlorpromazine can also be given orally or rectally

Noisy Breathing

Twenty-five percent to 50% of dying patients experience “death rattle”; nearly 65% will die within 48 hours of the emergence of this sign.[2] The presumed pathophysiology of this inspiratory and expiratory noise emanating from the upper airway near the end of life is the inability of the weakened, lethargic, dying patient to expectorate accumulated oropharyngeal and tracheobronchial secretions.[4] The potential magnitude of the problem is highlighted by the fact that normal adults produce 1.5 liters of saliva and 2 liters of oropharyngeal and tracheobronchial mucus daily.[6] This volume may be higher if a patient has an inflammatory pulmonary condition or lower if a person is moderately dehydrated.

In the absence of visible, copious secretions in the oropharynx, suctioning is not only ineffective for death rattle but it may increase patient discomfort and worsen death rattle by increasing edema of the oropharynx.

Nonpharmacologic interventions for death rattle include using music to mask the noisy breathing, positioning the patient on his or her side, and limiting or stopping parenteral fluids. It is essential to educate caregivers and family members that death rattle usually does not cause discomfort for the patient, who is usually in a semiconscious or comatose state.

Antimuscarinic medications (Table 4.4) reduce noisy breathing by reducing the production of secretions and relaxing tracheobronchial muscles. These medications do not affect existing secretions and so should be used early in the treatment of death rattle, rather than in the last minutes of life. They may be less effective in patients with pulmonary malignancies, pneumonia, or pulmonary edema. However, for most patients, these agents will reduce the noise of breathing. Subcutaneous or intravenous administration shortens the onset of action but does not necessarily improve efficacy compared with sublingual administration. A potential advantage of glycopyrrolate is that it does not cross the blood-brain barrier and is therefore less likely to contribute to delirium.

TABLE 4.4. MEDICATIONS TO TREAT DEATH RATTLE

Agent	Formulations	Onset of Action	Dosing
Atropine	• 1% eye drops	SL: 30 min	1-2 drops SL or PO every 4-6 h initially. Titrate to effect
Glycopyrrolate	• 1 mg, 2 mg tablets (may be crushed) • 1 mg/10 ml solution for oral or SL administration • 0.2 mg/ml ampule for injection	SL, PO: 30-40 min SC, IV: 1 min	• 1 mg PO 1-4 times daily (max 8 mg/d) • 0.1-0.4 mg SC/IM/IV initially. Repeat as needed • 400-1,200 mcg/24 h CSCI
Hyoscyamine	• 0.125 mg, 0.25 mg tablets • 0.125 mg/ml, 0.125 mg/5 ml elixir • 0.5 mg/ml solution for injection	SL: 10-15 min PO: 45-60 min IM: 3-5 min	• 0.125-0.25 mg tablet or elixir SL or PO 1-4 times daily • 0.25 mg (range 0.25-40 mg) SC bolus q 4 h • 1.5 mg/24 h (range 0.6-2.4 mg/24 h) SC or IV infusion
Scopolamine	• 0.4 mg tablet • 0.4 mg/ml for injection • 1.5 mg/72 h transdermal patch (Transderm Scop®)	PO: 45-60 min, SL: 10-15 min IM: 3-5 min Transdermal: Delayed several hours	• 0.3 – 0.6 mg • SC,IM,IV q 4-6 hours • Transdermal patch every 72 hours

CSCI- continuous subcutaneous infusion ; IM: intramuscular; IV: intravenous; PO : by mouth; SC: subcutaneous; SL: sublingual

Sources: Adapted from Elman et al, 2005;[6] Plonk and Arnold, 2005;[2] Wildiers and Menten, 2002.[4]

Pain

The assessment and treatment of pain in frail elderly patients living in long-term care settings is challenging. The following general principles of pain management are worth reiterating.

- Specify the goals of treatment (e.g., "Pain relief goal is 50% reduction from baseline" or "Reduce pain to less than 3 on scale of 10").
- Explicitly include orders for nonpharmacologic pain interventions in the plan of care.
- Administer pain medications orally or sublingually whenever possible. Oral administration simplifies nursing efforts, minimizes patient burden, and decreases the likelihood of serious adverse effects of opioids.
- Generally, for chronic or continuous pain, use medication around the clock, not as needed.
- Have a precise system to monitor the effects of chronic pain medications, adjusting the frequency of monitoring as appropriate (Appendix 4.7).
- Prescribe acetaminophen initially, limiting the total daily dose to 3 g.
- Avoid long-term use of nonsteroidal anti-inflammatory drugs because of their potential adverse effects on gastric mucosa and renal and cardiac function.
- Use adjuvant medications (e.g., anticonvulsants, antidepressants) when appropriate.
- Initiate a bowel regimen to prevent opioid-related constipation (Appendix 4.8).

Using Opioids to Treat End-of-Life Pain

When initiating opioid therapy for pain, choose a conservative dose of an immediate-release opioid (e.g., morphine, oxycodone). Elderly patients should usually receive lower doses of opioids than younger persons because they are more susceptible to adverse medication effects and have age-related changes in renal function and volume of distribution. Short dosing intervals or increasing doses may be required to obtain prompt relief of severe pain or dyspnea.

Certain opioids should be avoided in elderly patients. For example, generally, propoxyphene should not be prescribed to elderly patients because of its low therapeutic efficacy and its potential for adverse effects such as confusion and falls. Similarly, meperidine is rarely appropriate because accumulation of toxic metabolites can cause confusion and seizures.

Use methadone cautiously. Although this agent has some unique advantages in terms of its cost and adverse effect profile, its use is complicated by a very long half-life. Rapid dose escalation to achieve relief of acute pain results in a gradual accumulation of medication and can increase the risk of potentially lethal adverse effects. These characteristics make methadone a suboptimal agent for relief of acute pain. Practitioners with limited experience using methadone are advised to consult a practitioner with broad and varied experience in the use of this agent before prescribing it, especially when considering prescribing it to a frail elderly patient with multiple comorbid conditions.

Opioid Monitoring in Frail Elderly Patients

When initiating opioid therapy or increasing the total daily dose of opioid prescribed to a frail elderly patient, it is important to monitor the patient to document the effectiveness of symptom relief and to detect adverse medication effects. At a minimum, monitor every 4 hours (when the patient's scheduled dose of immediate-acting opioid is administered) for at least 48 hours. Then, if pain is controlled and the patient does not exhibit excessive drowsiness or signs of respiratory depression, it may be reasonable to decrease the monitoring interval to every 8 to 12 hours.

The practitioner should create an explicit plan, tailored to each patient's situation, that tells nurses what to monitor and how to respond to adverse effects such as confusion or signs of respiratory depression. The content of the monitoring plan will vary depending on the stage of the patient's illness, the goals of treatment, and the experience and concerns of the nursing staff.

For example, if a patient has severe dyspnea in the last hours of life, the goal of relieving this symptom will likely override concerns about sedation, decreased respiration, or hypoxia. In this situation, orders to specifically forego pulse oximetry or monitoring of respiratory rate would be appropriate. In addition, the practitioner might instruct the nursing staff to continue to administer opioids at the doses needed to control dyspnea despite the presence of sedation or very low respiratory rates.

When a patient is not close to death but has pain or dyspnea caused by an exacerbation of a chronic condition, it is important to optimize safety and minimize the adverse effects of opioids. For example, after hip surgery, a patient with severe pain could benefit from titration of opioids to relieve pain and allow restful sleep and participation in physical therapy while minimizing confusion, lethargy, and respiratory depression. For this patient, appropriate monitoring parameters might include respiratory rate, oxygenation (using pulse oximetry), the ability to be aroused if drowsy, and the ability to eat and drink as usual. These parameters should be assessed before the administration of each dose for 2 to 3 days. The practitioner should ask to be notified if the onset of sedation or respiratory depression is detected and should adjust the opioid dosage accordingly. Table 4.5 is an example of orders specifying parameters for withholding medication and notifying the practitioner.

TABLE 4.5. EXAMPLE OF ORDERS TO WITHHOLD OPIOID DOSE AND NOTIFY PRACTITIONER

Hold opioid dose and notify practitioner if:
- Respiratory rate ≤ 10/minute,
- Pulse oximetry < 92% on room air,
- Patient shows acute sedation (i.e., is unable to be aroused from a sleepy state),
- Patient shows increase in confusion,
- Patient not eating.

In the last hours of life, monitoring of all of the above parameters may not be appropriate.

Around-the-Clock Dosing

Once acute pain or dyspnea has been controlled, the care team can monitor the effectiveness of symptom control and adverse medication effects by using a flow sheet or graph such as the one in Appendix 4.6.

When the symptom is controlled with a stable daily dose of medication, it is appropriate to prescribe a scheduled dose of opioid that may be either a short-acting medication given every 4 hours or a long-acting agent given every 12 hours. When dosing every 4 hours, it may be helpful to specify dose times and to double the dose at bedtime so that the patient may sleep for 8 hours without interruption (e.g., "Morphine 4 mg PO or SL at 0600, 1000, 1400, 1800. Morphine 8 mg PO or SL at 2200").

It is important to prescribe an as-needed dose of opioids for breakthrough pain. Breakthrough opioid doses are usually given every hour as needed. If incident pain can be anticipated because it is associated with a recurring activity, such as therapy, dressing changes, or other care activities, it may be appropriate to prescribe a breakthrough dose 1 hour before the activity. A reasonable dose for breakthrough or incident pain is 15% of the total daily dose or an amount equal to the q4h dose.

It is good practice to write an order for practitioner notification if the patient needs more than 2 doses of breakthrough medication in a 12-hour period or more than 3 doses in a 24-hour period. A need for frequent doses of breakthrough pain medication suggests that the scheduled dose is too low and may need to be increased. In general, if the patient describes mild to moderate pain and requires 2 or 3 as-needed doses, the total daily dose can be increased by 25%. For moderate to severe pain, increase the total daily dose by 50%.

Delirium, Restlessness, and Agitation

Delirium is a general disturbance in brain function. Near the end of life, delirium may present with confusion and inability to focus attention or may produce extreme agitation, fear, hallucinations, restlessness, and violent behavior. Delirium can develop either quickly or insidiously. This symptom can be very distressing not only for the patient but also for family members and facility staff. However, some delusions and hallucinations are not disturbing to the patient and do not need treatment. A decision not to treat delirium must be explained to the family.[7]

Common causes of delirium include decompensated medical conditions (e.g., cardiopulmonary disease), infection, medications, sensory deprivation or over-stimulation, and unrelieved pain. In general, it is best to treat the root cause of delirium rather than to simply prescribe medication to control its symptoms. In end-of-life care, however, before reflexively ordering a battery of tests, it is important to consider the current stage of the patient's illness, the patient's goals of care and advance directives, and the balance of benefits and burdens associated with an extensive evaluation.

Most medications can be held or given at a reduced dose for at least 24 hours to determine whether they are contributing to delirium. Medications deemed absolutely essential for vital organ function or directly beneficial for symptom control might be exceptions to this rule. Environmental changes (e.g., changes in lighting or sensory stimulation) and emotional support (e.g., reassuring presence, reminiscence) can help to reduce the severity of delirium.

Most authorities recommend haloperidol as the first-line medication for delirium. Relatively small doses (0.5 to 1 mg SL, PO, IM, or IV) given every hour as needed are often adequate for elderly patients. Benzodiazepines are not first-line agents because they may worsen confusion and agitation.

Fever

Fever can be caused by infection, inflammation, malignancy, or advanced dehydration. Fever may or may not cause suffering for the patient. Evaluation and treatment of fever thus depends on the stage of illness, goals of treatment, and the patient's wishes. It is helpful to discuss in advance with patients, families, and facility staff the pros and cons of treating end-of-life infection and fever. Acetaminophen generally provides effective relief of fever.

Myoclonus

Myoclonus is a movement disorder characterized by sudden, brief, involuntary muscle contractions. Myoclonus may be triggered by stimuli or movement but may also occur at rest. Unlike all other movement disorders, it does not necessarily disappear with sleep. When pronounced, family members and caregiving staff may misidentify myoclonus as seizure activity.

Many conditions common near the end of life can cause myoclonus, including hypercarbia, hyponatremia, hypoxia, and renal or hepatic failure. Myoclonus may occur in chronic nervous-system diseases (e.g. Parkinson's, Huntington's), in degenerative dementias such as Alzheimer's disease, or with cerebral ischemia or hemorrhage. Numerous common medications are associated with myoclonus (Table 4.6).

Initial treatment of myoclonus includes treating the underlying condition or stopping an offending medication, if possible. Benzodiazepines, especially clonazepam, can effectively relieve myoclonus. Other medications used for myoclonus include valproic acid and dantrolene.

TABLE 4.6. COMMON MEDICATIONS ASSOCIATED WITH MYOCLONUS

- Antidepressants (selective serotonin reuptake inhibitors and tricyclics)
- Antipsychotics
- Buspirone
- Calcium channel blockers
- Cephalosporins
- Dopamine agonists
- Levodopa
- Metoclopramide
- Opioids
- Penicillins
- Quinolones

Dry Mouth

Patients who are near the end of life often have dry lips and oral mucous membranes because of decreased oral intake and increased mouth breathing. This can lead to discomfort as well as to an unsightly appearance. Many interventions can help to relieve these symptoms and provide an opportunity for family members to participate in direct care.

A comprehensive palliative care plan should link regular assessment of the mouth and lips to scheduled nursing interventions such as turning, symptom assessment, and medication administration. Generally, use whatever is effective (e.g., frequent sips of small amounts of liquid, popsicles, hard candy, artificial saliva) to relieve dry mouth. Avoid mouthwashes that contain alcohol and glycerin swabs because they cause further drying of the mouth. Consider eliminating anticholinergic medications. If a patient is unconscious, swab the mouth with plain water and apply a small amount of a water- or petroleum-based jelly to the front teeth and lips. (Do not use petroleum jelly in the presence of oxygen equipment because of the risk of combustion.)

Nausea and Vomiting

Many agents can be used to treat nausea. Promethazine is commonly used but may not always be appropriate in end-of-life care. Promethazine has potent anticholinergic effects and is useful for gastroenteritis and vertigo but not for opioid-related nausea. If nausea is caused by rising levels of opioids, an agent with potent anti-dopaminergic properties—e.g., prochlorperazine, 5 to 10 mg PO, IM, or IV every 3 to 4 hours—is preferred. Haloperidol is also an effective antidopaminergic antiemetic. If gastroparesis is suspected to be the cause of nausea, metoclopramide, 5 to 10 mg PO, IM, or IV every 6 to 8 hours, can be effective.

Nonhealing Chronic Wounds

Nonhealing wounds are common among patients who have advanced chronic illnesses, incontinence, limited mobility, and poor and deteriorating nutrition. It may be helpful to communicate to families that the skin is the largest organ system of the body and that patients with advanced illness can have “skin failure” just as they can have heart or kidney failure. This may help to mediate the unrealistic expectation that all skin ulcers can be prevented and the misconception that skin ulcers are always caused by inadequate nursing care.

Healing is unlikely when ulcers occur in the final stages of life, but it is possible to relieve pain, control odor, contain exudates, and treat infection. Wound odor is usually caused by necrotic tissue or bacteria. The use of mechanical or enzymatic debridement may decrease the amount of necrotic tissue. Topical antibiotics (e.g., metronidazole gel) may decrease the bacterial load, thus reducing odor. Oral antibiotics may be appropriate to treat cellulitis or osteomyelitis.

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APPENDIX 4.1. AGGRESSIVE COMFORT MNEMONIC

ANOREXIA (mnemonic for correctable causes)
- **A**ches
- **N**ausea
- **O**ral candidiasis
- **R**eactive depression
- **E**vacuation problems
- **X**erostomia
    - Reduce anticholinergic medications, consider artificial saliva
- **I**atrogenic (radiation or chemotherapy)
- **A**cid (gastritis or peptic ulcer disease)
    - Offer foods or fluids as tolerated
    - Consider appetite stimulants (e.g., dexamethasone, dronabinol, megestrol, mirtazapine, trazodone)

GASTROINTESTINAL

AGITATION (terminal delirium)
- *Fix the correctable causes*
- Haloperidol 0.5 mg – 2 mg PO/IM/IV/SC Q 30 min PRN
- Lorazepam 0.5 mg PO/SL/SC Q 30 min PRN (may cause paradoxical agitation)

GASTROINTESTINAL
- **CONSTIPATION** (give stimulants preventively when prescribing opioids)
    - Docusate sodium 100-250 mg daily to twice daily
    - Senna 1-6 tabs daily
- **NAUSEA**
    - Prochlorperazine 5-10 mg PO/IM/IV Q 3-4 H
    - Metoclopramide 5-10 mg PO/IM/IV Q 6-8 H
    - Haloperidol 0.5-2 mg PO/IM/IV Q 30 min
    - Scopolamine transdermal patch 1.5 mg Q 72 H
    - Ondansetron 4 to 8 mg PO Q 12 h

GENITOURINARY
- **BLADDER**
    - Discuss incontinence management (catheter?)
    - If spasms, consider oxybutynin

RESPIRATORY (dyspnea, air hunger)
- **B-R-E-A-T-H A-I-R** (for modifiable causes of dyspnea)
    - **B**ronchospasm
    - **R**ales
    - **E**ffusions
    - **A**irway obstruction
    - **T**hick secretions
    - **H**emoglobin low
    - **A**nxiety
    - **I**nterpersonal issues
    - **R**eligious concerns
- Dyspnea treatment of choice: Immediate release opioids, same doses as for acute pain

EMOTIONAL SUPPORT

SPIRITUAL SUPPORT

SECRETIONS (death rattle, noisy breathing)
- Glycopyrrolate: 1 mg PO 1-4 times daily (max 8 mg/d); 0.1-0.4 mg SC/IM/IV initially, repeat as needed
- Scopolamine transdermal 1.5 mg Q 72 H

INFLAMMATION (fever)
- Acetaminophen or aspirin scheduled dose (preferred) or PRN

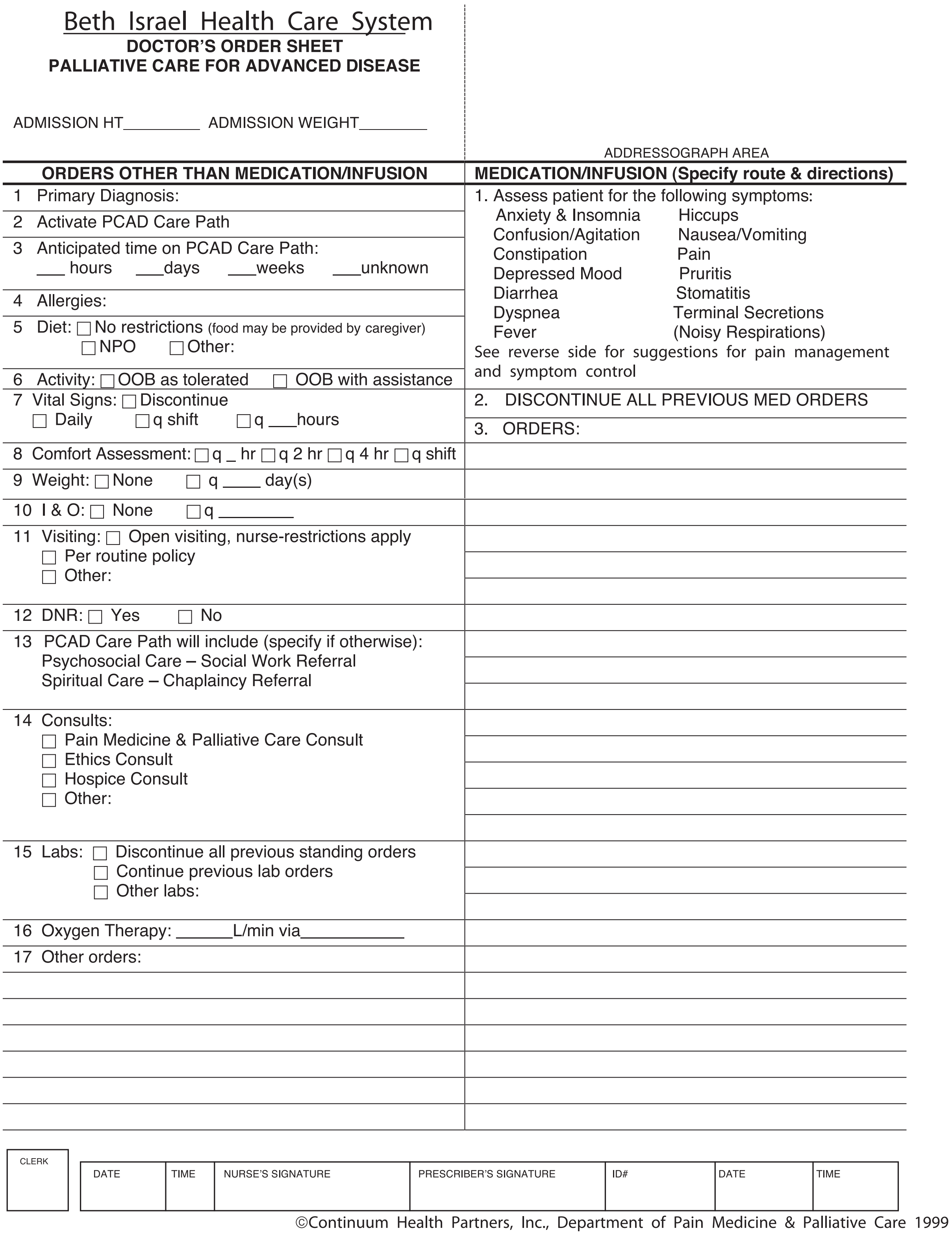
VOLUME (review with family, dehydration has no pain)

EMPATHY (secure your own emotional support)

IM: intramuscular; IV: intravenous; PO: by mouth; PRN: as needed; SC: subcutaneous; SL: sublingual.

Source: Adapted from Primer of Palliative Care, Porter Storey MD and Geri Pearls at geriatrics.unmc.edu, Ed Vandenberg, MD, CMD

APPENDIX 4.2. DOCTOR'S ORDER SHEET — PALLIATIVE CARE FOR ADVANCED DISEASE (BETH ISRAEL HEALTH CARE SYSTEM)



Beth Israel Health Care System

DOCTOR'S ORDER SHEET

PALLIATIVE CARE FOR ADVANCED DISEASE

ADMISSION HT_________ ADMISSION WEIGHT________

ADDRESSOGRAPH AREA

ORDERS OTHER THAN MEDICATION/INFUSION

1 Primary Diagnosis:

2 Activate PCAD Care Path

3 Anticipated time on PCAD Care Path:
___ hours ___days ___weeks ___unknown

4 Allergies:

5 Diet: ☐ No restrictions (food may be provided by caregiver)
☐ NPO ☐ Other:

6 Activity: ☐ OOB as tolerated ☐ OOB with assistance

7 Vital Signs: ☐ Discontinue
☐ Daily ☐ q shift ☐ q ___hours

8 Comfort Assessment: ☐ q _ hr ☐ q 2 hr ☐ q 4 hr ☐ q shift

9 Weight: ☐ None ☐ q ____ day(s)

10 I & O: ☐ None ☐ q _________

11 Visiting: ☐ Open visiting, nurse-restrictions apply
☐ Per routine policy
☐ Other:

12 DNR: ☐ Yes ☐ No

13 PCAD Care Path will include (specify if otherwise):
Psychosocial Care – Social Work Referral
Spiritual Care – Chaplaincy Referral

14 Consults:
☐ Pain Medicine & Palliative Care Consult
☐ Ethics Consult
☐ Hospice Consult
☐ Other:

15 Labs: ☐ Discontinue all previous standing orders
☐ Continue previous lab orders
☐ Other labs:

16 Oxygen Therapy: ______L/min via____________

17 Other orders:

MEDICATION/INFUSION (Specify route & directions)

1. Assess patient for the following symptoms:

Anxiety & Insomnia	Hiccups
Confusion/Agitation	Nausea/Vomiting
Constipation	Pain
Depressed Mood	Pruritis
Diarrhea	Stomatitis
Dyspnea	Terminal Secretions
Fever	(Noisy Respirations)

See reverse side for suggestions for pain management and symptom control

2. DISCONTINUE ALL PREVIOUS MED ORDERS

3. ORDERS:

CLERK	DATE	TIME	NURSE'S SIGNATURE	PRESCRIBER'S SIGNATURE	ID#	DATE	TIME

Source: Bookbinder MB, Blank AE, Arney E, et al. Improving end-of-life care: Development and pilot test of a clinical pathway. *J Pain Symptom Manage* 2005; 29(6):529-543. Reprinted with permission.

APPENDIX 4.2. DOCTOR'S ORDER SHEET — PALLIATIVE CARE FOR ADVANCED DISEASE (BETH ISRAEL HEALTH CARE SYSTEM) (CONTINUED)

The following are medications for consideration in treating pain and symptoms of patients on PCAD:

PAIN MANAGEMENT
For Opioid-Naïve Patient:
Morphine Sulfate 15 mg po or 5 mg SQ/IV.
Repeat q 1 hr until pain relief is adequate. Begin Morphine Sulfate 30 mg po or 10 mg SQ/IV q 4 hr ATC or begin IV Morphine Sulfate basal infusion at 2 mg per hour and 2 mg SQ/IV q 1 hr prn.

For Opioid-Treated Patient:
If pain uncontrolled, increase fixed schedule dose by 50%.

Many non-opioid analgesics are available and should be considered after opioid therapy has been optimized. If pain remains uncontrolled, consider consult to Department of Pain Medicine and Palliative Care (Beeper #6702).

ANXIETY & INSOMNIA
Lorazepam 0.5mg po/SQ/IV BID-TID q HS for anxiety.
Temazepam 15 – 30 mg po q HS for anxiety/ insomnia.
Clonazepam 0.5 – 2 mg po BID-TID for anxiety/myoclonus.

CONFUSION/AGITATION
Haloperidol 0.5 mg po/SQ/IV. Repeat q 30 minutes until symptom intensity declines.
Haloperidol 0.5 – 5 mg po/SQ/IV q 4 hr prn.

CONSTIPATION
Lactulose 30 ml po q 2 hr prn until constipation relieved. When symptom improves, begin Lactulose 30 ml po q 12 hr.
Warm Fleets Enema TIW prn

To prevent constipation:
Senokot 1 – 2 tabs po BID and
Colace 1 – 2 tabs po BID.

SYMPTOMS OF DEPRESSION
If anticipated survival is in weeks:
Begin SSRI, e.g., Paroxetine 20 mg po daily, and titrate to effect.

If anticipated survival is in days:
Methylphenidate 2.5 mg po q morning and at noon and escalate daily to 5 – 10 mg po q morning and at noon or
Pemoline 18.75 mg po q morning and at noon and escalate daily to 37.5 mg po q morning and at noon.
Higher doses may be needed.

Consider Liaison Psychiatry consultation

DIARRHEA
Loperamide 4 mg po q 4 hr prn

DYSPNEA
For Opioid-Naïve Patient:
Morphine Sulfate 5 – 15 mg po or 2 – 5 mg SQ/IV. Repeat q 1 hr, if needed. When symptom is improved, begin Morphine Sulfate 30 mg po or 10 mg SQ/IV q 4 hr ATC; or begin Morphine Sulfate basal infusion at 2 mg per hour and 2 mg SQ/IV q 1 hr prn.

For Opioid-Treated Patient:
If dyspnea uncontrolled, increase fixed schedule dose by 50%. If breathlessness continues , add Lorazepam 0.5mg po or SQ/IV prn. Repeat q 60 minutes if needed until symptom intensity declines, then begin 1 mg po/SQ/IV q 3 hr.

Additional therapies may include:
Dexamethasone 16 mg po/IV, followed by 4 mg po/IV q 6 hr
Albuterol 2.5 mg via nebulization q 4 hr prn if wheezing present

FEVER
Acetaminophen 650 mg po/PR q 4 hr prn, and/or
Dexamethasone 1.0 mg po/SQ/IV q 12 hr prn

HICCUPS
Chlorpromazine 10 – 25 mg po/IM TID prn
Haloperidol 0.5 – 2 mg po/SQ/IV TID – QID

INTRACTABLE SYMPTOMS, MANAGEMENT OF
Consider referral to Department of Pain Medicine & Palliative Care (Beeper # 6702).

IV HYDRATION
Consider decreasing IV rate to 0.5 – 1 liter/24 hr

NAUSEA/VOMITING
Metoclopromide 10 mg po/IV q 4 hr prn, or
Prochlorperazine 10 mg po/IV q 4 hr or 25 mg PR q 8 hr prn with or without Dexamethasone 4 mg po/IVPB q 6 hr

PRURITIS
Diphenhydramine 25 – 50 mg po/IV q 12 hr
Hydrocortisone 1 % cream to affected areas q 6 hr
Dexamethasone 1.0 mg po daily alone or in combination with above

STOMATITIS
Viscous lidocaine 2 % to painful areas prn
Clotrimazole 10 mg troche 5 times daily
Nystatin S & S q 6 hr prn
Magic Mouthwash prn

TERMINAL SECRETIONS (NOISY RESPIRATIONS)
Scopolamine patches 1.5 – 3 mg 72 hr, or
Scopolamine 0.4 mg SQ q 4 – 6 hr

APPENDIX 4.3. CAREPATH: PALLIATIVE CARE FOR ADVANCED DISEASE—DAILY PATIENT CARE FLOW SHEET (BETH ISRAEL HEALTH CARE SYSTEM)

		Time			
M	A	Bedbound			
O		OOB Chair			
B		Amb w Assist			
I		OOB ad lib			
L		BR Privileges			
I	I	T&P per pt comfort			
T		ROM q___			
Y		Assistive Device			
		__Ted Stocking(s)			
		Side Rails Up			
E	A	Voiding qs			
L		Anuria			
I		Incontinent Urine			
M		Bowel Movement			
I		Incontinent Feces			
N		Diarrhea			
A		Constipation			
T					
I	I	__Foley Catheter			
O		Texas Catheter			
N		Inc't Pads			
		__Enema			
		Meds as ordered			
S	A	Normal/Intact			
K		Feverish			
I		Diaphoretic			
N		Pressure Ulcer Stg___			
		Ostomy site D/I			
		Edema___			
		Pruritis			
		Cool/Mottled			
W	I	Site			
O		Dressing_______			
U		Dry & Intact			
N		Drain_________			
D		Drainage			
		Odor			
C		Ostomy site care			
A		Tube site care			
R					
E					

		Time			
S	A	Normal			
L		Interrupted Cycle			
E		Insomnia			
E					
P	I	Modify Environment			
		Relaxation			
		Meds as order			
P	A	Awake/alert			
S		Responds to voice			
Y		Resp to tactile stim			
C		Unresponsive			
H		Oriented			
O		Confused			
S		Hallucinating			
O		Calm			
C		Anxiety			
I		Agitated			
A		Depression			
L		Spiritual distress			
	I	Emotional support			
		Verbal/tactile stimulation			
		Social Worker visit			
		Chaplain visit			

		Time			
F	A	Engaged w pt			
A		Coping w loss			
M		Distressed			
I					
L					
Y	I	Goals of care reviewed			
		Encourage verbal & non-verbal communication w pt			
		Family Meeting			
		Bereavement support			
M		AM Care			
I		PM Care			
S		PresUlcer Prev Plan			
C		Fall Prev Plan			
E		Precautions:			
L		Isolation:			
L		Siderails Up			
A		ID Bracelet			
N		Allergy Bracelet			
E		DNR Bracelet			
O		Post Mortem care			
U					
S					

Comments/Progress Notes

PATIENT/FAMILY EDUCATION: ☐ **See IPFER**

PCAD Care Path: ☐ **Initiated** ☐ **Reviewed/Continue With Plan Of Care** ☐ **Revised (See Progress Note)**

OTHER NURSING DOCUMENTATION:
☐ **I & O SHEET** ☐ **RESTRAINT FLOW SHEET** ☐ **NEURO-ASSESSMENT** ☐ **OTHER_______________**

SIGNATURE/TITLE	DATE	SHIFT	INITIALS	SIGNATURE/TITLE	DATE	SHIFT	INITIALS
1.				**6.**			
2.				**7.**			
3.				**8.**			
4.				**9.**			
5.				**10.**			

APPENDIX 4.3. CAREPATH: PALLIATIVE CARE FOR ADVANCED DISEASE—DAILY PATIENT CARE FLOW SHEET (BETH ISRAEL HEALTH CARE SYSTEM) (CONTINUED)

Beth Israel Health Care System
Carepath: Palliative Care for Advanced Disease
DAILY PATIENT CARE FLOW SHEET

ADDRESSOGRAPH

DATE:

☐ **DNR** ☐ **NO DNR** ☐ **HCP** ☐ **NO HCP** **HCP AGENT:** **CAREGIVER:**

COMFORT ASSESSMENT: Comfort Level Patient states or appears to be
1. Always comfortable 2. Usually comfortable 3. Sometimes comfortable 4. Seldom comfortable 5. Never comfortable

TIME (per MD order)													
PATIENT Comfort Level (Indicate number)													
VITAL SIGNS ONLY AS ORDERED	T												
	P												
	R												
	BP												

P A I N	TIME																
	LOCATION																
	PAIN RATING																
	RELIEF/SEDATION																

PAIN/RELIEF SCALE KEY
NONE ◄——► WORST
0 1 2 3 4 5 6 7 8 9 10
COMPLETE RELIEF NO RELIEF

SEDATION SCALE
0 Alert
1 Awake but drowsy
2 Drowsy/Easily awakened
3 Sleeping/Easily awakened
4 Sleeping/Difficult to awaken
5 Unarousable

*** See Progress Note A = Assessment I = Intervention Check mark = present or done __ Needs MD Order**

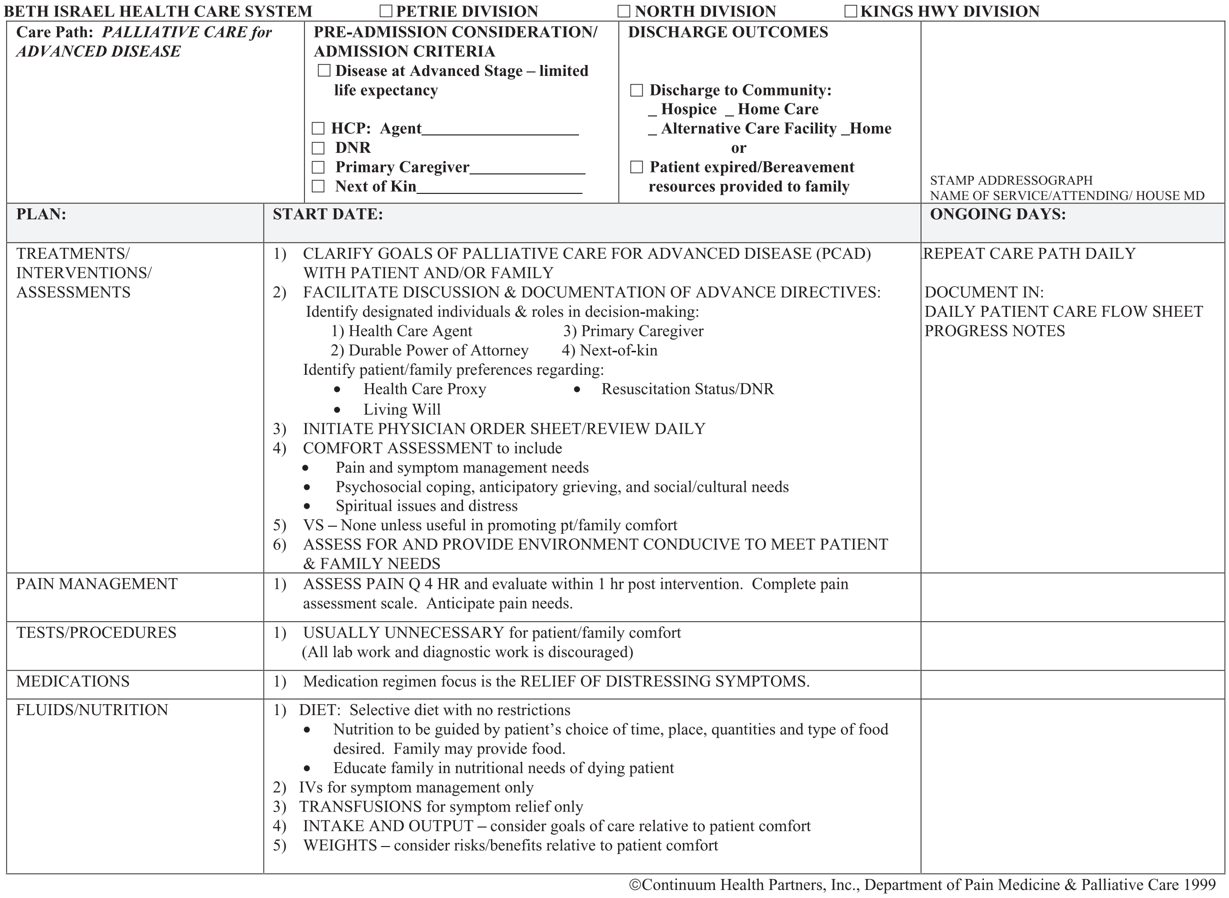
		Time			
E	A	Moist/Clear			
Y		Inflamed			
E		Dry/Crusted			
S					
	I	Routine Care			
		__Artificial Tears			
		__Oint/Lubricant			
L	A	Smooth/moist			
I		Dry/Cracked			
P		Ulcerated			
S					
	I	Routine Care			
		Topical Lubricant			
M	A	Moist			
O		Dry			
U		Coated			
T		Stomatitis			
H					
	I	Routine Care			
		__Artificial Saliva			
		__Magic Wash			
		Meds as ordered			

		Time			
B	A	**Rate**: Normal			
R		Rapid			
E		Slow			
A		**Rhythm**: Reg			
T		Irregular			
H		**Depth**: Normal			
I		Shallow			
N		Labored			
G		**Secretions**: None			
		Mild			
		Copious			
		Breath sounds:			
		Clear			
		Diminished			
		Absent			
		Crackles			
		Wheeze			
		Dyspnea			
	I	None			
		Reposition			
		__O2 via___@___lpm			
		Suctioning q____			
		Trach Care			
		Elevate HOB			
		Fan			
		Meds as ordered			

		Time			
N	A	Full meal			
U		> 50%			
T		< 50%			
R		Refused			
I		Nausea/vomiting			
T		NPO			
I		Dysphagia			
O					
N					
	I	Diet as tolerated			
		NG/G tube			
		Enteral feeding			
		Feeding set changed			
		Residual vol-cc's			
		Placement check			
		Meds as ordered			
I	A	IV site________			
V		No S&S infil/phleb			
		Dry & intact			
L					
I	I	IV Dsg change			
N		IV Tubing change			
E		See progress note			
S		Cap Change			
		Huber needle change			

Source: Bookbinder MB, Blank AE, Arney E, et al. Improving end-of-life care: Development and pilot test of a clinical pathway. *J Pain Symptom Manage* 2005; 29(6):529-543. Reprinted with permission.

APPENDIX 4.4. CARE PATH: PALLIATIVE CARE FOR ADVANCED DISEASE (BETH ISRAEL HEALTH CARE SYSTEM)



BETH ISRAEL HEALTH CARE SYSTEM ☐ PETRIE DIVISION ☐ NORTH DIVISION ☐ KINGS HWY DIVISION

Care Path: *PALLIATIVE CARE for ADVANCED DISEASE*	**PRE-ADMISSION CONSIDERATION/ ADMISSION CRITERIA** **☐ Disease at Advanced Stage – limited life expectancy** **☐ HCP: Agent____________________** **☐ DNR** **☐ Primary Caregiver______________** **☐ Next of Kin____________________**	**DISCHARGE OUTCOMES** **☐ Discharge to Community:** **_ Hospice _ Home Care** **_ Alternative Care Facility _Home** **or** **☐ Patient expired/Bereavement resources provided to family**	STAMP ADDRESSOGRAPH NAME OF SERVICE/ATTENDING/ HOUSE MD

PLAN:	**START DATE:**	**ONGOING DAYS:**
TREATMENTS/ INTERVENTIONS/ ASSESSMENTS	1) CLARIFY GOALS OF PALLIATIVE CARE FOR ADVANCED DISEASE (PCAD) WITH PATIENT AND/OR FAMILY 2) FACILITATE DISCUSSION & DOCUMENTATION OF ADVANCE DIRECTIVES: Identify designated individuals & roles in decision-making: 1) Health Care Agent 3) Primary Caregiver 2) Durable Power of Attorney 4) Next-of-kin Identify patient/family preferences regarding: • Health Care Proxy • Resuscitation Status/DNR • Living Will 3) INITIATE PHYSICIAN ORDER SHEET/REVIEW DAILY 4) COMFORT ASSESSMENT to include • Pain and symptom management needs • Psychosocial coping, anticipatory grieving, and social/cultural needs • Spiritual issues and distress 5) VS – None unless useful in promoting pt/family comfort 6) ASSESS FOR AND PROVIDE ENVIRONMENT CONDUCIVE TO MEET PATIENT & FAMILY NEEDS	REPEAT CARE PATH DAILY DOCUMENT IN: DAILY PATIENT CARE FLOW SHEET PROGRESS NOTES
PAIN MANAGEMENT	1) ASSESS PAIN Q 4 HR and evaluate within 1 hr post intervention. Complete pain assessment scale. Anticipate pain needs.	
TESTS/PROCEDURES	1) USUALLY UNNECESSARY for patient/family comfort (All lab work and diagnostic work is discouraged)	
MEDICATIONS	1) Medication regimen focus is the RELIEF OF DISTRESSING SYMPTOMS.	
FLUIDS/NUTRITION	1) DIET: Selective diet with no restrictions • Nutrition to be guided by patient's choice of time, place, quantities and type of food desired. Family may provide food. • Educate family in nutritional needs of dying patient 2) IVs for symptom management only 3) TRANSFUSIONS for symptom relief only 4) INTAKE AND OUTPUT – consider goals of care relative to patient comfort 5) WEIGHTS – consider risks/benefits relative to patient comfort	

Source: Bookbinder MB, Blank AE, Arney E, et al. Improving end-of-life care: Development and pilot test of a clinical pathway. *J Pain Symptom Manage* 2005; 29(6):529-543. Reprinted with permission.

APPENDIX 4.4. CARE PATH: PALLIATIVE CARE FOR ADVANCED DISEASE (BETH ISRAEL HEALTH CARE SYSTEM) (CONTINUED)

ACTIVITY	1) ACTIVITY DETERMINED BY PATIENT'S PREFERENCES AND ABILITY. Patient determines participation in ADLs, i.e., turning and positioning, bathing, transfers	REPEAT CARE PATH DAILY DOCUMENT IN: DAILY PATIENT CARE FLOW SHEET PROGRESS NOTES
CONSULTS	1) INITIATE referrals to institutional specialists to optimize comfort and enhance quality of life (QOL) only.	
PSYCHOSOCIAL NEEDS	1) PSYCHOSOCIAL COMFORT ASSESSMENT of: • Patient • Primary caregiver • Grieving process of patient & family 2) PSYCHOSOCIAL SUPPORT: Referral to Social Work • Offer emotional support • Support verbalization and anticipatory grieving • Encourage family caring activities as appropriate/individualized to family situation and culture • Facilitate verbal and tactile communication • Assist family with nutrition, transportation, child care, financial, funeral issues • Assess bereavement needs	
SPIRITUAL NEEDS	1) SPIRITUAL COMFORT ASSESSMENT • Spiritual supports • Spiritual needs and/or distress 2) SPIRITUAL SUPPORT: Referral to Chaplain • Provide opportunity for expression of beliefs, fears, and hopes • Provide access to religious resources • Facilitate religious practices	
PATIENT/FAMILY EDUCATION	1) ASSESS NEEDS AND PROVIDE EDUCATION REGARDING: • Goals of Palliative Care for Advanced Disease • Physical and psychosocial needs during the dying process • Coping techniques/Relaxation techniques • Bereavement process and resources	
DISCHARGE PLANNING	1) FOR DISCHARGE TO COMMUNITY: Referral to Pain Medicine & Palliative Care/ Hospice/Home Care/Social Work as needed. 2) AT TIME OF DEATH: • Post Mortem care observing cultural and religious practices and preferences • Provide for care of patient's possessions as per family wishes • Bereavement support for family and staff	

This document is to be used as a guideline only. Each case should be evaluated and treated individually based upon clinical findings.

APPENDIX 4.5. TITRATION OPTIONS FOR OPIOIDS TO TREAT ACUTE, SEVERE PAIN

- Severe pain is pain ≥7 on a scale of 0 to 10, described as severe or excruciating by the patient or judged debilitating or severe on the basis of nursing observation.
- Rapid titration of opioids is intended to achieve control of acute severe pain.
- Titration to relieve severe pain should follow one of the evidence-based methods below.
- Oral titration is preferred in frail elderly patients in long-term care facilities.
- Subcutaneous or intravenous opioid titration should be reserved for extreme situations. These titration options require intensive monitoring that may not always be available in long-term care facilities.
- Titration regimens should adhere to the *Guide to Safe Titration of Opioids* (below).

Guide to Safe Titration of Opioids

- Use frequent doses of immediate-acting opioids. Titrate to obtain a well-defined level of pain relief (e.g., pain reduced by 50%, pain level of <3 on a scale of 0 to 10).
- Opioids administered orally are less likely to cause acute sedation than those given SC, IM, or IV.
- Hold titration dose if acute sedation occurs.
  - Acute sedation is defined as the inability to be aroused from sleepy state.
  - Acute sedation precedes respiratory suppression.
- Hold titration dose if respiratory rate ≤8/minute.

Oral Opioid Titration - Option 1

- Immediate-release morphine (2-5 mg) or equivalent, PO or SL every 30 minutes until pain relief is observed or reported. (This dose is recommended for frail opioid-naïve patients. A higher dose may be appropriate for less-frail individuals.)
- Assess pain relief, level of consciousness, respiratory rate, and pulse oximetry every 30 minutes.
  — Hold titration dose if acute sedation occurs.
  — Hold titration dose if respiratory rate ≤8/minute.
- Calculate the total amount of PO morphine used during titration to relieve pain. Give 25% of this total amount as the scheduled q4h dose.
- Note that such conversions are estimates. Follow the patient closely for 24 to 48 hours to assess for signs and symptoms of an excessive dose, or conversely, the need for PRN doses if the estimated dose does not control pain adequately.

Oral Opioid Titration - Option 2

- Immediate-release morphine (2-5 mg) or equivalent, PO or SL. (This dose is recommended for frail, opioid-naïve patients. A higher dose may be appropriate for less frail individuals.)
- Assess pain, respiratory rate, and sedation after 1 hour.
  — If pain is still severe (≥7), double the dose (to 4-10 mg).
  — If pain level is moderate (4-6), repeat the first dose.
  — If pain level is mild (0-3), give the most recent dose q4h around the clock.
- If no decrease in pain severity after 2-3 hours, consider SC loading or titration.
- Calculate the total amount of PO morphine used during titration to relieve pain. Give 25% of this total amount as the scheduled q4h dose.

- Note that such conversions are estimates. Follow the patient closely for 24 to 48 hours to assess for signs and symptoms of an excessive dose, or conversely, the need for PRN doses if the estimated dose does not control pain adequately.

Subcutaneous Opioid Titration

- Morphine (1-2 mg) SC every 5 minutes until pain relief is observed or reported.
- Assess pain relief, level of consciousness, respiratory rate, and pulse oximetry every 5 minutes during titration.
  - — Hold titration dose if acute sedation occurs.
  - — Hold titration dose if respiratory rate < 8/minute.
- Once pain is controlled, calculate a PO dose.
  - — Calculate the total amount of SC morphine used during titration to relieve pain and multiply by 0.75 to determine scheduled q4h PO morphine dose. (This is equivalent to determining the q4h SC dose by dividing the total SC titration amount by 4 and converting that SC dose to PO by multiplying by 3.)
- Note that such conversions are estimates. Follow the patient closely for 24 to 48 hours to assess for signs and symptoms of an excessive dose, or conversely, the need for PRN doses if the estimated dose does not control pain adequately.

IM: intramuscular; IV: intravenous; PO: by mouth; PRN: as needed; SC: subcutaneous; SL: sublingual.

Sources: William D Smucker, MD, CMD, Altenheim Nursing Home, Strongsville, Ohio.

Adapted from Walsh D, Rivera BI, Davis MP, et al. Strategies for pain management: Cleveland Clinic Foundation guidelines for opioid dosing for cancer pain. *Supportive Cancer Therapy* 2004: 1: 157-164.

APPENDIX 4.6. USING THE SYMPTOM ASSESSMENT GRAPH

Procedure for Assessing and Graphing Symptoms

Assessment and treatment of pain and other distressing symptoms (e.g., shortness of breath, nausea, agitation) should be integrated into the patient's plan of care. It is helpful to think of pain and other distressing symptoms as "vital signs" that should be regularly monitored to allow proper treatment. The goal of assessing and treating distressing symptoms is to achieve symptom control without unwanted medication side effects.

Indications for Symptom Assessment

Complete a symptom assessment using the *Initial Pain Assessment* tool:

- Upon admission,
- When residents or caregivers report pain or distressing symptoms, or
- If a resident shows a persistent decline in function.

If a resident reports pain or other distressing symptoms, complete a *Symptom Assessment Graph.*

Completing the Symptom Assessment Graph

This graph has four sections:

1. <u>Distressing symptoms:</u>
   Use the first set of large boxes on the left-hand side of the graph to list the patient's symptoms (e.g., pain, dyspnea, agitation, anxiety, nausea).
2. <u>Adverse effects of medications:</u>
   Beneath the symptom section, list common side effects of narcotics or anti-anxiety agents (e.g., lethargy, confusion, constipation).
3. <u>Routine medications:</u>
   List all routine symptom medications. Include agent, dose, route, frequency, and duration. When applicable, discontinue routine symptom medication as per facility policy.
4. <u>Breakthrough medication:</u>
   Use this section to record the medication ordered. Record the dose given in the small boxes.

Symptom Rating Scale

Symptom rating involves assigning a numerical score to the severity of the symptom. Symptoms are scored on a scale from 0 (absence of symptom) to 10 (worst imaginable severity of symptom). Record this numerical score on the Symptom Assessment Graph. Because function is so important, monitor pain and other symptoms with ADLs, care, and treatments.

<u>Assigning a numerical value to symptoms by using verbal report or observation</u>

Determine the best way to rate the patient's distressing symptoms. Those with adequate verbal and cognitive skills can use either a 0 to 10 rating system or a visual aid (like frowning or smiling faces). For patients who are unable to cooperate with visual or verbal scales, rate symptom severity on the basis of nursing observation by using the Non-Communicative Tool (Nurse) located on the Initial Pain Assessment Sheet. Record the symptom score on the Symptom Assessment Graph.

Assigning a numerical value to side effects

Side effects such as worsening of confusion, lethargy, and constipation should also be rated on a scale of 0 to 10 (absent to severe) on the basis of nursing observation. The side effect score is recorded on the Assessment Graph.

Frequency of Symptom Monitoring

The frequency of symptom monitoring is based on the nurse's assessment of the patient's condition. When the patient's symptoms are controlled without adverse effects and the medication regimen is stabilized, the nurse may lengthen the symptom monitoring interval in a stepwise manner. The medication interval and dose are considered stabilized when the symptom remains controlled and breakthrough medication is needed no more than once per monitoring interval.

For example, if a new patient is admitted with uncontrolled pain after a hip fracture, monitor the patient for hip pain hourly until pain is absent or minimal (0-2 on a scale of 10), then monitor the patient every 3 hours.

Shorten the monitoring interval if the patient's pain is >2 on a scale of 10 or the patient exceeds the amount of breakthrough medication listed below.

Monitoring intervals

1. Hourly monitoring
   - When symptoms are severe (>7 on a scale of 0 to 10)
   - When starting a new symptom control medication or nonpharmacologic intervention.
2. Every 3 hours
   - When symptoms have been controlled ($\leq$ 2 on a scale of 0 to 10) for at least three 1-hour monitoring periods, with no breakthrough medication needed.
3. Every shift
   - When symptoms monitored every 3 hours have been controlled for 24 hours, with no more than one dose of breakthrough medication in that time.
4. Weekly
   - When symptoms have been controlled for 3 days with no more than one dose of breakthrough medication per 24-hour period.

Notification of practitioner

Notify practitioner urgently (ASAP) if:

- Pain remains $\geq$5 on a scale of 0 to 10 after three doses of medication per symptom-control protocol, or
- Patient shows increasing confusion or lethargy that affects ADLs or creates a safety risk to patient or staff.

Notify practitioner at next check-in with the nursing supervisor if breakthrough pain occurs more than once daily.

PAIN SYMPTOM ASSESSMENT GRAPH.

NAME: ______________________________ **Month** ____________ **Year** _____ **SYMPTOM ASSESSMENT GRAPH**

FACES ☺ Little to mild pain 😐 Moderate pain ☹ Severe/ excruciating	NURSING OBSERVATION	**NUM**	**SYMPTOMS**	**For Severe Symptoms (Shaded Area), Give Breakthrough Medication or Notify Physician**
☹	Severe	10	**PAIN WITH ADLS**	MEDICATE or NOTIFY PHYSICIAN
☹	7-10			
☹		8		
☹				
😐	Moderate	6		
😐	4-6			
😐		4		
☺	Mild			
☺	0-3	2		
☺				
☺		0	**CIRCLE SCALE USED:** **FACES OBSERVATION NUMERICAL**	
☹	Severe	10	**SHORTNESS OF BREATH**	MEDICATE or NOTIFY PHYSICIAN
☹	7-10			
☹		8		
☹				
😐	Moderate	6		
😐	4-6			
😐		4		
☺	Mild			
☺	0-3	2		
☺				
☺		0	**CIRCLE SCALE USED:** **FACES OBSERVATION NUMERICAL**	
☹	Severe	10	**AGITATION/ RESTLESSNESS**	MEDICATE or NOTIFY PHYSICIAN
☹	7-10			
☹		8		
☹				
😐	Moderate	6		
😐	4-6			
😐		4		
☺	Mild			
☺	0-3	2		
☺				
☺		0	**CIRCLE SCALE USED:** **FACES OBSERVATION NUMERICAL**	
			ADVERSE EFFECTS	**Notify Physician if SEVERE**
Severe Increase			**CONFUSION**	NOTIFY PHYSICIAN
Moderate Increase				
Minimal Increase				
No change				
Severe Increase			**SLEEPINESS**	NOTIFY PHYSICIAN
Moderate Increase				
Minimal Increase				
No change				
			NAUSEA **P = PRESENT A = ABSENT**	
			CONSTIPATION **P = PRESENT A = ABSENT**	
			ROUTINE MEDICATIONS	
			BREAKTHROUGH MEDICATIONS	
			DATE	
			TIME	
			ASSESSED BY	

NURSING OBSERVATION
(Non-communicative patients)

MILD (0-3): Whimper/moan, No grimace, Body at Rest, No Rubbing, No Pain When touched
MODERATE (4-6): Crying, Frown/grimace, Pacing, restless, Rubbing/Patting
SEVERE:(7-10) Screaming, Clenched Teeth, Tense, holding still, Extremely tender to touch

ADLs: activities of daily living.

Source: William D. Smucker, MD, CMD, Altenheim Nursing Home, Strongsville, Ohio.

APPENDIX 4.7. OPIOID INITIATION AND TITRATION WORKSHEET

Patient Name		
GOAL level of Pain or Breathlessness Control (Record goal)	Symptom Scale (Choose one)	Activity for Symptom Measurement (Choose one)
	0 to 10 Scale	At Rest
	Mild /Moderate/Severe	With Care
	Nursing Observation	With ADLs
	(other)	With Therapy
		(other)

Current Vitals and Behavior				
Respiratory Rate	Pulse Ox	Level of consciousness (circle choice)	Confusion (circle choice)	Fluid intake per shift
		Alert Sleepy but easily aroused Drowsy, hard to arouse Unarousable	No confusion Mild confusion Moderate confusion Severe confusion	

Monitor & record level of symptom, Respiratory rate, Pulse Ox, Level of consciousness, Confusion Q 1 H until at goal symptom level, then Q 3 H while awake x 24 H, then Q shift x 3 days

Physician Notification Parameters		
Respiratory Rate	Pulse Ox	Fluid intake per shift

Pain level																	
Breathlessness level																	
Level of consciousness																	
Alert																	
Sleepy, but easily aroused																	
Drowsy, hard to arouse																	
Unarousable																	
Confusion																	
No confusion																	
Baseline confusion unchanged (mild/moderate/severe)																	
Mild increase from																	
Moderate increase from baseline confusion																	
Severe increase from baseline confusion																	
Respiratory Rate																	
Pulse Oximetry																	
Nausea																	
Fluid intake/shift																	
Date																	
Time																	
Nurse initial																	

ADLs: activities of daily living.

Source: William D Smucker, MD, CMD, Altenheim Nursing Home, Strongsville, Ohio.

APPENDIX 4.8. REGIMEN TO PREVENT OR TREAT OPIOID-RELATED CONSTIPATION

Step 1: Docusate 100 mg, 1 capsule twice daily
Step 2: Senna or bisacodyl, 1 tablet daily
Step 3: Senna or bisacodyl, 1 tablet twice daily
Step 4: Senna or bisacodyl, 2 tablets twice daily
Step 5: Senna or bisacodyl, 3 tablets twice daily
Step 6: Senna or bisacodyl, 4 tablets twice daily + sorbitol 15 cc, twice daily
Step 7: Senna, 4 tablets twice daily + sorbitol 30 cc, twice daily
Step 8: Senna, 4 tablets twice daily + sorbitol 30 cc, 3-4 times daily

If no bowel movement in 2 days despite preventive treatment, consider:
- Sodium phosphate 30 cc PO, repeated in 2 hours if needed,
- Mineral oil or enema, or
- Digital disimpaction.

After bowel movement, intensify preventive regimen at least one step higher than previous regimen.

PO: by mouth.

Source: Adapted from Storey P, Knight CS. UNIPAC-3. Assessment and treatment of pain in the terminally ill. 2nd ed. In: Hospice/Palliative Care Training for Physicians. American Academy of Hospice and Palliative Medicine. 2003. New York: Mary Ann Liebert, Inc.

5 SECTION 5: ETHICAL AND LEGAL CONCERNS

> "While there is much legal and ethical consensus about care of the dying, some confusion and gray areas remain. Some legal barriers are more mythical than real, but many times there is a grain (or more) of truth in the myth, which is probably the reason that physicians may overestimate the legal risks of some practices."[1]

Those involved in end-of-life care share some of life's most intimate, misunderstood, and feared experiences. Near the end of life, not only patients but also those who care for them, those who provide emotional and spiritual support, and those who are involved in decision making face challenges that can lead to discord and dysfunction.

Decision making about appropriate types of treatment for patients receiving palliative and end-of-life care may result in conflicts arising from differing personal values, spiritual beliefs, or understanding of relevant medical and legal issues. Most often, these challenges or conflicts arise from miscommunication or misunderstanding rather than from complex legal or ethical dilemmas and they can often be resolved through respectful listening and education without resorting to confrontational legal or administrative interventions.

The AMDA white paper *Surrogate Decision-Making and Advance Care Planning in Long-Term Care*[2] is an excellent resource for information relevant to end-of-life care in the long-term care facility. This paper addresses many legal and ethical issues relevant to palliative and end-of-life care, including competence, decision-making capacity, methods for determining a decision maker when one has not been appointed, a framework for surrogate decision making, and cardiopulmonary resuscitation and artificial nutrition and hydration for long-term care residents.

This section offers suggestions and resources for approaching the determination of decision-making capacity and the choosing of an appropriate decision maker, responding to common myths and misconceptions about end-of-life care, identifying and resolving conflicts about treatment decisions, and keeping records of decisions.

Decision-Making Capacity

A potentially contentious issue is whether the long-term care patient with mild to moderate dementia or delirium is "competent" to make an informed decision about complex health issues. The more relevant question is whether the patient has sufficient functional decision-making capacity.

Decision-making capacity is not synonymous with competence. "A person is legally either competent or incompetent, with no gray areas in between. An adult is assumed to be competent unless he or she is determined by a court to lack the ability to make the decisions required for living safely, at which time the court deems that person incompetent."[2] All competent adults retain their legal status as competent until that status is revoked by a court, most often as part of the process of appointing a guardian.

All adults are presumed competent and retain their legal status as such unless this status is revoked in a court of law. Nevertheless, the practitioner can and should determine a person's decision-making capacity. Decision-making capacity is best thought of as a cognitive function with a spectrum that ranges from minimal to robust and that may fluctuate with illness and vary according to the type of decision concerned (e.g., financial, medical, personal).

Key steps in addressing legal and ethical issues related to decision making include the following:[3]

1. Identify existing advance care instructions (living will, advance directive, durable power of attorney for health care).

2. Assess the individual's decision-making capacity. Table 5.1 lists the core elements of an assessment of medical decision-making capacity.
3. Assess the individual for reversible conditions such as delirium or depression that may adversely affect decision-making capacity. Table 5.2 suggests questions that may help to ascertain decision-making capacity.
4. Identify an alternative decision maker if the patient lacks decision-making capacity (Table 5.3).
5. Present treatment options and probable outcomes to the decision maker.
6. Clarify the treatment choices.
7. Implement the care plan according to the decision maker's choices.
8. Resolve conflicts and problems through a deliberative process (e.g., family/team meeting, consultation with a qualified practitioner, ethics committee referral).

Table 5.4 suggests data-gathering questions for the practitioner to ask during the interview with the patient and family. Once the practitioner has interviewed the patient, it is advisable to document the patient's capacity to:[3]

- Understand the nature, extent, or probable consequences of the proposed treatment or course of treatment, or alternatives to the treatment;
- Make a rational evaluation of the burdens, risks, and benefits of treatment; and
- Effectively communicate a decision.

The practitioner should then document the patient's capacity to make the specific decision being made at the time.

Conflict Resolution

When patients, families, and care teams address decisions to limit treatment, conflicts may arise because of miscommunication or misconceptions about perceived legal and ethical barriers to limiting treatment. Once misconceptions are identified and understood, it may be possible to resolve concerns by offering relevant information (Tables 5.5, 5.6).

The process of deciding whether to limit or discontinue treatments can produce conflicts because of misunderstandings about the diagnosis, the prognosis, or the risks and benefits of receiving or refusing a particular treatment. Several types of conflict can arise in the course of caring for seriously ill patients (Table 5.7). The wise practitioner is aware of and avoids common pitfalls that can frustrate the resolution of these difficult issues (Table 5.8).

Using a stepwise approach, the practitioner can analyze the conflict and create a plan to resolve it (Table 5.9). Open-ended, nonjudgmental questioning aimed at achieving understanding can facilitate the ensuing discussion (Table 5.10).

When practitioners and families are unsure about whether to choose or forego a therapy, it may be appropriate to negotiate a time-limited treatment trial. This process implies that if the treatment does not reach the stated goals within a prospectively agreed-upon period of time, then the treatment will be discontinued. (Table 5.11).

Advance Care Directives

Once care decisions have been made, they must be recorded and the patient's wishes communicated to members of the care team. In addition to formal advance directives and living wills, it may be appropriate to document the types of decisions relevant to long-term care residents (e.g., hospital transfer for intensive care, use of cardiopulmonary resuscitation, use of a feeding tube). Appendix 5.1 is a worksheet and documentation tool that the practitioner or social worker can use to begin the discussion about advance care planning and documentation. Appendix 5.2 suggests talking points to facilitate the discussion of treatment goals and choices. Appendix 5.3 is a worksheet that the practitioner can use to guide the advance care planning discussion and to document the process and decisions reached.

The use of advance directives is governed by state law. Information specific to each state's advance-directive documents and regulations is available on the Caring Connections Web site (http://www.caringinfo.org/i4a/pages/Index.cfm?pageid=3425).

The Physician Orders for Life-Sustaining Treatment (POLST) form is an increasingly popular method for recording relevant treatment choices. This form facilitates the documentation of choices such as whether to transfer the patient to the hospital for full intensive treatment, limit the use of antibiotics to certain circumstances, use tube feeding, or attempt cardiopulmonary resuscitation. However, the POLST form is not accepted in all states. State-specific information about POLST, sample forms, and other resources are available at http://www.ohsu.edu/polst/edmat.shtml.

The *present* health care directive (Appendix 5.4) can serve as a guide for practitioners and caregivers as to the patient's current wishes (i.e., in his or her present state of health) concerning medical treatments. This document does not replace the advance health care directive (Appendix 5.5), which applies to future situations in which the patient may be unable to express his or her wishes. Both of these documents direct providers toward care that promotes the patient's own values and care goals. These documents may be updated at any time.

Advance directives are subject to state laws and regulations. Protocols that emulate statutory language may be less difficult to implement and more useful when a conflict arises. For this reason, care teams need to be aware of language or requirements specific to their state. In addition to resuscitation status and other state-directed components, documentation of the patient's wishes with regard to hospitalization or emergency department transfer provides valuable guidance to staff should a patient's condition suddenly worsen. State advance directive documents and instructions are available on the Caring Connections Web site (http://www.caringinfo.org/i4a/pages/Index.cfm?pageid=3425).

TABLE 5.1. A FRAMEWORK FOR ASSESSING CAPACITY TO MAKE MEDICAL DECISIONS

Can the person make and express personal preferences at all?
Can the person give reasons for the alternatives selected?
Are the supporting reasons rational in the sense that the person begins with a plausible idea and reasons logically from that premise to a result?
Can the person comprehend the personal implications, namely, the probable risks and benefits, of the various choices presented and selected?

Sources: Adapted from Kapp, 1994;[4] Applebaum and Grisso, 1988.[5]

TABLE 5.2. QUESTIONS THAT MAY HELP TO ASCERTAIN DECISION-MAKING CAPACITY

Domain	Suggested Questions
Ability to understand the medical problem	• Do you understand what is making you ill right now? • Do you understand why you are here (i.e., in the hospital or long-term care facility)?
Ability to understand treatment options	• Do you understand that the treatment is for the problem that is making you ill? • Is there more than one way to treat the problem you have?
Ability to understand the right to refuse or stop treatment	• Do you understand that you can say no if you don't want this treatment? • Do you understand that you can ask for treatment to stop if you decide you no longer want it?
Ability to understand the possible consequences of treatment	• Do you understand what could happen to you if you have this treatment? • Do you understand how the treatment could help you? • Do you understand that the treatment could cause side effects?
Ability to understand the possible consequences of refusing treatment	• Do you understand what could happen to you if you decide not to have this treatment?
Ability to make a rational decision	• Can you tell me why you have decided to have (or to refuse) this treatment? • Do you think that we are trying to help you or to harm you?
Absence of cognitive signs of depression	• Do you feel you are being punished? • Do you feel you are a bad person?

Source: Adapted from Etchells et al, 1999.[6]

TABLE 5.3. HIERARCHY OF MEDICAL DECISION MAKING FOR INCAPACITATED PATIENTS

Advance directives specified by the patient before he or she became incapacitated prevail, even over the contrary wishes of guardians and other surrogate decision makers.

The decisions of the guardian or of a surrogate designated in an advance directive prevail over all others except in the presence of a written advance directive.

Decisions of surrogates, including guardians, should be guided by:

- Substituted judgment (if the incapacitated person's wishes were known but not formalized in an advance directive)
- Best interest of the patient, based on clinical evidence, prognosis, life expectancy, risk and benefit of proposed treatments, comfort, and dignity

Family members and friends take precedence next, usually in the following order:

- Spouse
- Adult children
- Siblings
- Other family members
- Friend
- Health care providers, in the absence of other decision makers (not optimal)

Source: AMDA, 2003.[2]

TABLE 5.4. DATA-GATHERING QUESTIONS FOR PHYSICIANS

Ask the Family:
What do you understand about what is going on?
Why have you decided to ______________?
What are you hoping we can accomplish/achieve?
What do you think ________________ would want us to accomplish for him/her?
What else would he/she want us to accomplish?
Which of these are the most important?
In what situations, if any, could you imagine ______________ not wanting to continue to live?
Are your questions getting answered? Do you have concerns about the care you/your loved one is getting?
Are there disagreements among family members?

Ask yourself:
What do I think are this patient's chances of surviving to discharge/recovering function?
What have I told the patient/family are his/her chances of surviving to discharge/recovering function?
How sure am I about his/her prognosis? On what is it based?
What do I know about what this patient wants (or would have wanted)? How do I know? How sure am I?
Is this patient competent to make his/her own decisions? How do I know? How sure am I?
Could it be fluctuating or reversible incompetence?
Did I/we contribute to a bad outcome in any way (eg, missed diagnosis, delayed treatment)?
How do I feel about discussing this patient's death with him/her (his/her family)?
Who is this patient's "family doctor"? Clergy of choice? Primary nurse? Social worker?
What words or phrases have I (or others) used that might be contributing to the conflict (eg, "stopping treatment," "comfort measures only," "hopeless," "certain")?
What aspect(s) of this patient's life do I feel justify withholding or withdrawing life-sustaining treatment?
Does the family trust us? If not, why not?

Ask about social/organizational influences:
Are there financial pressures on the family?
Are there financial pressures on the hospital?
Are there financial pressures on the medical team?
Are families allowed to see what the patient's day is like?
Are there any concerns about malpractice or legality?
Are there cultural or religious differences among the patient/family/physicians/hospital?

Source: Goold et al, 2000.[7] Reprinted with permission.

TABLE 5.5. CURRENT LEGAL MYTHS AND REALITIES

Myth	Reality
Foregoing life-sustaining treatment for patients without decision-making capacity requires evidence that this was patient's actual wish	Such treatment may be forgone if the patient's surrogate relates that this was the patient's actual wish or, in most states, if it was the patient's probable wish. Only a few states require "clear and convincing" evidence of patient wishes. In a few states, it is even permissible to terminate life support if the patient's wishes are not known, if termination of treatment is in the patient's "best interests."
Withholding or withdrawing of artificial fluids and nutrition from terminally ill or permanently unconscious patients is illegal.	Like any other medical treatment, fluids and nutrition may be withheld or withdrawn if the patient refuses them or, in the case of an incapacitated patient, if the appropriate surrogate decision-making standard is met.
Risk management personnel must be consulted before life-sustaining medical treatment may be terminated.	There is no legal requirement that a risk manager be consulted before making end-of-life decisions though some hopsital policies may require it.
Advance directives must comply with specific forms, are not transferable between states, and govern all future treatment decisions. Oral advance directives are unenforceable.	Advance directives, often the best indication of an incapacitated patient's wishes, may guide end-of-life decision making even if all legal formalities are not met. A living will or surrogate should not be consulted if the patient retains decision-making capacity unless expressly authorized by the patient. Oral statements previously made by the patient can also be legally valid advance directives.
If a physician prescribes or administers high doses of medication to relieve pain or other discomfort in a terminally ill patient, resulting in death, he/she will be criminally prosecuted.	If a patient inadvertently dies from the use of high doses of medication intended to treat pain, the physician has not committed murder or assisted suicide.
When a terminally ill patient's suffering is overwhelming despite palliative care, and he/she requests a hastened death, there are no legally permissible options to ease suffering.	Although physician-assisted suicide is illegal in most states, terminal sedation is a legal option to treat otherwise intractable symptoms in the imminently dying.
The 1997 Supreme Court decisions outlawed physician-assisted suicide.	Physician-assisted suicide is currently legal in Oregon. Other states are free to legalize or prohibit it.

Source: Meisel et al, 2000.[1] Reprinted with permission.

TABLE 5.6. STATUS OF PREVIOUSLY IDENTIFIED LEGAL MYTHS

Myth	Current Status
There must be a law authorizing the termination of life support.	Currently existing law supports the termination of life support in all 50 states for both competent patients and for those who have lost capacity if there is consensus among those who care about the patient that it would be the patient's will or in his/her best interests.
Termination of life support is murder, assisted suicide, or suicide.	Termination of life support is considered to be freeing the patient from unwanted bodily invasion. Death is legally considered to be a result of the patient's underlying disease. The law clearly distinguishes such acts from suicide, assisted suicide, or euthanasia.
A patient must be terminally ill for life support to be stopped.	The law allows any patient to refuse any treatment that he/she does not want, in the interest of protecting bodily integrity, even if that treatment would be life sustaining and the patient is not terminally ill.
It is permissible to terminate extraordinary treatments, but not ordinary ones.	The distinction between ordinary and extraordinary treatments is not relevant as a matter of law or ethics. The patient has the right to terminate any treatment, potentially life sustaining or not.
It is permissible to withhold treatment, but once started, it must be continued.	Although many clinicians think and feel differently about these types of actions, the law and medical ethics treat the withholding and the cessation of life-sustaining treatment the same.
Stopping artificial nutrition and hydration is legally different from stopping other treatments.	In most states, artificial hydration and nutrition are considered medical treatments like any other.*
Termination of life support requires going to court.	The courts generally want clinicians to make these decisions without going to court, provided there is a consensus among those who care about the patient about how to proceed.*
Living wills are not legal	Living wills have legal support in all 50 states, either through legislation or case law.*

*See 'Myth 2' section for further explanation.

Source: Meisel et al, 2000.[1] Reprinted with permission.

TABLE 5.7. COMMON EXAMPLES OF CONFLICT

COMMON EXAMPLES OF CONFLICT	
Family vs Clinician	
Son prefers life-sustaining treatment for patient	Physician thinks life-sustaining treamtent would increase patient suffering
Husband is uncertain about patient's wishes	Physician finds the husband is inconsistent when discussing patient's wishes
Husband does not trust that clinician is acting in patient's best interests	Nurse thinks family is not acting in patient's best interests
Wife does not believe prognosis given by clinicians	Physician believes wife is in denial
Clinician vs Clinician	
Specialist physician wishes to continue interventions targeted at disease	Palliative physician wishes to focus on quality of life and patient goals
Physician wants to continue life-sustaining treatment based on small chance of cure	Nurse wants to focus on quality of life based on large chance of treatment failure
Physician thinks that medical decisions are his/her responsibility	Nurse thinks his/her input is excluded from decision making
Attending physician gives resident increasing responsibility	Nurse thinks that resident decisions are inadequately supervised.
Family vs Family	
Daughter thinks she knows patient wishes best	Son thinks medical options have not been exhausted
Wife has come to accept her husband's imminent death	Daughter has just arrived from out of town, insists on not giving up
Patient vs Clinician	
Patient wants to try another chemotherapy regimen	Physician thinks that more chemotherapy is futile
Patient wants to live independently	Physician thinks patient's debility requires assisted living

Source: Back and Arnold, 2005.[8] Reprinted with permission.

TABLE 5.8. PITFALLS IN HANDLING CONFLICT: BEHAVIORS TO AVOID WHEN DEALING WITH CONFLICT

Pitfall	Consequences
Avoiding or denying conflict	Issue may percolate, become worse; in long term, avoidance or denial creates perception of lack of leadership
Assuming that you know the whole story	Misses opportunity to improve mutual understanding
Repeatedly trying to convince the other party	Misses opportunity to understand true concerns and annoys the other person, who may stop listening
Assuming you know the other party's intentions	Labeling other party's character rather than focusing on behavior leads you to view him/her as inflexible
Holding the other party responsible for fixing the issue	Resolution more difficult unless both parties take responsibility for finding reasonable outcome
Proceeding as if the issue can be settled rationally or based on evidence	Ignores emotions that have been triggered by conflict
Declaring other party as ethically questionable	Condescending and potentially insulting to other party
Using anger or sarcasm as coercive threat	Creates resentment and undermines trust in relationship
Ignoring one's own strong emotions	Emotions tend to leak out and become obvious to other party and may complicate negotiation
Proceeding in the heat of the moment	Strong emotions tend to narrow perspective and reinforce existing conflict

Source: Back and Arnold, 2005.[8] Reprinted with permission.

TABLE 5.9. A STEP-WISE APPROACH TO ADDRESSING CONFLICTS

Step	Self-assessment Questions	What to Say to a Family
1. Notice the conflict	Am I feeling angry, or irritated, or bored, or having my usual response to conflict?	This is an internal reflective step
2. Prepare yourself		
Get into a “ready to negotiate” state of mind	Am I too angry to listen fully? Am I still rehearsing why I’m right? Am I feeling punitive?	This is an internal reflective step
Examine the 3 stories.[11]	What happened? What are my feelings? How does this involve my identity?	This is an internal reflective step
Decide on the purpose of working through the conflict	What are the consequences of not addressing this conflict? What are my needs that should be addressed in dealing with this?	This is an internal reflective step
3. Find a nonjudgmental starting point for the conversation	What would an impartial third person say that this conflict is about?	“Let’s start with the big picture about what we are hoping for in Mrs X’s situation.”
4. Reframe emotionally charged issues	How can I describe the issue so that it is something that we both need to work together on? Am I moving back into the me against you stance?	For a lot of people, providing food is a way of showing love. If that’s part of the issue, let’s talk about other ways you can do that.” I don’t think of withholding intravenous fluid as starvation. It’s a medical treatment that isn’t always good for someone who is in the last phase of life.”
5. Respond empathetically	Have I given explicit feedback that shows that I understand how the other person is feeling?	“I know that you would never want to feel that you were starving your mother. These decisions definitely require a lot of thought.”
6. Look for options that meet the needs of both parties	Does this option address the other person’s concerns? Does this option address my concerns?	“How about if I describe a treatment trial and you can tell me your reactions, both positive and negative?”
7. If no satisfactory agreement can be reached, get help	What resources exist to help us negotiate?	“I think it would be helpful to have another impartial person help us

Source: Back and Arnold, 2005.[8] Reprinted with permission.

TABLE 5.10. USEFUL COMMUNICATION TOOLS FOR ADDRESSING CONFLICT

Tool	Useful Phrases
Active listening: Turn full attention to speaker rather than focusing on your own concerns or on counterarguments and provide feedback showing that you have understood	"What I'm hearing you say is that you want us to do everything possible to prolong your father's life" "It sounds like you are concerned about this patient's suffering being made worse."
Self-disclosure: Reveal to listener some aspect of how you are feeing without blaming the other party for your emotions	"I am worried that even the best medical care will not be able to achieve your hopes." "I need a few minutes to cool off because I'm irritated; but later we need to talk about the next steps."
Explaining: Provide listener with information about which aspects of the situation you are most concerned about	My view of this situation is that providing intravenous fluid would give her, at best, a 50-50 chance of improving."
Empathizing: Provide listener with evidence that you understand his emotional state	"I can see that you care a great deal about what happens to your mother." "This just feels like a sad situation." "I think anyone would feel as worried as you given the circumstances."
Reframing: Describe situation as a mutual problem to be solved collaboratively	Now I think we should look at the issue of intravenous fluid as not just 'Do we do it?' but as part of the bigger picture of her care."
Brainstorming: Propose potential solutions without critiquing them as a first step in problem solving	"Let's try to come up with a few ideas about how to prepare for her death and then pick a few to work on."

Source: Back and Arnold, 2005.[8] Reprinted with permission.

TABLE 5.11. NEGOTIATING A TREATMENT TRIAL

What to do	What to Talk About
1. Include all the relevant people: patient, family, staff in discussion	How the treatment can meet the patient's values and goals
2. Define the purpose of the trial, and the treatment intervention	Procedures, monitoring, adverse effects, time to likely response
3. Discuss milestones	Parameters that will be monitored and how they relate to treatment response Milestones that are evidence of improvement
4. Discuss treatment success	What treatment success would look like, from the patient's pont of view What treatment failure would look like
5. Check reactions of patient, family, or both to the treatment trial	How they are feeling now How they might feel if the treatment worked, and if it failed Emphathize—common issues are anxiety related to uncertainty, sadness about the patient's situation, frustration at lack of improvement
6. Document steps 1 through 5 of the trial (above) in the chart.	Mention to the family that you will be sharing the purpose of the trial and other details with other clinical staff

Source: Back and Arnold, 2005.[8] Reprinted with permission.

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APPENDIX 5.1. ADVANCE CARE PLANNING-SOCIAL SERVICE FAMILY INTAKE SHEET

Resident's Name: ____

Living arrangements prior to admission: Independent/Own home With family

Nursing Facility Independent Living Assisted Living

Comments: ____

Anticipated outcome of stay: Long-term Short-term

Overall goal: Curative therapy Restorative therapy Palliative care

Durable power of attorney: ____

Durable power of attorney for health care: ______________________________

Principal caregiver: ____

Living will: Yes No

DNR-CC form in place: Yes No

Is the resident able to make complex medical decisions about life-sustaining treatments:
Yes No

Comments: ____

If resident has not completed DNR-CC:
Has resident ever expressed his/her wishes regarding treatment? Yes No

Options: ____ Family is unable to make decision/ needs more information

____ Resident would like to be a Full Code

____ Resident would like to be a DNR

SUMMARY:

____
____
____
____
____
____
____

DNR-CC: Do not resuscitate - comfort care

Source: William D. Smucker, MD, CMD, Altenheim Nursing Home, Strongsville, Ohio.

APPENDIX 5.2. ADVANCE CARE PLANNING-SOCIAL SERVICE FAMILY INTAKE SHEET: TALKING POINTS

Starting the conversation	We want to be able to provide the best care for [patient]. To do this, we need you to help us understand his or her values. We need to know what you know about • Your loved one's condition, • His or her ability to make medical decisions • His or her treatment goals of therapy • Any prior advance care planning decisions and documents
Understanding the patient's condition	What do you know about the patient's current condition? How did you find out? What important medical and psychological conditions does he or she have? What do you think is likely to happen in the next several months or year? What are you hoping will happen? What are you hoping we can do for your loved one? What are you most worried about?
Treatment goals	What is the most important thing from here on out? (Cure, return home, regain prior level of function, maintain current function, control symptoms, relieve suffering, maintain dignity, prolong life) What is the overall goal of care? If the patient cannot regain his or her prior mental abilities, physical function, or independence, would that change the goals of treatment?
Decision-making capacity	Does the patient have any problems with memory or judgment? Can he or she manage money and medications without supervision? Is the patient currently able to understand his or her medical condition? Can he or she understand the benefits and burdens (pros and cons) of different medical treatments? If not currently able, do you think the patient is likely to regain his or her ability to make complicated decisions about medical treatments? If the patient is not able, who should make decisions for him or her now? Does the patient have a Durable Power of Attorney for Health Care?
Treatment choices	Has the patient ever talked to you about his or her wishes or treatment choices if he or she became seriously ill? Has he or she stated his or her wishes about specific treatments like CPR or tube feeding? Does the patient have a living will? Has the patient completed a Do Not Resuscitate form?

CPR: cardiopulmonary resuscitation.

Source: William D. Smucker, MD, CMD, Altenheim Nursing Home, Strongsville, Ohio.

APPENDIX 5.3. PRACTITIONER ADVANCE CARE PLANNING FORM

Patient Name ______________________________

Family contact, power of attorney, durable power of attorney for health care

Name

____

Relationship

____

Phone #

____

Hospital of choice

____

Hospital physician of choice

____

Patient's decision-making capacity:
Is the patient able to make complex medical decisions about life-sustaining treatments?
☐ Yes ☐ No
If NO, reason: ☐ Dementia ☐ Aphasia ☐ Psychosis ☐ Other

____

Health care decision maker

____

Advance care planning discussion
People present for discussion
______________________________ Date __________

Advance directives:
☐ Patient verbalized wishes prior to incapacity
☐ Living will ☐ Durable power of attorney for health care

Diagnoses of progressive medical illnesses discussed:
☐ Dementia ☐ COPD ☐ CHF ☐ Renal disease ☐ Cancer
☐ Stroke/atherosclerosis ☐ Diabetes ☐ Parkinson's ☐ Other

____

Diagnoses and potential medical complications associated with progressive decline discussed:
☐ Dementia, COPD, CHF, stroke, cancer, Parkinson's
☐ Unsafe or inadequate intake of nutrition & fluid, resulting in:
  ☐ Functional decline ☐ Recurrent pneumonia ☐ Pressure sores ☐ Terminal dehydration
  ☐ Pros and cons of artificial nutrition and hydration discussed

APPENDIX 5.3. PRACTITIONER ADVANCE CARE PLANNING FORM (CONTINUED)

☐ CHF, atherosclerosis, stroke, advanced age:
  ☐ Cardiac arrest ☐ MI ☐ CHF recurrence ☐ Stroke
  ☐ CPR efficacy <1:1K success with normal mental and physical function due to age, comorbidities

Life-sustaining treatment choices
☐ Full code ☐ 911 for TIA or stroke
☐ Full medical management in hospital, but no ICU care
☐ **Trial of intensive care, including mechanical ventilation for ____ (days/weeks) but discontinue if treatment is unlikely to result in benefits such as:**
____
(independence, current cognitive or physical function, etc)

☐ DNR / No CPR because unlikely to return to current level of function, unlikely to be effective.
☐ No tube feeding because of prior wishes, benefit unlikely, quality of life would be low.
☐ No transfer to hospital ☐ No ICU treatment ☐ No mechanical ventilation

Rationale for decisions
____
____
____
____
____

CHF: congestive heart failure; COPD: chronic obstructive pulmonary disease; CPR: cardiopulmonary resuscitation; DNR: do not resuscitate; ICU: intensive care unit: MI: myocardial infarction; TIA: transient ischemic attack.

Source: William D. Smucker, MD, CMD, Altenheim Nursing Home, Strongsville, Ohio.

APPENDIX 5.4. EXAMPLE OF A PRESENT HEALTH CARE DIRECTIVE

Participant Name:____ MR #: ________________

As long as I remain substantially similar to my present conditions as of this date, and if I am not determined to have a terminal or incurably incapacitating condition, then my general wishes for care now, should I need emergency, acute, or routine medical care, are

General wishes (Pathway)

____ Prolong life; treat everything, including CPR and 911 (Longevity Path)
____ Treat and attempt to cure if my recovery is likely, but reassess often (Function Path)
____ Limit to less invasive and less burdensome treatments (Function Path)
____ Provide comfort care only, no CPR, no 911, no hospitals (Palliation Path)
____ Other: ____

Specific wishes (Complete only for exceptions to general wishes)

Please initial appropriate boxes: (When updating, line out the old mark AND initial/date the new choice.)	**I want**	**I want to try treatment, but stop if no clear improvement.**	**I do not want**
Cardiopulmonary resuscitation (CPR—chest compressions, and mechanical breathing to revive a person who is at the point of dying.)		Not applicable	
Major surgery (for example, cardiac bypass, removing the gall bladder or part of the colon)		Not applicable	
Mechanical breathing (breathing by machine with a tube in the throat, except for surgery and CPR.)			
Hospital admission, for tests and treatments			
Chronic kidney dialysis (cleaning the blood by machine or fluid passed through the belly).		Not applicable	
Blood transfusion or blood products		Not applicable	
Artificial nutrition and hydration (given through a tube in the vein or stomach)			
Simple diagnostic tests (blood tests or x-rays.)		Not applicable	
Antibiotics (drugs to fight infections)			
Comfort measures (including medications and treatments to relieve suffering near the end of life)		Not applicable	

☐ I wish medical information to be shared with ___ the participant/self only; ___ the family only; ___ both the participant/self and family.

☐ I decline to complete this healthcare directive at this time.

Plan of Care updated to reflect above
Date ___________
SW Initial _______
This Directive reviewed by PCP: _______

Date ______ Signature of Participant or Proxy ____

Date ______ Signature of Witness ____

Date ______ Signature of Witness ____

Sources: Adapted with permission from Alexian Brothers Community Services.

Schamp RO, Tenkku L. Managed death in a PACE: Pathways in present and advance directives. J Am Dir Assoc 2006; 7: 339-344.

APPENDIX 5.5. EXAMPLE OF AN ADVANCE HEALTH CARE DIRECTIVE

Participant Name:____ MR #: ________________

If I am in a coma or a persistent vegetative state or other condition of persistent unconsciousness or terminal illness or incurably incapacitating condition, and, in the opinion of my physician and another healthcare provider, I have no known hope of regaining higher functions no matter what is done, then my general and specific wishes for this and any additional illness would be

General wishes (Pathway)

____ Prolong life; treat everything, including CPR and 911 (Longevity Path)
____ Treat and attempt to cure if my recovery is likely, but reassess often (Function Path)
____ Limit to less invasive and less burdensome treatments (Function Path)
____ Provide comfort care only, no CPR, no 911 (Palliation Path)
____ Other: ____

Specific Wishes (complete only for exceptions to general wishes)

Please initial appropriate boxes: (When updating, line out the old mark AND initial/date the new choice.)	**I want**	**I want to try treatment, but stop if no clear improvement.**	**I do not want**
Cardiopulmonary resuscitation (CPR—chest compressions, and mechanical breathing to revive a person who is at the point of dying.)		Not applicable	
Major surgery (for example, cardiac bypass, removing the gall bladder or part of the colon)		Not applicable	
Mechanical breathing (breathing by machine with a tube in the throat, except for surgery and CPR.)			
Hospital Admission, for tests and treatments			
Chronic kidney dialysis (cleaning the blood by machine or fluid passed through the belly).		Not applicable	
Blood transfusion or blood products		Not applicable	
Artificial nutrition and hydration (given through a tube in the vein or stomach)			
Simple diagnostic tests (blood tests or x-rays.)		Not applicable	
Antibiotics (drugs to fight infections)			
Comfort measures (including medications and treatments to relieve suffering near the end of life)		Not applicable	

☐ I wish medical information to be shared with ___ the participant/self only; ___ the family only; ___ both the participant/self and family.

☐ I decline to complete this healthcare directive at this time.

Plan of Care updated to reflect above
Date ___________
SW Initial _______
This Directive reviewed by PCP: _______

Date Signature of Participant or Proxy

______ ____

Date Signature of Witness

______ ____

Date Signature of Witness

______ ____

Sources:
Adapted with permission from Alexian Brothers Community Services.

Schamp RO, Tenkku L. Managed death in a PACE: Pathways in present and advance directives. J Am Dir Assoc 2006; 7: 339-344.

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6 SECTION 6: QUALITY ASSURANCE

“But let us never forget: while death is inevitable, dying badly is not.”[1]

Long-term care providers are accustomed to monitoring and responding to quality indicators that track adverse outcomes or focus on preserving or improving the functional status of long-term care residents. Obviously, many long-term care residents have limited life expectancies as the result of advanced medical conditions with an expected course of further decline and death. The goals of care for such patients differ from those for patients with non-life-threatening acute or chronic illnesses.

To address this issue, several organizations have proposed process and outcome indicators specific to palliative and end-of-life care in the long-term care facility. These indicators may be used to assess current performance and guide quality improvement activities. The medical director can exercise medical leadership in the facility’s Continuous Quality Improvement program by promoting the monitoring of process and outcomes of care relevant to palliative and end-of-life care. This section catalogs some of the most relevant quality indicators.

A National Institutes of Health consensus conference on improving end-of-life care arrived at several conclusions that are relevant to residents of long-term care facilities:[2]

- No precise definition exists to identify the transition to end-of-life, but it may generally be considered to be defined by:
  - The presence of one or more chronic illnesses,
  - Symptoms or persistent functional impairments that require assistance with care or can lead to death, and
  - Older age and frailty, which may be surrogates for life-threatening illness.
- Communication among patients, families, and providers is crucial to high-quality end-of- life care.
- Measures designed for cancer victims at the end of life may not be valid when applied to elderly patients with chronic illness.
- Tools for measuring the quality of end-of-life care and evaluating outcomes have not been validated in patients with dementia.
- Current end-of-life care includes some untested interventions that need to be validated.
- Many measures may not be useful among persons with severe cognitive or communication disorders.

Thompson and McClement identified the following major elements of a “good death” and of high-quality end-of-life care:[3]

- Effective pain and symptom management,
- Clear decision making,
- Preparation for death,
- Completions (e.g., life review, saying goodbye, resolving conflicts, spending time with family and friends),
- Contributions to others (e.g., giving gifts or time, imparting knowledge),
- Affirmation of the whole person,
- Avoidance of inappropriate prolongation of dying,
- Achievement of a sense of control,
- Relieving burden, and
- Strengthening of relationships with loved ones.

The American Geriatrics Society in 1997 noted that no method existed to measure the quality of care at the end of life, but suggested 10 pertinent domains to guide the creation of performance standards:[4]

- Physical and emotional symptoms;
- Support of function and autonomy;
- Advance care planning;
- Aggressive care near death – site of death, cardiopulmonary resuscitation, and hospitalization;
- Patient and family satisfaction;
- Global quality of life;
- Family burden;
- Survival time;
- Provider continuity and skill; and
- Provision of bereavement services to family members.

This section provides examples of tools specifically designed to assess the processes and outcomes of end-of-life care in nursing homes (Appendixes 6.1, 6.2), which serve as a starting place for measuring a facility's current practices and informing quality improvement.

In addition to facility-based assessments, instruments exist that measure the individual practitioner's performance in end-of-life care (Appendix 6.3). Examples of process and outcome measures that could guide medical directors interested in not only improving palliative care but also assessing effective collaboration with hospice organizations are listed in Appendix 6.4.

Advocates of quality improvement in palliative care recommend, in addition to choosing what to measure, addressing the educational needs of both caregiving and administrative staff and considering targeted education for key practitioners. Success in quality improvement is most likely when organizations use rapid Plan-Do-Study-Act (PDSA) cycles based on measures that can answer questions of interest and importance to the facility (e.g., is pain assessed and controlled in patients who are near the end of life?). The PDSA should set a specific goal (e.g., 80% of patients with pain will have their pain reduced to less than 4 on a scale of 10 within 48 hours) and decide on the "who, what, when, and how" of data collection to measure progress toward the goal. Tools exist to help facilities new to the PDSA process get started (Appendix 6.5).

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APPENDIX 6.1. MEDICAL CHART REVIEW OF RESIDENT DEATH

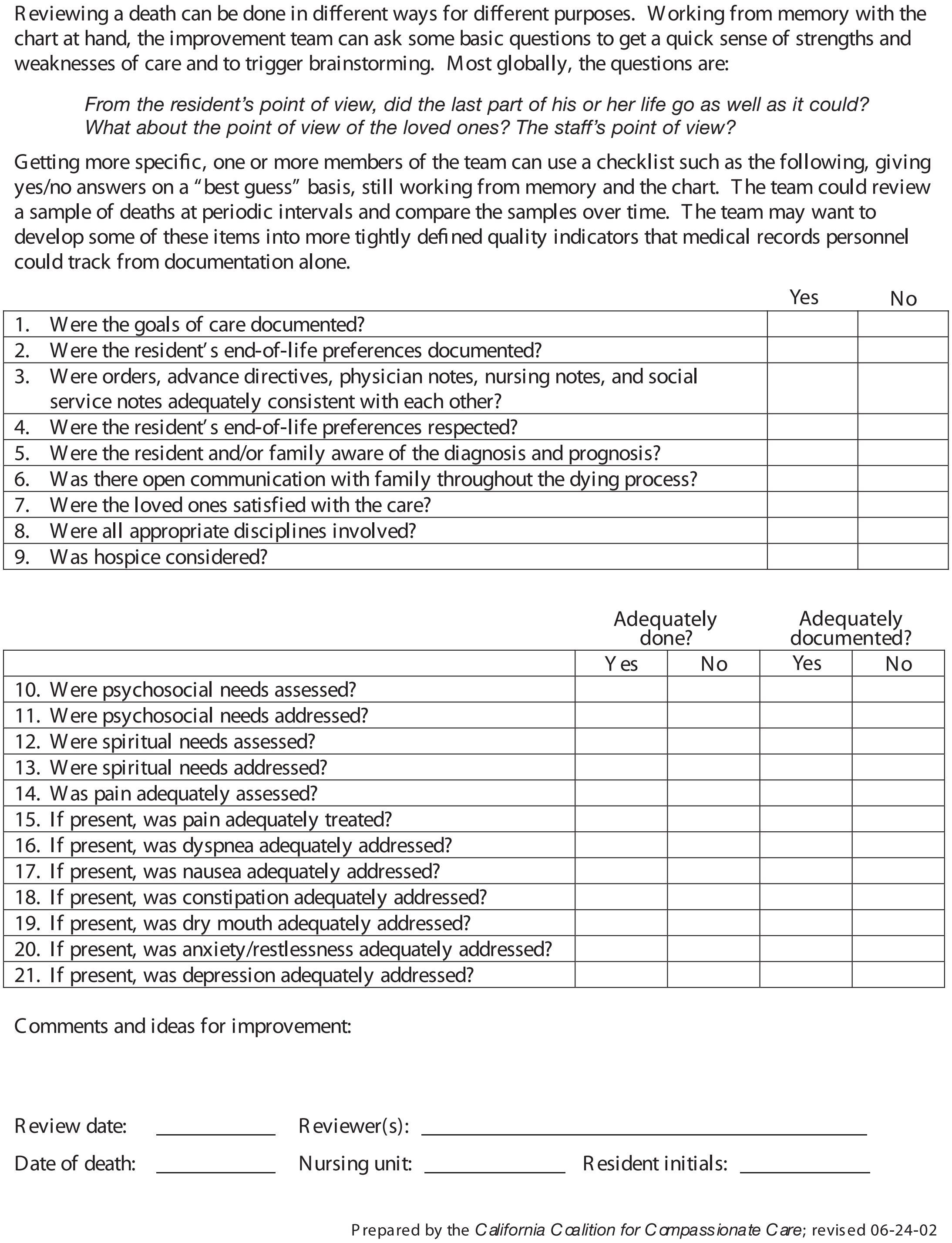
Instructions: Complete following each resident death. Indicate Y if answer is yes, N if answer is no, or U if unknown, as appropriate. Present to care team and Medical Director for review within one week of death. Review current chart for the last 6 months of customer stay. Accumulate data and review in monthly or quarterly QI meetings.

Resident Initials	**Social Security Number**	
Date of Death (mm/dd/yy)		
Date of Admission		**Chart Location of Data**
	Y/N/U	
On most recent MDS or care plan was resident anticipated for discharge to community (home/ ALF/ boarding home)?		Last MDS, care plan
Did resident experience serious clinical event or injury in the month prior to death (fall, abuse, sepsis, malnutrition, medical procedure, stage 4 pressure ulcer?)		Clinical notes, diagnoses, incident reports
Did resident complete an advance directive (living will or designated decision maker)?		Certification section
Was resident documented to lack capacity to make health care decisions?		Certification section
Was resident certified by physician to have terminal or end-stage illness?		Certification section
Did physician document discussion of advance care plan with resident/family?		Clinical notes
Principle cause of death or main diagnosis: cancer (**C**), non-cancer (**NC**) or Alzheimer's or other dementia (**A**)		Clinical notes, Admission Hx
Orders limiting medical intervention at time of death?		
Do-Not-Resuscitate		Order sheet
Do-Not-Hospitalize		Order sheet
No artificial nutrition or hydration		Order sheet
Comfort measures or Palliative Care		Order sheet
Was CPR begun?		Order sheet
Location of Death: **H** = Hospital **ER** = Emergency Room **NC** = Nursing Center		Discharge note
Was resident admitted to Hospice care?		Discharge note
Was resident sent to ER or hospital in last month of life?		Clinical note, orders
Was resident complaining of pain in last two weeks of life?		Clinical notes
Was resident treated for pain in last two weeks of life?		MAR, Order sheet
Did care plan address Hospice referral, bereavement or resident/family spiritual concerns related to dying process?		Care plan
Family satisfied with care resident received at end of life?		Clinical notes

ALF: Assisted Living Facility; CPR: cardiopulmonary resuscitation; MAR: Medication Administration Record; MDS: Minimum Data Set; QI: quality improvement.

Source: Created by and printed with permission of Howard Tuch, MD.

APPENDIX 6.2. CHECKLIST REVIEW FOLLOWING AN EXPECTED DEATH



Reviewing a death can be done in different ways for different purposes. Working from memory with the chart at hand, the improvement team can ask some basic questions to get a quick sense of strengths and weaknesses of care and to trigger brainstorming. Most globally, the questions are:

> *From the resident's point of view, did the last part of his or her life go as well as it could? What about the point of view of the loved ones? The staff's point of view?*

Getting more specific, one or more members of the team can use a checklist such as the following, giving yes/no answers on a "best guess" basis, still working from memory and the chart. The team could review a sample of deaths at periodic intervals and compare the samples over time. The team may want to develop some of these items into more tightly defined quality indicators that medical records personnel could track from documentation alone.

	Yes	No
1. Were the goals of care documented?		
2. Were the resident's end-of-life preferences documented?		
3. Were orders, advance directives, physician notes, nursing notes, and social service notes adequately consistent with each other?		
4. Were the resident's end-of-life preferences respected?		
5. Were the resident and/or family aware of the diagnosis and prognosis?		
6. Was there open communication with family throughout the dying process?		
7. Were the loved ones satisfied with the care?		
8. Were all appropriate disciplines involved?		
9. Was hospice considered?		

	Adequately done?		Adequately documented?	
	Yes	No	Yes	No
10. Were psychosocial needs assessed?				
11. Were psychosocial needs addressed?				
12. Were spiritual needs assessed?				
13. Were spiritual needs addressed?				
14. Was pain adequately assessed?				
15. If present, was pain adequately treated?				
16. If present, was dyspnea adequately addressed?				
17. If present, was nausea adequately addressed?				
18. If present, was constipation adequately addressed?				
19. If present, was dry mouth adequately addressed?				
20. If present, was anxiety/restlessness adequately addressed?				
21. If present, was depression adequately addressed?				

Comments and ideas for improvement:

Review date: ____________ Reviewer(s): ____

Date of death: ____________ Nursing unit: ______________ Resident initials: _____________

Prepared by the *California Coalition for Compassionate Care*; revised 06-24-02

Source: California Coalition for Compassionate Care. Checklist review following an expected death. 2002. Available at: http://www.finalchoices.calhealth.org/C4_textfiles/Checklist_Review_2002.pdf [accessed 1/24/07]

APPENDIX 6.3. PERFORMANCE MONITORING OF PHYSICIANS' CARE OF TERMINALLY ILL PATIENTS

Monitoring of the following indicators will give an indication of the performance of a particular physician in a particular nursing home:

Indicator	Performance Standard	Exceptions
Documentation of patient's wishes or advance directive is present	100%	Patient was always incapacitated and without advance directive or legal proxy
If terminally ill patient is reported to be in pain, this is addressed by the physician and active attempts are made to reduce pain	100%	Minor pain symptoms in cognitively intact patient
Dyspnea, if present, is addressed and attempts are made to minimize it	100%	Physician not made aware of dyspnea
If patient has pain, this is followed to assess results of intervention and pain is reduced	>80%	Intractable pain even after consultation
Uncomfortable symptoms are addressed and attempts are made to reduce symptoms	>80%	Untreatable symptoms; physician not notified of symptoms
Psychological or social support is documented in the patient's medical record	>80%	Patient death within a few hours of being declared terminally ill; patient cognitively impaired and family or friends are not reasonably available
Interventions not wanted by the patient are not performed	>80%	Conflicting patient directives
Hygiene status is noted by the physician	Variable option	
Family/patient counseling by physician	Variable option	
Follow-up/ bereavement counseling is offered by the physician	Variable option	

Source: Adapted from Keay TJ, Fredman L, Taler GA, et al. Indicators of quality medical care for the terminally ill in nursing homes. J Am Geriatr Soc 1994; 42: 853-860.

APPENDIX 6.4. EXAMPLES OF INDICATORS TO GUIDE PALLIATIVE AND HOSPICE CARE QUALITY IMPROVEMENT

Palliative Care Quality Measurement

The purpose of monitoring relevant processes is to identify areas for improvement and set benchmarks for quality. Because so many long-term care patients have palliative care needs, the Quality Assurance Committee may choose to monitor multiple elements of palliative care processes and outcomes for all residents in the facility, not just those enrolled in hospice. Indicators specific to hospice patients may measure effectiveness of collaboration and cooperation between the facility and the hospice provider.

Examples of quality measures within the domains of palliative and hospice care include

Indicator	Goal	Measures
Control of pain and non-pain symptoms	Assessment and control of pain and non-pain symptoms	– Percentage of those assessed for pain or other distressing symptoms whose symptoms were controlled in the 1-month, 1-week, and 48-hour time periods before death – Percentage of families reporting good control of pain, dyspnea, agitation, and other distressing symptoms in the past month, week, and 48 hours of life
Advance care planning	Timely discussions with patients and families about advance care planning documents such as durable power of attorney for health care, living wills, and do-not-resuscitate orders	– Percentage of advance care planning discussions recorded within 60 days of admission – Percentage of advance care plans that specify goals of care beyond DNR – Percentage of patients with documentation of discussion of diagnoses, prognosis, and goals of care – Percentage of families reporting that advance care plans and end-of-life wishes were honored
Site of end-of-life care	To provide end-of-life care within the facility when possible	– Percentage of deaths occurring in the facility – Percentage of deaths that were anticipated and had a palliative care plan
Emotional and spiritual support for patients and families	To provide emotional, spiritual, and bereavement support to patients and families of patients with palliative care needs and those in the last months of life	– Percentage of residents or families who report an assessment of their emotional and spiritual needs – Family satisfaction with emotional and spiritual support provided – Percentage of families offered bereavement care – Percentage of families satisfied with bereavement care – Percentage of charts with documentation of bereavement needs assessment and care provided – Percentage of families who report respectful, clear, and timely communication with physician, nurses, and other caregivers about the dying resident
Utilization of and satisfaction with hospice and palliative care programs	To provide timely access to palliative care and hospice consultation that improves quality of life for patients	– Percentage of residents or families reporting being offered a hospice or palliative care referral – Family satisfaction with the care the patient received from the hospice team – Family satisfaction with emotional, spiritual, and bereavement support for the family
Collaboration between the facility and the hospice program	To ensure optimum communication and cooperation between facility staff and hospice staff	– Percentage of facility caregiving staff reporting being asked for input to the hospice care plan – Percentage of facility staff reporting that they maintained meaningful roles in the care provided to the patient – Percentage of facility staff reporting timely educational support from hospice staff – Percentage of facility staff reporting timely and effective assessment of the patient when needed – Percentage of facility staff reporting clear and timely communication of the hospice care plan

DNR: do not resuscitate.

Source: William D. Smucker, MD, CMD, Altenheim Nursing Home, Strongsville, Ohio.

APPENDIX 6.5. PROCESS IMPROVEMENT WORKSHEET

Question	Topics
What area/practice/process do we want to improve?	• Advance care planning, ethics, communication, IDT coordination and care-planning • Assessment/management of symptoms/issues (physical, psychological, social, spiritual) - e.g., pain, dyspnea, food/nutrition, oral care, grief • Organizational capacity, environment, community - e.g., hospice utilization, ethics consultation, coordination of spiritual care volunteers • Emotional and/or spiritual support to patient/ family/staff • Culturally appropriate care for any of the above • Other
What do we know/believe about the process?	• **Who is involved?** – Patient, family, RN, LVN, CNA, MD, MSW, social service coordinator, activities staff, ST, OT, PT, dietitian, chaplain, DON, DSD, medical director, administrator, hospice staff, acute hospital staff, clergy – Other: (list) • **What are the actual steps that occur?** – (e.g.) Patient reports pain to CNA ⇨ CNA tells RN ⇨ RN assesses pain ⇨ RN gives PRN ⇨ RN reassesses… └⇨ RN calls MD ⇨ MD orders med… └⇨ RN begins nonpharmacological intervention… – Note which steps are sometimes problematic, needing simplification or improvement. • **What are the problems in:** – Knowledge – Attitudes – Performance – Policies and procedures – Interdisciplinary team communication and care planning – System, organizational capacity, and communication – Resources • **What are the sources of variation?** – Why does the process sometimes work really well? – Why does it sometimes not work well? • **What useful data are available?** What data could we easily gather? –e.g.: – Series of single case reviews – Reviews of 5-10 charts – Surveys of 5-10 people (patients, families, staff, other) – Other
What interventions should we try?	• Education • Policy/procedure change • New resources • Monitoring with feedback to staff • Other
Who needs to be involved?	Who will have oversight/organizing responsibility?
What are the barriers and supports?	• **What barriers will we encounter?** – Time, staffing, turnover, money, other resources – Knowledge, attitudes, performance (staff, physician, administration) – Competing priorities – Regulatory fears • **What forces, factors, strengths, and motivations support this effort?** – Potential allies within and outside the organization? – How can we show that this effort supports the priorities of allies and skeptics? • **How does knowledge of barriers and supports inform our strategy?** What have we learned from prior efforts to change practice?
How will we check to see if the intervention(s) worked?	• Compare new data with previous data • Develop new data points
How often will we reevaluate and decide on our next steps?	• When will we meet next? • What is our target date for completing project?

CNA: certified nursing assistant; DON: director of nursing; DSD: director of staff development IDT: interdisciplinary team; LVN: licensed vocational nurse; MSW: medical social worker; OT: occupational therapist ; PRN: as needed; PT: physical therapist ; RN: registered nurse; ST: speech therapist.

Source: California Coalition for Compassionate Care (http://www.finalchoices.calhealth.org).

7

SECTION 7: HOSPICE CARE IN THE LONG-TERM CARE FACILITY

> “Hospice programs have emerged as the single most widely used source of care specifically designed for dying patients, and currently provide care for approximately one-quarter of all patients who die in this country and for approximately two-thirds of patients who die of chronic progressive illness.”[1]

Long-term care facilities (LTCFs) and hospice programs share several core principles. Both strive to provide high-quality palliative and end-of-life care, relieve pain and other distressing symptoms, promote informed decision making, encourage advance care planning, and provide patients and families with emotional and spiritual support. Some LTCFs offer bereavement support for caregivers and families, as hospice programs do. These core domains of palliative and end-of-life care for older adults are essential components of the mission of both LTCFs and hospice programs.

Given these shared values, one would expect a high level of hospice utilization in LTCFs. In fact, enrollment of long-term care patients in hospice programs is fairly low. In two studies, 6%[2] and 22%[3] of patients dying in LTCFs were enrolled in hospice programs. Hospice referral of long-term care patients often occurs close to the time of death, with 32% of patients having a hospice stay of 14 days or less and 20% having a hospice stay of 1 week or less.[4]

In a study comparing the palliative care needs of long-term care patients with those of community-dwelling older patients at the time of hospice enrollment, Casarett et al[1] found that hospice patients living in LTCFs differed in several ways from those living in the community. Long-term care patients were less likely than community-dwelling patients to have a primary diagnosis of cancer, more likely to have a diagnosis of failure to thrive, and more likely to have a primary diagnosis of dementia. Hospice team members identified fewer new care needs in long-term care patients at the time of hospice enrollment than in community-dwelling patients. For example, long-term care patients were less likely to need the addition of a bowel regimen, a change in pain management, or anticipatory grief management.

Thus, although families report improved symptom management and bereavement support when hospice is involved in the care of LTCF patients,[5] many facilities may be providing good emotional support and symptom control prior to the patient’s enrollment in hospice. The report of improved pain and symptom relief and bereavement support with hospice involvement would be expected because these are among the core services that hospices are required to provide and in which hospice personnel have specialized skills.[5]

Another option for symptom management may be palliative care consultation by a provider who may or may not be sponsored by a hospice program. This option is covered by Medicare Part B.

Medicare Hospice Benefit

The Medicare Hospice Benefit (MHB) was instituted in 1983 in response to consumer demand for coverage of palliative treatments for patients with life-threatening illnesses who no longer desired life-sustaining medical treatments. Medicare beneficiaries are eligible for the hospice benefit when their life expectancy is less than 6 months if their disease runs it usual course and if they meet other admission criteria that a specific hospice program may establish.

The MHB provides a capitated package of benefits, including nursing, social work, counseling, and other services necessary both to treat the diagnosis that renders the patient eligible for hospice care and to relieve pain and suffering, The MHB specifies four levels of service (routine home care, respite inpatient, general inpatient, and continuous care). Because an LTCF is a resident's "home," hospice care in LTCFs is a covered benefit, subject to the limitations described below.

Hospices operate under Title 18 of the Code of Federal Regulations, whereas skilled nursing facilities operate under Title 19. Thus, the two entities must develop a contract that allows them to work together and comply with their respective regulatory requirements. When such a contract is in place, hospice personnel can deliver services to eligible patients in the skilled nursing facility (Table 7.1). The hospice is reimbursed by means of a daily capitated amount.

TABLE 7.1. SERVICES PROVIDED BY A HOSPICE PROGRAM

- Management of pain and nonpain symptoms
- Emotional, psychological, and spiritual support for the patient and family
- Provision of medication and durable medical equipment directly related to the patient's terminal illness
- Education of family and others in caring for the terminal patient
- Special services (e.g., physical therapy, speech therapy) when needed
- Additional nursing assistant to supplement facility care, based on intensity of need
- Bereavement care and counseling to family and friends before and up to 12 months after the patient's death
- Education and grief support for nursing home staff

Source: Hirschman et al, 2005.[4] Reprinted with permission.

Challenges of Providing Hospice Care in the Long-Term Care Setting

Although LTCFs and hospice programs have many common values and patient care goals, the two entities have different funding incentives, regulatory oversight concerns, and underlying assumptions about the goals of care.

Most importantly, in LTCFs the care model, quality indicators, and regulatory oversight prioritize and reward restorative and rehabilitative care. The Omnibus Budget Reconciliation Act of 1987 (OBRA 87, also known as the Nursing Home Reform Act) states that a nursing home "must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident…." This phrase is often cited in the opening remarks of regulatory and legal actions that allege poor care by an LTCF. This requirement may create both real and perceived barriers to the adoption of a palliative approach to care until a patient is very close to death.

Other major challenges to the use of hospice services in LTCFs are the following:

- Medicare will not pay for *both* services received under Medicare Part A (skilled nursing care) *and* services received under the Medicare Hospice Benefit. Medicare Part A pays for all costs associated with treatment, including skilled nursing services, rehabilitative therapy, medications, and room and board costs. By contrast, residents who elect to receive hospice care upon admission to an LTCF may be able to receive some skilled nursing services related to the terminal diagnosis that is covered by the hospice program, but must assume financial responsibility for their room and board costs. Thus, many patients with palliative care needs who are admitted to a skilled nursing facility from a hospital, and who meet the criteria for skilled nursing care or rehabilitation reimbursable under Medicare Part A, will opt to have their LTCF stay covered by Medicare Part A and will forego formal hospice care. Only after they have exhausted, or are no longer eligible for, Part A skilled nursing benefits and are transitioned to usual nursing care can they enroll in the MHB. Once enrolled in the MHB, patients become responsible for their room and board costs in the LTCF, unless they are eligible for Medicaid, in which case Medicaid will cover their room and board costs.

- Patients enrolling in hospice care may be encouraged to forego certain expensive (e.g., chemotherapy) or marginally effective (e.g., cardiopulmonary resuscitation) treatments. Some hospice programs may not be able to provide treatments that are too costly to be covered within their per diem capitation fee. For example, a patient with advanced cancer or HIV might still receive important benefits from active treatments, some of which are provided in specialized settings. Such a patient may have a prognosis that would qualify him or her for the hospice benefit, but the hospice program may be reluctant to accept the patient because of the expense associated with these specialized treatments.

Interaction Between the Long-Term Care Facility Medical Director, Attending Physician, and Hospice Medical Director

The LTCF medical director, the patient's attending physician, and the facility's interdisciplinary care team share responsibility for coordinating the care of a patient enrolled in hospice. Implementation of the following principles can help the medical director, attending physician, and LTCF optimize care for patients receiving hospice services:

- The LTCF medical director should play an active role in the development, implementation, and monitoring of policies and procedures that improve palliative care for all long-term care residents, including those enrolled in hospice.
- The attending physician should continue to be the patient's primary care provider after the patient is enrolled in hospice.
- Either the LTCF medical director or the attending physician should retain responsibility for overseeing the patient's overall plan of care, contingent on the advice, counsel, and agreement of the hospice medical director.
- When a patient enrolls in hospice, the LTCF medical director should work proactively with the medical director of the hospice program to optimize communication and collaboration between the two organizations, provide relevant education to hospice personnel as needed, and help to resolve concerns or problems that might arise in the shared care of a patient receiving hospice services.

To enhance communication between the LTCF and the hospice program, the LTCF medical director should meet regularly with a hospice program liaison person and periodically with the hospice medical director. The LTCF medical director should receive regular reports from the hospice program on the timeliness of hospice consultation, the appropriateness of care provided by the LTCF staff and the hospice team, and the satisfaction of both the LTCF staff and families with hospice services.

The medical directors of both the LTCF and the hospice program have roles in providing education to the patient's caregiving team. The hospice medical director should promote knowledge and competence in palliative care for all members of the caregiving team, including nursing assistants, nurses, and attending physicians as appropriate. The long-term care facility medical director should support the provision of education on palliative and hospice care for facility staff (Table 7.2) and offer the hospice medical director and staff his or her expertise on clinical practice in the long-term care setting.

Administrative collaboration can benefit both the long-term care facility and the hospice program. Table 7.3 suggests steps that the LTCF medical director can take to enhance the facility's provision of palliative care and facilitate collaboration with a hospice program. When appropriate, the LTCF medical director may participate in patient care rounds, home visits, or family conferences to serve as a clinical resource on palliative care.

Collaboration on quality improvement can be mutually beneficial to both the LTCF and the hospice program. The LTCF medical director can exercise medical leadership in the facility's Continuous Quality Improvement program by monitoring the processes and outcomes of care relevant to palliative and hospice care. Many quality improvement efforts could be a joint effort between the medical directors of the LTCF and the hospice. Over time, the data reported to the Continuous Quality Improvement committee could be used to help to establish quality of care benchmarks for the LTCF.

TABLE 7.2. POSSIBLE TOPICS FOR EDUCATION SESSIONS ON PALLIATIVE AND HOSPICE CARE FOR LONG-TERM CARE FACILITY STAFF

- Assessment and management of pain and distressing nonpain symptoms
- Bereavement
- End-of-life decision making
- Healthy coping skills for caregivers
- Medicare regulations on hospice care
- Principles of medical ethics
- Principles of palliative care

TABLE 7.3. ENHANCING PALLIATIVE CARE AND IMPROVING COLLABORATION WITH HOSPICE: STEPS THE LTCF MEDICAL DIRECTOR CAN TAKE

- Encourage implementation of policies and procedures to recognize, assess, treat, and monitor pain and distressing nonpain symptoms associated with chronic illness and the dying process
- Encourage the integration of emotional and spiritual elements into patients' care plans
- Act as liaison as necessary with the attending physician, consultants, and medical directors of hospitals, nursing homes, and managed care programs
- Have the ability to assume temporary responsibility for patient care on an emergency basis if the attending physician or designee is not available
- Use interdisciplinary meetings to review and monitor elements of physician performance, the care process, and patient outcomes relevant to palliative and end-of-life care.

Attending Physician Billing for Services Provided to Hospice-Enrolled Patients

Most patients enrolled in hospice care have important medical conditions that require attending physician oversight. For this reason, the attending physician can and should continue to provide appropriate care to the patient.

Attending physicians who are not employed or paid by the hospice provider may bill for patient care by using appropriate codes for diagnosis (ICD-9 codes) and for evaluation and management services (CPT codes). For patients enrolled in the MHB, the attending physician should add the modifier "GV" to the CPT code if the diagnosis is a condition related to the patient's terminal hospice diagnosis. The modifier "GW" is added for diagnoses unrelated to the terminal condition.

For example, if a patient with end-stage congestive heart failure (CHF) is enrolled in hospice and the attending physician manages aspects of CHF care, including symptom control and family communication, he or she would submit a bill for care of CHF (i.e., ICD-9 code 428.0) and an appropriate CPT code with the GV modifier (i.e., 99308-GV). The patient remains responsible for any copayments associated with attending physician services. If a patient is enrolled in a Medicare HMO, the attending physician continues to bill the HMO for medical services.

Further information about billing for physician services provided to patients enrolled in hospice and about the modifier GV can be found in the *Medicare Carriers Manual – Part 3,* published 11/1/01, section 4175.1.

Legally and Ethically Appropriate Marketing of Hospice Programs

A hospice program can be represented to practitioners, the medical community, medical facilities, and the community in general through articles, presentations, or videos. Any gifts offered by a hospice program to LTCF practitioners or staff should be seen as aids to providing good care, should be of nominal value, and should not be contingent on the receipt of referrals to the hospice program.

Tools for Determining Hospice Eligibility

Appendixes 7.1, 7.2, and 7.3 are tools that medical directors and practitioners may find helpful for assessing whether a patient is an appropriate candidate for hospice care.

Local coverage determinations by Centers for Medicare and Medicaid Services fiscal intermediaries are posted at http://www.cms.hhs.gov/mcd/index_lmrp_bystate.asp. (Select the appropriate regional home health intermediary [the fiscal intermediary] for a given hospice.)

References

1. Casarett DJ, Hirschman KB, Henry MR. Does hospice have a role in nursing home care at the end of life? *J Am Geriatr Soc* 2001; 49: 1493-1498.
2. Miller SC, Gonzalez P, Mor V. Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med* 2001; 111: 38-44.
3. Campbell DE, Lynn J, Louis TA, Shugaman LR. Medicare program expenditures associated with hospice use. *Ann Intern Med* 2004; 140: 269-271.
4. Hirschman KB, Kapo JM, Straton JB, et al. Hospice in long term care. Ann Long Term Care 2005; 13(10): 25-29.
5. Ersek M, Wilson SA. The challenges and opportunities in providing end-of-life care in nursing homes. *J Palliat Med* 2003; 6: 45-57.

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Keay TJ, Schonwetter RS. The case for hospice care in long-term care environments. Clin Geriatr Med 2000; 16(2): 211-223.

Miller SC, Mor V, Wu N, et al. Does receipt of hospice care in nursing homes improve the management of pain at the end of life? J Am Geriatr Soc 2002; 50(3): 507-15.

National Hospice and Palliative Care Organization
— Hospice and Nursing Home Collaboration Opinion Questionnaire
— Hospice Care in Nursing Facilities Toolkit
— National Consensus Project Voluntary Clinical Practice Guidelines for Quality Palliative Care
Available at http://www.nhpco.org

Wisconsin Department of Health and Family Services. Guidelines for Care Coordination for Hospice Patients Who Reside in Nursing Homes. 2nd edition. October 2001. Available at http://www.dhfs.state.wi.us/rl_DSL/Publications/01042a.htm [accessed 12/20/06]

APPENDIX 7.1. KANAWHA HOSPICE CARE SCREENING TOOL

The following guidelines suggest criteria for appropriate hospice referral for non-cancer patients. Patients with 2 or more items within a diagnostic group might qualify for hospice (seek full evaluation). Especially important criteria are marked with *.

Yes No **General Guidelines (May be used for any diagnosis)**
____ ____ Life-limiting condition(s)
____ ____ Progression of disease(s)
____ ____ Need for frequent hospitalization, office, or ER visits
____ ____ Dependence in most ADLs (activities of daily living)
____ ____ Weight loss greater than 10% over past 6 months
____ ____ Serum albumin less than 2.5 g/dl
____ ____ Recent decline in performance status

Yes No **End-Stage Heart Disease (e.g., CHF, CAD)**
*____ ____ Functional class III and IV NYHA Assessment
*____ ____ Symptomatic despite optimal treatment with diuretics and vasodilators, especially ACE inhibitors
____ ____ Arrhythmias resistant to treatment
____ ____ Ejection fraction <20%
____ ____ History of cardiac arrest
____ ____ Unexplained syncope
____ ____ Persistent resting tachycardia

Yes No **End-Stage Lung Disease (e.g., COPD)**
*____ ____ Disabling dyspnea at rest
____ ____ FEV 1 <30% after bronchodilators
____ ____ Recurrent pulmonary infections
____ ____ Cor pulmonale/right heart failure
*____ ____ pO2 <55 mm Hg or O2 sat <88% (on O2)
*____ ____ Recurrent hospitalizations/ER visits/MD visits

Yes No **End-Stage Renal Disease**
*____ ____ CrCl <10 cc/min (<15 cc/min in diabetics) or Cr >8 mg/dl (>6 mg/dl in diabetics)
*____ ____ Not a candidate for dialysis, renal transplant
____ ____ Signs of uremia (confusion, nausea, pruritus, restlessness)
____ ____ Oliguria <400 cc/24 hrs
____ ____ Hyperkalemia >7.0 mEq/L

Yes No **End-Stage Liver Disease**
*____ ____ PT >5 sec above control or INR >1.5
____ ____ Ascites despite maximum diuretics
____ ____ Peritonitis, spontaneous bacterial
____ ____ Hepatorenal syndrome
____ ____ Encephalopathy with asterixis, somnolence, coma
____ ____ Recurrent variceal bleeding
*____ ____ Albumin <2.5 gm/dl

Yes No **End-Stage Neurologic Diseases (e.g., ALS)**
____ ____ Unable to walk, needs assistance in all ADLs
____ ____ Barely intelligible speech
____ ____ Impaired nutritional status
____ ____ Declines feeding tube
____ ____ Significant dyspnea on O2

APPENDIX 7.1. KANAWHA HOSPICE CARE SCREENING TOOL (CONTINUED)

Yes No End-Stage Dementia

* _____ _____ FAST score of 7

_____ _____ Medical complications: aspiration, pneumonia, UTI, sepsis, advanced decubitus, fever despite antibiotics

Yes No CVA and Coma

_____ _____ Decreased level of consciousness

_____ _____ Persistent vegetative state

_____ _____ Dysphagia

_____ _____ Dependence in ADLs, paralysis

_____ _____ Post-stroke dementia

_____ _____ Impaired nutritional status (despite feeding tube, if present)

_____ _____ Increased medical complications (recurrent, frequent)

Yes No AIDS

* _____ _____ CD4 <25/ml or viral load >100,000/ml

_____ _____ Wasting syndrome

_____ _____ Lymphoma

_____ _____ PML (progressive multifocal leukoencephalopathy)

_____ _____ Cryptosporidiosis

_____ _____ MAC (Mycobacterium avium complex)

* _____ _____ Visceral Kaposi’s sarcoma, unresponsive to treatment

_____ _____ AIDS dementia

_____ _____ Toxoplasmosis

_____ _____ Pneumocystis carinii pneumonia

_____ _____ Tuberculosis

_____ _____ Current substance abuse

* _____ _____ Decreased performance status (KPS <50%)

ECOG/KARNOFSKY Performance Scale

ECOG		Karnofsky	
0	Fully active; no performance restrictions	100	Normal; no complaints; no evidence of disease
1	Unable to do strenuous activity but capable of self-care and light work	90 80 70	Able to carry on normal activity; minor signs/symptoms of disease Normal activity with effort; some signs or symptoms of disease Care of self; unable to carry on normal activity or do active work
2	Ambulatory, up 50% or less of waking hours; able to do all or most of self-care	60	Requires occasional assistance; able to care for most of own needs
3	Confined to bed/chair more than 50% of waking hours; needs assistance with personal care	50 40	Requires considerable assistance and frequent medical care Disabled; requires special care and assistance
4	Totally confined to bed or chair, completely disabled; complete care	30 20 10	Severely disabled; active supportive care necessary Death imminent Moribund; fatal processes progressing rapidly
5		0	Death

Functional Assessment Staging (FAST)

Please check highest consecutive level of disability. Hospice is appropriate if FAST score is 7. *Occurs occasionally or more frequently over the past weeks

____ 1 No difficulty either subjectively or objectively
____ 2 Complains of forgetting location of objects. Subjective work difficulties.*
____ 3 Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organization capacity.*
____ 4 Decreased ability to perform complex tasks.*
- Planning dinner for guests
- Handling personal finances (e.g., forgetting to pay bills)
- Difficulty shopping, etc.

____ 5 Requires assistance in choosing proper clothing to wear for the day, season, or occasion*
- Patient may wear the same clothing repeatedly, unless supervised

____ 6 Improperly putting on clothes without assistance or cueing (e.g., may put street clothes on over nightclothes, put shoes on wrong feet, may have difficulty buttoning clothing)*
- Unable to bathe properly (e.g., difficult adjusting bathwater temperature)*
- Unable to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue)*
- Urinary incontinence*
- Fecal incontinence*

____ 7 Limited ability to speak 6 intelligible different words in an average day or interview*
- Speech ability is limited to the use of a single intelligible word in a normal interaction. Repetitive actions.*
- Ambulatory ability is lost (cannot walk without personal assistance)*
- Cannot sit up without assistance*
- Individual falls over if no lateral arm rests on chair*
- Loss of ability to smile*
- Loss of ability to hold up head independently*

New York Heart Association (NYHA) Functional Classification

____ CLASS I Patients with cardiac disease without resulting limitations of physical activity
- Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea, or anginal pain

____ CLASS II Patients with cardiac disease, resulting in slight limitation of physical activity; comfortable at rest
- Ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain

____ CLASS III Patients with marked limitation of physical activity; comfortable at rest
- Less than ordinary activity causes fatigue, palpitation, dyspnea, or anginal pain

____ CLASS IV Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort
- Symptoms of heart failure or anginal syndrome may be present at rest. If any physical activity is undertaken, discomfort is increased

ACE: angiotensin-converting enzyme; ALS: amyotrophic lateral sclerosis; CAD: coronary artery disease; CHF: congestive heart failure; COPD: chronic obstructive pulmonary disease; CrCl: creatinine clearance; CVA: cerebral vascular accident ; ER: emergency room; FEV: forced expiratory volume; INR: international normalized ratio ; KPS: Karnofsky performance scale ; PT: prothrombin time ; UTI: urinary tract infection.

Sources:
Stuart B, Alexander K, Arenella C, et al. Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases, 2nd ed. 1996. Washington, DC: National Hospice Organization.

Field MJ, Cassel CK, eds; Committee on Care at the End of Life, Institute of Medicine. Approaching Death: Improving Care at the End of Life. 1997. Washington, DC: National Academy Press.

APPENDIX 7.2. SAMPLE CRITERIA FOR DETERMINING ELIGIBILITY FOR MEDICARE HOSPICE BENEFIT

Condition	Primary Criteria	Secondary Criteria/Notes
Heart Disease	Patient 1. Has a poor response to (or chooses not to pursue) optimal treatment with diuretics, vasodilators, and/or ACE inhibitors; 2. Has angina pectoris at rest that is resistant to standard nitrate therapy; 3. Is not a candidate for or declines invasive procedures; 4. Has significant symptoms of recurrent CHF at rest and/or refractory angina; and 5. Is classified as NYHA IV	Other factors supporting diagnosis of end-stage heart disease: 1. Treatment-resistant symptomatic supraventricular or ventricular arrhythmias; 2. A history of cardiac arrest or resuscitation and unexplained syncope; 3. A brain embolism of cardiac origin; 4. An ejection fraction of 20% or less; and 5. Concomitant HIV disease.
HIV/AIDS	Patients are considered to be in the terminal stage of their disease if they have: 1. CD4+ count <25 cells/mcL or persistent viral load >100,000 copies/mL, plus one of the following: a. CNS lymphoma; b. Loss of 33% lean body mass; c. Mycobacterium avium complex bacteremia, untreated, unresponsive to treatment, or treatment refused; d. Progressive multifocal leukoencephalopathy; e. Systemic lymphoma, with advanced HIV disease and partial response to chemotherapy; f. Visceral Kaposi's sarcoma unresponsive to therapy; g. Renal failure in the absence of dialysis; h. Cryptosporidium infection; or i. Toxoplasmosis, unresponsive to therapy. 2. Decreased performance status (50% on Karnofsky Performance Status scale)	Documentation of the following factors will support eligibility for hospice care: 1. Chronic persistent diarrhea for 1 year; 2. Persistent serum albumin <2.5; 3. Concomitant, active substance abuse; 4. Age >50 years; 5. Absence of antiretroviral, chemotherapeutic, and prophylactic drug therapy related specifically to HIV disease; 6. Advanced AIDS dementia complex; 7. Toxoplasmosis; and 8. Congestive heart failure, symptomatic at rest.
Pulmonary Disease	For patients with various forms of advanced pulmonary disease who eventually follow a final common pathway to end-stage pulmonary disease: 1. Severe chronic lung disease as documented by both a and b: a. Disabling dyspnea at rest, unresponsive to bronchodilators, with decreased functional capacity; and b. Progression of end-stage pulmonary disease, evidence including prior increasing visits to the emergency department or prior hospitalizations for pulmonary infections and/or respiratory failure. 2. Hypoxemia at rest on room air; evidence: $p0_2$ </= 55 mm Hg or oxygen saturation </= 88% or hypercapnia; evidence pCO_2 </= 50 mm Hg.	To lend supporting documentation: 1. Cor pulmonale and right heart failure secondary to pulmonary disease (e.g., not secondary to left heart disease or valvulopathy); 2. Unintentional progressive weight loss of greater than 10% of body weight over the preceding 6 months; and 3. Resting tachycardia > 100/minute.

APPENDIX 7.2. SAMPLE CRITERIA FOR DETERMINING ELIGIBILITY FOR MEDICARE HOSPICE BENEFIT (CONTINUED)

Condition	Primary Criteria	Secondary Criteria/Notes
Renal Disease	Patients are considered to be in the terminal stage of renal disease if: For chronic renal failure: 1. The patient is not seeking dialysis or renal transplant; 2. Creatinine clearance < 10 cc/minute (< 15 cc/minute for diabetes); and 3. Serum creatinine > 8.0 mg/dL (> 6.0 mg/dL for diabetes).	Supporting documentation Signs and symptoms of renal failure: 1. Uremia; 2. Oliguria (< 400 cc/day); 3. Intractable hyperkalemia (> 7.0) not responsive to treatment; 4. Uremic pericarditis; 5. Hepatorenal syndrome; and 6. Intractable fluid overload, not responsive to treatment.
ALS	Patients are considered to be in the terminal stage of ALS if 1 of the following 3 situations occurs within the 12 months preceding initial hospice certification: 1. Critically impaired breathing capacity as demonstrated by all of the following characteristics 12 months before initial hospice certification: • Vital capacity less than 30% of normal; • Significant dyspnea at rest; • Requiring supplemental oxygen at rest; and • Patient declines artificial ventilation. 2. Rapid progression of ALS and critical nutritional impairment demonstrated by all of the following characteristics: a. Rapid progression: • Progression from independent ambulation to wheelchair or bedbound status; • Progression from normal to barely intelligible or unintelligible speech; • Progression from normal to pureed diet; and • Progression from independence in most or all ADLs to major assistance by caretaker in all ADLs. b. Critical nutritional impairment: • Oral intake of nutrients and fluids insufficient to sustain life; • Continuing weight loss; • Dehydration or hypovolemia; and • Absence of artificial feeding methods. 3. Both rapid progression of ALS and life-threatening complications: a. Rapid progression of ALS, see 2.a. above; and b. Life-threatening complications: • Recurrent aspiration pneumonia (with or without tube feedings); • Upper urinary tract infection (e.g., pyelonephritis); • Sepsis; and • Recurrent fever after antibiotic therapy.	Some general considerations: 1. ALS tends to progress in a linear fashion over time, so the overall rate of decline in each patient is fairly constant and predictable. 2. Multiple clinical parameters are required to judge the progression of ALS. 3. Although ALS usually presents in a localized anatomic area, the location of initial presentation does not correlate with survival time. 4. Progression of disease differs markedly from patient to patient. 5. In end-stage ALS, 2 factors are critical in determining prognosis: ability to breathe and, to a lesser extent, ability to swallow.

APPENDIX 7.2. SAMPLE CRITERIA FOR DETERMINING ELIGIBILITY FOR MEDICARE HOSPICE BENEFIT (CONTINUED)

Condition	Primary Criteria	Secondary Criteria/Notes
Stroke	The following are important indicators of functional and nutritional status, respectively, and support a terminal prognosis if met: 1. A Palliative Performance Scale score of </= 40. a. Degree of ambulation: mainly in bed b. Activity/extent of disease: unable to do work; extensive disease c. Ability to do self-care: mainly assistance d. Food/fluid intake: normal to reduced e. State of consciousness: either fully conscious or drowsy/confused 2. Inability to maintain hydration and caloric intake with 1 of the following: a. Weight loss > 10% during previous 6 months; b. Weight loss > 7.5% in previous 3 months; c. Serum albumin < 2.5 g/dL; d. Current history of pulmonary aspiration without effective response to speech language pathology interventions; or e. Calorie counts documenting inadequate caloric/fluid intake.	If the patient does not meet both of the primary criteria, there should be documentation that describes a relevant comorbidity and/or rapid decline.
Alzheimer's Disease and Related Disorders*	For Alzheimer's disease and related disorders, the identification of specific structural/functional impairments, together with any relevant activity limitations, should serve as the basis for palliative interventions and care planning. The structural and functional impairments associated with a primary diagnosis of Alzheimer's disease are often complicated by comorbid and/or secondary conditions. Comorbid conditions affecting beneficiaries with Alzheimer's disease are by definition distinct from the Alzheimer's disease itself. Examples include coronary heart disease and chronic obstructive pulmonary disease. Secondary conditions are directly related to a primary condition. In the case of Alzheimer's disease, examples include delirium and pressure ulcers. Ultimately, the combined effects of the Alzheimer's disease (FAST stage 7) and any comorbid or secondary condition should be such that the patient with Alzheimer's disease and similar impairments would have a prognosis of 6 months or less.	The FAST Scale has been used for many years to describe Medicare beneficiaries with Alzheimer's disease and a prognosis of 6 months or less. The FAST Scale is a 16-item scale designed to parallel the progressive activity limitations associated with Alzheimer's disease. FAST stage 7 identifies the threshold of activity limitation that would support a 6-month prognosis. The FAST Scale does not address the impact of comorbid and secondary conditions.

ACE: angiotensin-converting enzyme; CHF: congestive heart failure; CNS: central nervous system; NYHA: New York Heart Association; ALS: amyotrophic lateral sclerosis; ADLs: activities of daily living; FAST Scale: Reisberg Functional Assessment Staging Scale.

*Some fiscal intermediaries may have a list of specific secondary conditions and comorbidities that determine eligibility. However, some RHHIs (Regional Home Health Intermediaries), such as Palmetto GBA, have recently changed this policy, stating that because of the complexity of the condition, they now encourage the active participation of clinical staff in the identification and documentation of relevant comorbid or secondary conditions.

Sources:
Palmetto GBA. Public Information: Local Coverage Determination (LCD). Available at http://www.palmettogba.com/palmetto/providers.nsf/Home/Providers+Regional+Home+Health+&+Hospice+Intermediary+(RHHI)+Home?OpenDocument [accessed August 3, 2004]

Adapted from Fine P. Hospice referral and care: Practical guidance for clinicians (CME/CE). Available at http://www.medscape.com/viewprogram/3345 [accessed 1/16/07]

APPENDIX 7.3. NATIONAL HOSPICE ORGANIZATION GUIDELINES FOR ESTIMATING PROGNOSIS IN NONCANCER DISEASES

A patient who fulfills the criteria in any category may be deemed to have a prognosis of less than 6 months and therefore to be appropriate for hospice care and referral for the Medicare Hospice Benefit. (NOTE: Other criteria may apply.)

1. General. The patient meets all of the following criteria:
   a. Life-limiting condition;
   b. Treatment goals are for comfort rather than cure;
   c. In the past 6 months, the patient has either documented terminal disease-related decline in nutritional status (weight loss >10%) or clinical progression of disease (repeated emergency room or inpatient admissions, or functional status decline).

2. Congestive Heart Failure. On optimal treatment, the patient meets the following criteria:
   a. Class IV heart failure or ejection fraction <20%; and
   b. Syncope, cardiac arrest, cardiogenic stroke, or symptomatic arrhythmia.

3. Chronic Obstructive Pulmonary Disease. The patient meets some of the following criteria:
   a. Dyspnea at rest unresponsive to bronchodilators. Forced expiratory volume (FEV1) after bronchodilator less than 30% of predicted.
   b. Dyspnea limits walking to a few steps.
   c. Resting pCO2 >50; O2 Saturation <88% or pO2 <55 on supplemental oxygen; Cor pulmonale.
   d. Weight loss >10% of body weight; resting tachycardia >100.

4. Renal Failure. Chronic renal failure with creatinine >8.0 mg/dL, off dialysis.

5. Cirrhosis and/or Liver Failure. With clinical judgment, the patient:
   a. Spends most time in bed, INR >1.5, albumin <2.5 g/dL.
   b. Evidences comorbidity: encephalopathy, spontaneous bacterial peritonitis, refractory ascites, recurrent variceal bleeding, hepatorenal syndrome, or wasting.

6. Dementia. The patient meets all of the following criteria:
   a. Speech limited to 6 words;
   b. Bed-bound;
   c. Incontinent;
   d. Unable to ambulate, dress, and bathe without assistance; and
   e. A comorbidity in prior year; i.e., pyelonephritis, pressure ulcer, sepsis, fever after antibiotics, difficulty feeding with aspiration pneumonia or weight loss >10%.

7. Human Immunodeficiency Virus (HIV) Disease. The patient meets some of the following criteria:
   a. CD4+ count below 25 cells/m L;
   b. Viral load >100,000/ml;
   c. Declining functional status;

APPENDIX 7.3. NATIONAL HOSPICE ORGANIZATION GUIDELINES FOR ESTIMATING PROGNOSIS IN NONCANCER DISEASES (CONTINUED)

d. Certain opportunistic infections;
e. Albumin <2.5 g/dL.

8. Strokes and/or Coma

a. **Acute Phase.** The patient meets any of the following criteria:
  (1) Coma or persistent vegetative state 3 days after stroke.
  (2) Any four of the following on day 3 of coma:
    i. No verbal response.
    ii. Abnormal brain stem response.
    iii. No response to pain.
    iv. Serum creatinine >1.5 mg/dL, age >70.
    v. Dysphagia preventing adequate intake in a patient who is not a candidate for artificial nutrition.

b. **Chronic Phase.** The patient meets some of the following criteria:
  (1) Poor functional status.
  (2) Dementia dependent in ambulation, dressing, bathing and toileting.
  (3) Weight loss >10%, albumin < 2.5g/dL.
  (4) Complications to include: aspiration pneumonia, pyelonephritis, sepsis, stage 3 or 4 decubitus, and/or fever after antibiotic.

9. Amyotrophic Lateral Sclerosis (ALS). The patient evidences a rapid progression of ALS, with decline in one of the following:

a. Ventilatory capacity,
b. Swallowing, or
c. Functional status.

INR: International normalized ratio.

Source: Adapted from Stuart B, Alexander K, Arenella C, et al. Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases, 2nd ed. 1996. Washington, DC: National Hospice Organization.

— NOTES —

Dedicated To Long Term Care Medicine

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