

**Essentials of Hospice: What Every Practitioner Needs to Know but Are Afraid to Ask**

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ABSTRACT

Every practitioner, regardless of specialty and setting of patient care, must advocate for and facilitate timely patient access to comprehensive palliative and hospice care as patients enter the last phase of life due to advanced serious life-limiting illness. Accordingly, practitioners need to be familiar with both the general and disease-specific eligibility guidelines for hospice, the four different levels of hospice care under the Medicare Hospice Benefit, reimbursement for services provided, and be proficient and culturally competent in advance health care planning as well as acquire expertise in the treatment of pain and non-pain symptoms that occur at end-of-life. This is critical to alleviate both patient and family suffering and to ensure dignity and a peaceful death. The main objective of this review is to familiarize practitioners to the administrative and clinical processes that underlie the provision of hospice care and to encourage practitioners to remain engaged in the provision of end-of-life palliative care rather than “hand-off” total care to the hospice medical director or a palliative care specialist.

INTRODUCTION

In the late 1960's Dame Cicely Saunders of renown St. Christopher's Hospice in England promulgated core principles of hospice that recognized that persons who have a life-limiting illness suffer from unique physical, emotional, social and spiritual / religious needs. <sup>(1)</sup>

**Persons on hospice** have unique medical, functional, financial and practical needs that must be met through a holistic and interdisciplinary / interprofessional team approach.

While in the United States, Elizabeth Kubler-Ross had been doing research on dying and published her book titled "On Death and Dying" in 1969. <sup>(2)</sup> She described five common stages of dying: denial, anger, bargaining, depression, and acceptance (remember the mnemonic D-A-B-D-A), with subsequent publications, "Living with Death and Dying" (1981) <sup>(3)</sup> and "Working It Through" (1982) <sup>(4)</sup>. A dying person does not necessarily progress through these stages in a consecutive manner nor experience all these stages. Caregivers and family members may also transition through these stages.

In the United States the first hospice (as an inpatient unit) was established in 1974 while the Medicare Hospice Benefit (MHB) only became authorized in 1983 under Title XVIII of the Social Security Act. At the time it became evident that death occurred more as a result of chronic disease rather than acute illness. Though initially the majority of hospice patients suffered from cancer, currently the leading diagnoses are cancer (27%), dementia (18%), cardiac and circulatory (18.7%), respiratory conditions (11%), stroke (9.5%) and other (15.6%) such as neurologic conditions and end-stage renal disease. <sup>(5)</sup> In 2014 it is estimated that a total of 1.6 to 1.7 million persons in the US received hospice services either through

Medicare, Medicaid (not covered by all state Medicaid programs) or other insurance plans though the benefit period may be more limited than that of Medicare. <sup>(6)</sup> While in 2016, 1.43 million Medicare beneficiaries were enrolled in hospice and 48% of Medicare decedents were on hospice at the time of death (1.04 million persons).

Currently Caucasians account for 86.5% of Medicare hospice enrollees, African American 8.3%, Hispanic 24%, Native American 0.4%, while hospice utilization at time of death is 48.9% by Caucasians, 37.4% by Hispanics, African Americans 35.6%, Native American 32.9% and Asian 31.7%. <sup>(5,6)</sup> **Location of hospice deaths** in the US is 44.6% at the patient's home, 32.8% at a nursing or assisted living facility, 14.6% at a hospice or palliative inpatient facility and only 7.4% in an acute hospital. <sup>(5,6)</sup> **The percentage of total days on hospice care that occur at home** is 55.6%, nursing / assisted living facility 41.9%, hospice inpatient facility 1.3% and acute care hospital 0.5%. <sup>(5,6)</sup> In 2014, there were over 6,100 hospice care agencies. Sixty percent (60%) were free-standing, 20% affiliated to a hospital or health care system, 16% affiliated to a home health agency, and 5% to a nursing home. Sixty-eight percent (68%) were for-profit, 28% non-profit and 4% government funded. These statistics reveal that a majority of practitioners will be either directly or indirectly providing services to patients who are either eventually referred to or enrolled in hospice. Accordingly, this review intends to be a resource to all practitioners irrespective of discipline specialty or setting of patient care. A recent article by Betty Ferrell et al <sup>(7)</sup>, updating the National Consensus Project clinical practice guidelines for quality palliative care highlights the need for high quality end-of-life palliative and hospice care.

ILLNESS TRAJECTORIES AND PROGNOSTICATION

Generally, *Illness trajectories* that lead to death can manifest in one of *four ways*<sup>(8)</sup>:

- ***A short period of rapid decline*** before death (usually a few weeks or months) as often seen in cancer.
- ***Prolonged dwindling over several years.*** Often seen in those afflicted with dementia or progressive frailty and debility due to neurologic disease such as Parkinson's, multiple sclerosis and Lou Gehrig's.
- ***Long term progressive functional decline over 2 to 5 years with intermittent serious episodes of acute illness,*** often associated with multiple ER visits and hospitalizations, with only partial recovery of functional status after each episode, leading to eventual death, often seen in late stage cardiac or pulmonary disease.
- ***An acute catastrophic event leading to death in 7 to 14 days.*** Often seen with an acute stroke, myocardial infarction, respiratory or renal failure, coma, or severe gastrointestinal bleeding for which blood transfusion may have been refused.

Thus, when patients manifest such a trajectory practitioners should be cognizant as to the need to “breaking bad news” and take the initiative to engage patients,

caregivers and family members in “advance care planning” that will eventually transition to “terminal care planning” as death approaches.

GENERAL INDICATORS AND CLINICAL PARAMETERS AT END-OF-LIFE

General indicators and clinical parameters that should forewarn a practitioner that a patient is at risk of death within the next 6 to 12 months include the following:

- Repeated ER Visits and more frequent hospitalizations
- Recurrent life-threatening infections such as pneumonia, UTI, and sepsis.
- Decline in functional status as determined by the Palliative Performance Score<sup>(9)</sup> of less than 50 to 70%, (see Table 1) or increasing dependency in 2 or more Basic Activities of Daily Living (i.e. BADLs).
- Progressive ***unavoidable*** weight loss, of 5% body weight in 3 months or 10% in 6 months.
- Serum albumin less than 2.5 gm/dl
- Presence of one or more stage 3 or 4 pressure ulcers (a.k.a. “injuries”)
- ***Progressive decline*** in Body Mass Index to less than 22, (especially <20).
- Advanced age greater than 88.
- Severe refractory symptoms such as fatigue, shortness of breath, peripheral edema or bowel obstruction.

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**TABLE 1.** Palliative Performance Scale (PPS) <sup>(9)</sup>

<b>%</b>	<b>Ambulation</b>	<b>Activity and Evidence of Disease</b>	<b>Self-Care</b>	<b>Intake</b>	<b>Level of consciousness</b>
100	Full	Normal activity, no evidence of disease	Full	Normal	Full
90	Full	Normal activity, no evidence of disease	Full	Normal	Full
80	Full	Normal activity, no evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal work, some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby or some housework, significant disease	Occasional assistance	Normal or reduced	Full or confusion
50	Mainly Sit/lie	Unable to do any work extensive disease	Considerable assistance	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work extensive disease	Mainly assistance	Normal or reduced	Any
30	Totally bed bound	Unable to do any work, extensive disease	Total Care	Reduced	Any
20	Totally bed bound	Unable to do any work, extensive disease	Total Care	Minimal sips	Any
10	Totally bed bound	Unable to do any work, extensive disease	Total Care	Mouth care only	Drowsy or coma
0	Death	-	-	-	-

In addition, a patient's emotional demeanor, acknowledgement and acceptance of imminent death can be an opportunity to review patient values and preferences, DNR status, any advance health care directives, presence or not of a power of attorney or guardian for health care decisions and financial matters. For patients who reside in a nursing facility, prognostication can be challenging. In such cases the Flacker Mortality Score may help determine the percentage probability of death in one year for newly admitted residents aged 65 and older.<sup>(10)</sup>

Timely recognition by practitioners of a patient's serious life threatening acute and / or chronic illness, disease burden (i.e. multimorbidities), together with taking into consideration of a patient's poor prognosis, should trigger a timely review of the patient's *goals of life* and *goals of care* in order to choose between treatment options that benefit and hopefully outweigh risk. This requires practitioners to respect patient values, preferences and informed choices (i.e. informed consent) as well as the following:

- Determine the patient's and / or surrogate decision maker's current (and past) decision making capacity as to healthcare, practical and financial matters.
- Acknowledge how patient culture, ethnicity, and religious / spiritual beliefs can impact values, preferences and choice of desired treatments, ***including no treatment.***
- Be aware that educational level and medical literacy can impact patient, caregiver and family understanding or misunderstanding.
- Obtain and review any advanced health care directives (e.g. "Living Will"), directive to physicians, power of attorney (whether durable or not),

guardianship, and their limitations, if any.

- Remember such documents are often state-specific and may not be applicable to State law where the patient now resides.
- Inquire as to any previously written or orally expressed patient wishes.
- Remember the ethical principles of health care; ***autonomy*** (the right to patient self-determination), ***beneficence*** (the duty to do good); ***nonmaleficence*** (to avoid harm); ***justice*** (*to treat fairly equally and equitably*); and ***fidelity***, the duty of practitioners to be truthful, support patient dignity and to not abandon patients.

#### GUIDING PRINCIPLES OF HOSPICE CARE

Hospice can be considered the ***gold standard of palliative care***. Irrespective of the age of the patient, diagnosis, the setting of care, disease trajectory leading to death, the core principles of palliative care are the same for hospice.

- Reduce the symptom burden from pain and other distressful symptoms, including the relief of suffering.
- Recognize and address the physical, psycho-emotional, social and religious / spiritual needs, and dimensions of pain and other symptoms experienced by both the ***patient and family***.
- Provide medical treatment congruent with the wishes, values, preferences, beliefs, culture, and concerns of the patient and family.
- Provide care that is interdisciplinary / interprofessional.
- Assist the patient, family, and practitioners with the resolution of ethical and legal issues, and advanced care planning.

Practitioners must be committed to the highest quality (palliative) care that is both timely and comprehensive. To do so, requires regular clinical assessment, diagnosis, care planning, interventions, and monitoring the patient's response to these interventions while recognizing the natural trajectory of the disease. Also, practitioners should anticipate and prevent/alleviate distressful symptoms, and suffering. Care should be *patient-centered* and *family-focused*. Practitioners and the hospice interdisciplinary team are challenged on many levels to be able to provide seamless transitions in care between institutional, hospital, and home where effective communication skills are essential.

While on hospice it is important for practitioners and the interdisciplinary team to support the patient, caregiver and family goals of care that include:

- To strive for the highest practical quality of life, despite late stage illness.
- To be in control (autonomy) and to maintain one's dignity.
- To relieve distressful symptoms and suffering (physical, emotional, psychologic, social, and spiritual).
- To alleviate family burden (can also be psycho-emotional, financial, practical).
- To mend estranged relationships, if possible.

#### DISEASE-SPECIFIC ELIGIBILITY GUIDELINES FOR HOSPICE

In addition to the previously reviewed general indicators and clinical parameters that may forewarn the likelihood of a patient's terminal stage of illness, disease-specific guidelines can support a patient's eligibility for hospice.<sup>(11)</sup> (see Table 2). These guidelines can further assist

in determining whether a patient has a likely prognosis of less than 6 months to live if their condition follows its natural progression and expectation to cause eventual death, if the patient has decided to no longer pursue disease-modifying curative treatment. It should be noted that "adult failure to thrive", generalized "debility" and "non-specific terminal illness" no longer qualify as eligible hospice diagnoses under the Medicare Hospice Benefit (MHB).

Note that the regional Local Coverage Determinations (LCDs) as to a patient's hospice eligibility may differ geographically. A patient "*elects*" to receive the hospice benefit. Hospice certification is based upon the referring practitioner's and hospice medical director's clinical judgment regarding eligibility supported by the general and disease specific guidelines, and in some cases further supported by a "constellation of conditions". The latter may occur under specific circumstances when a patient and family are under overwhelming psychologic, social or emotional distress. Significant co-morbidities can also support hospice eligibility. For example, a patient with heart failure may not quite meet hospice eligibility for end stage heart disease, but a comorbidity of advanced renal failure or dementia may do so.

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**TABLE 2.** Disease Specific Eligibility Criteria/Guidelines for Hospice<sup>(11)</sup>

<p>Cancer</p> <ul style="list-style-type: none"> <li>Widespread metastatic disease</li> <li>Palliative Performance Scale (PPS) <math>\leq</math> 70%</li> <li>No longer seeking curative care</li> </ul>
<p>Dementia (Alzheimer's Disease)</p> <ul style="list-style-type: none"> <li>Inability to ambulate due to dementia (FAST 7c)</li> <li>No consistent meaningful speech</li> <li>Life threatening infections, multiple stage 3 or 4 skin ulcers</li> <li>Inability to maintain sufficient fluid and calorie intake</li> </ul>
<p>Heart Disease</p> <ul style="list-style-type: none"> <li>Poor response or intolerant to optimal medical treatment</li> <li>NYHA class IV CHF</li> <li>EF <math>\leq</math> 20% (helpful, not required)</li> </ul>
<p>HIV /AIDS</p> <ul style="list-style-type: none"> <li>CD 4 count <math>&lt;</math>25</li> <li>Persistent viral loads <math>&gt;</math> 100,000/ ml</li> <li>Major AIDS-defining refractory infections or other medical conditions</li> <li>Significant functional decline in ADLs</li> </ul>
<p>Neurologic Diseases (PD, ALS, MS, MD, myasthenia gravis)</p> <ul style="list-style-type: none"> <li>Rapid disease progression and critical nutritional state</li> <li>Life threatening infections in preceding 12 months</li> <li>Stage 3, 4 decubitus ulcers</li> <li>Critically impaired breathing capacity, declines ventilator</li> </ul>
<p>Pulmonary Disease</p> <ul style="list-style-type: none"> <li>Disabling dyspnea at rest or with minimal exertion</li> <li>Increasing visits to ER, hospitalizations</li> <li>Hypoxemia on room air (<math>&lt;</math>88 %); hypercapnia of <math>p_{CO_2}</math><math>&gt;</math>50 mmHg</li> <li>FEV 1<math>&lt;</math>30% (helpful, not required)</li> </ul>
<p>Renal failure</p> <ul style="list-style-type: none"> <li>Not seeking dialysis, not a candidate (or refusing further dialysis)</li> <li>Calculated creatinine clearance <math>&lt;</math>10 (<math>&lt;</math>15 for diabetics)</li> <li>Creatinine <math>&gt;</math>8 (<math>&gt;</math>6 for diabetics)</li> </ul>
<p>Stroke</p> <ul style="list-style-type: none"> <li>Coma (acute phase)</li> <li>Dysphagia with insufficient intake of fluids and calories</li> <li>Post stroke dementia (See dementia criteria)</li> </ul>
<p>LIVER DISEASE</p> <ul style="list-style-type: none"> <li>INR <math>&gt;</math> 1.5 not on Warfarin</li> <li>Serum albumin <math>&lt;</math> 2.5 g/dl</li> <li>Refractory ascites</li> <li>Previous spontaneous bacterial peritonitis</li> <li>Hepatorenal syndrome</li> <li>Recurrent variceal bleeding</li> </ul>

Adapted from: National Hospice and Palliative Care Organization

MEDICARE HOSPICE LEVELS OF CARE

The Medicare Hospice Benefit has *four levels of care* (see Table 3) for which hospice agencies are reimbursed at a different daily rate based on the patient's setting of hospice care, intensity of needed care and geographic location (state, county, and city).<sup>(12)</sup> The rates are usually updated annually<sup>(16)</sup>.

Every patient enrolled in hospice receives services at a *level based on need* as summarized in Table 3 and can transition from one level to another. *Routine home care* occurs for the majority of patients upon admission to hospice when symptoms are well controlled.<sup>(13, 14)</sup> The daily rate is decreased after 60 days from a national

average of \$192.78 to \$151.41 for Medicare fiscal year 2018.

*General inpatient care* (i.e. GIP) occurs when a patient requires a higher level of care than manageable under routine home care, necessitating a brief hospitalization, usually several days. This may also occur when an acutely ill hospital inpatient is determined to be within days of dying, though the hospital must have a contract with the hospice to be able to do so. Once symptoms are under control, the patient will be able to return to routine home care. Occasionally symptoms may be so severe during last days of life that the patient may actually require GIP to enable death with comfort and dignity. The national average daily rate is \$743.55 for Medicare fiscal year 2018.<sup>(16)</sup>

**TABLE 3. MEDICARE HOSPICE LEVELS OF CARE<sup>(13)</sup>**

<p><b>Routine Home Care</b></p> <ul style="list-style-type: none"> <li>• Care provided at a patient's place of residence, either private home, assisted living, or long-term nursing facility</li> <li>• Does <u>not</u> cover costs of room and board</li> </ul>
<p><b>Continuous Home Care</b></p> <ul style="list-style-type: none"> <li>• Care provided for brief periods for crisis management of acute symptoms</li> <li>• Requires a skilled nurse need</li> <li>• Requires a minimum of 8 hours direct care in a 24-hour period with 50% or more of total hours provided by a licensed nurse and remainder by a hospice nurse aide.</li> </ul>
<p><b>Respite Care</b></p> <ul style="list-style-type: none"> <li>• Covers no more than 5 consecutive days in a benefit period.</li> <li>• Provided by a Medicare-approved facility (hospice inpatient facility, hospital, or nursing facility)</li> <li>• May entail a 5% copayment by the patient (often waived by the hospice)</li> </ul>
<p><b>General Inpatient Care</b></p> <ul style="list-style-type: none"> <li>• Intended for crisis management of acute symptoms not adequately controlled at patient's place of residence that requires a skilled level of care</li> <li>• No specific limit to number of days, with daily evaluation for ongoing necessity</li> <li>• May be needed for management of the acute phase of dying and / or complicated psychosocial issues, yet requiring a skilled need</li> <li>• Provided as short-term care in hospital or skilled nursing facility with hospice continuing as the manager of care.</li> </ul>



*Inpatient respite care* occurs when the patient’s caregiver is overcome with exhaustion, be it physical or emotional, such that relief i.e. respite, is needed. Hospice will pay for 5 consecutive days’ respite with the costs negotiated between the hospice and the respite care setting. Most often it occurs at a long-term care nursing facility, rarely in a hospital. ***Patients must be medically stable***, though on occasion an acute crisis may occur. For example, a patient may fall and suffer a broken hip, have sudden death, or an unsuspected worsening of their medical condition. Other circumstances may justify this benefit such as the caregiver wanting to attend a family gathering or wedding or have need for medical care, either scheduled or emergent. The national

average daily rate is \$172.78 for Medicare fiscal year 2018.<sup>(16)</sup>

*Continuous care* is provided either in the home setting or a long-term care facility for a brief period of time, usually a few days, for crisis management of acute symptoms. Once controlled, the patient will transition back to routine home care. The national average daily rate is \$976.42 for Medicare fiscal year 2018.<sup>(16)</sup>

HOSPICE MYTHS (Table 4)<sup>(15)</sup>

Myths held by practitioners, patients and /or families related to hospice eligibility can delay timely access to hospice. These include the following misbeliefs.

**Table 4.** Hospice Myths<sup>(15)</sup>

<b>Myth #1:</b>	A hospice patient must have a DNR.
<b>Myth #2:</b>	A hospice patient must have an advance directive for health care.
<b>Myth #3:</b>	A patient must have an in-home caregiver to be eligible for hospice.
<b>Myth #4:</b>	A hospice patient must give up aggressive treatments.
<b>Myth #5:</b>	A hospice patient must move to a hospice facility to receive hospice care.
<b>Myth #6:</b>	A hospice patient must be discharged from hospice if they live more than 6 months beyond the date of admission to the hospice.
<b>Myth #7:</b>	A hospice patient cannot be hospitalized nor receive skilled nursing facility (SNF) care.
<b>Myth #8:</b>	The hospice will pay for all the costs of care of a patient.
<b>Myth #9:</b>	The hospice will pay for all the patient’s medications.

**Myth #1: A hospice patient must have a DNR.**

A patient *without* a DNR *can* be admitted to hospice. However, as the patient's medical condition deteriorates, the patient and family will often choose to complete a DNR. The hospice staff will periodically discuss such end-of-life care decisions with the patient.

**Myth #2: A hospice patient must have an advance directive for health care (i.e. living will).**

Though the presence of such a directive can help guide care and health care decision making, a patient *without* an advance directive for healthcare (i.e. living will or directive to physicians) can still be admitted to hospice. Over time, goals of care will be discussed with the patient. Any advance directive for health care or durable power of attorney for health care must be completed and signed by the patient when they still have the decision making capacity (i.e. able to give informed consent) to have understood what they are signing. Such a document's applicability will vary in each State.

**Myth #3: A patient must have an in-home caregiver to be eligible for hospice.**

Though the provision of hospice care in a patient's home will be greatly facilitated by the presence of in-home caregiver, this is not required. When care needs outstrip the patient's and hospice's ability to meet their needs, it is not uncommon for either a friend or family member to move into the home or the patient to agree to move into an assisted living facility or nursing home. On occasion adult protective services may need to be notified.

**Myth #4: A hospice patient must forgo aggressive treatments.**

This is not true. Treatments that aggressively palliate symptoms related to the hospice diagnosis can be continued and should be covered under the hospice benefit, as long as these treatments are both truly palliative (i.e. not curative seeking) and will not extend the patient's terminal life expectancy to greater than six months. A life expectancy of six months or less if the medical condition follows its normal expected course is the fundamental guideline to ascertain a patient's eligibility for hospice.

**Myth #5: A hospice patient must move to a hospice facility to receive hospice care.**

This is not true, though the patient or family members often believe this to be the case and then unfortunately opt not to receive hospice because they believe they would have to move from where they are living. Hospice will go to wherever the patient is, be it the home, hospital, assisted living facility or nursing home.

**Myth #6: A hospice patient must be discharged from hospice if they live more than 6 months beyond the date of admission to hospice.**

This is not the case. Patients may be re-certified for consecutive periods as long as it is in the judgment of the hospice medical director that patients have a prognosis of less than 6 months to live if the patient's conditions follow its natural / expected course to death.

**Myth #7: A hospice patient cannot be hospitalized nor receive skilled nursing facility (SNF) care.**

In fact, a hospice patient can be admitted to the hospital or a SNF, for care either related to the hospice diagnosis or a non-hospice related diagnosis. For care related to the hospice diagnosis, the hospice would be responsible for all the costs of

care. Since this would likely exceed the hospice per diem, the hospice will usually have the patient revoke their hospice benefit while hospitalized and have hospice reinstated upon hospital discharge assuming the patient still meets the eligibility guidelines for hospice.

**Myth #8: The hospice will pay for all the costs of care of a hospice patient.**

The hospice is only responsible for the costs of care related to the terminal (hospice) diagnosis. For example, if a patient is on service for CHF, who falls and breaks a hip, then the costs of care related to the hip fracture (hospital and SNF) are covered under Medicare A and B and not the hospice.

**Myth #9: The Hospice will pay for all the patient's medication**

This is often a misunderstanding by families and practitioners. Under the current Medicare Hospice Benefit (MHB) the hospice is only obligated to provide those medications that are related to the terminal diagnosis, as well as medication prescribed for co-morbid medical conditions that contribute to the patient's terminal prognosis. For example, a patient on hospice for cancer, would not have the cost of the medication for diabetes and hypertension covered by the hospice.

**THE HOSPICE ADMISSION**

When a practitioner recognizes that a patient faces a serious life-threatening illness with a poor prognosis supported by both the general hospice and disease-specific guidelines already reviewed in this article, the practitioner should then proceed to engage the patient and/ or proxy decision maker in advance care planning. This discussion should include the patient's understanding as to treatment options and a

shared decision as to whether the patient is either to continue aggressive (curative) treatment or elect to receive "active" palliative care under hospice. More recently a patient/ family may decide to remain at home and receive non-hospice palliative care if the illness is determined to have a *prognosis greater than 6 months to live*. Such a program can be considered as "pre-hospice" and is often associated with a hospice agency to which the patient may eventually transition once determined to have a prognosis of less than 6 months to live.

Under the Medicare Hospice requirements, certification for hospice eligibility requires the agreement of two physicians, the hospice medical director and the referring physician (or the primary care physician). One exception is when the hospice medical director is both the referring physician and will continue to follow the patient, in which case he/she is the only physician that need sign the *certification of terminal illness* (i.e. CTI). It is the responsibility of the hospice medical director to write a *narrative* that supports the patient's eligibility for hospice.

The Medicare Hospice Benefit (MHB) is funded under Medicare part A. This benefit consists of two initial and consecutive 90-day certification periods. This is followed by an unlimited number of 60 day periods. Each period requires a certification narrative by the medical director attesting as to the patient's continued eligibility. A patient may revoke hospice at any time if they decide to seek aggressive treatment and/or hospital care treatment of an acute illness that is non-related to the hospice diagnosis, such as a fall that has resulted in a hip fracture. Also, the patient has the right to change from one

hospice agency to another *only once during any certification period*.

#### CONTINUATION OF HOSPICE AFTER 180 DAYS

After the first two 90-day certification periods (i.e. after receiving services for 180 days) each subsequent 60-day certification period requires a *face-to-face* visit to determine continued eligibility (or not). This visit can only be performed by the hospice medical director or a nurse practitioner, the latter either employed by or contracted to the hospice. Neither the hospice designated physician of record nor a physician assistant can perform the FTF visit. It is not infrequent for a patient receiving hospice services to undergo a *live discharge* if the patient's condition plateaus and is no longer deteriorating and is determined to have a prognosis of *greater than 6 months to live*. In the author's experience this may occur in up to 5% to 10% of patients on hospice. However once discharged a person can elect to be re-admitted at a later time if further decline occurs to support a limited prognosis of 6 months or less.

Rarely a person may elect hospice for one diagnosis, for example cancer, while continuing to receive non-hospice treatment for another diagnosis such as heart failure or hemodialysis. However, if that person is subsequently hospitalized for the non-hospice diagnosis, then the person would need to temporarily revoke hospice to ensure that the hospice not be billed for the costs of hospitalization. Upon hospital discharge the patient may re-enroll in hospice if in the judgement of the hospice medical director that the patient has a prognosis of 6 months or less. This may require a face-to-face visit.

#### PRACTITIONER BILLING AND CODING FOR SERVICES PROVIDED

When a patient is enrolled in hospice, the attending physician of record should continue to bill under Medicare Part B as is usual for any clinical non-hospice visit. However, there are several exceptions to this. *First*, if the hospice medical director is serving as the attending physician of record, then he/she would directly bill the hospice using the appropriate place of service E/M code, who in turn would bill Medicare Part A. Upon receipt of payment, the hospice would then pay the medical director. *Second*, if the medical director, as the physician of record, is seeing the patient for a non-hospice diagnosis, then the visit should be billed under Medicare Part B and not bill the hospice. *And third*, if the patient on hospice sees a specialist who is not the hospice physician of record for the same hospice diagnosis (for example a cardiologist who is seeing a patient already on hospice services for CAD or heart failure) then the specialist should directly bill the hospice for their service including the costs of any related procedure or treatment and *not* bill Medicare under Part B. Often this requires the specialist to have a contractual agreement with the hospice. It is not uncommon that this does not occur and remains undetected by insurance payers. The hospice will often encourage that any potentially high cost hospice-related procedure or treatment be performed before admission to hospice. If not, the hospice will only be reimbursed by Medicare on the fixed hospice daily rate, irrespective of the cost of the specialist's treatment for which the hospice should be responsible.

#### SERVICES COVERED UNDER THE MHB

Medicare requires hospices to provide core services that include those of the hospice medical director, nursing (RN,

LPN, Aide), licensed medical social worker and counselling (chaplain, social worker), the former for spiritual and bereavement support.

*Non-core services* must also be available either based on appropriateness or medical necessity, that are supportive and congruent with the patient's goals of care as well as safety issues. Such services are either provided directly by the hospice staff or under contract. These may include physical, occupational, or speech language therapy, for example fall assessment and prevention, mobility issues, durable medical equipment or difficulty swallowing.

Dietary consultation may also be needed to determine appropriate food consistency and special diets including medical foods and recommendation on tube feeding as to the daily formula and water requirements. Other non-core services *may* include home maker services, though usually the family is responsible for such costs. The hospice agency *must have* a robust *volunteer program* that can provide company and errands, but *not hands-on care*. Medicare requires that a minimum of 5% of total patient hours under hospice be performed by volunteers. Some hospices may exceed this and achieve up to 10% or more!

All medication, durable medical equipment, medical and wound care supplies, laboratory and x-ray services that are related to the hospice diagnosis must be covered, as well as any emergency and transport services. Note that the costs of medication related to the hospice diagnosis and other comorbidities that support hospice eligibility, should be covered by the hospice. While medications not related to the hospice diagnosis are not required to be covered by the hospice and thus should be processed under the patient's health insurance. At present the hospice has the *option* to cover

the costs of non-hospice related medications, though in the future, Medicare may require hospice agencies to cover the costs of all the patient's medications.

In addition, procedures performed by a specialist such as a palliative thoracentesis or a paracentesis with / without placement of a Pleur-x drain should be charged to the hospice agency if the procedure is related to the terminal diagnosis. Agency's with a large patient census (usually over 100), may be able to cover expensive treatments such as a limited course of "palliative" radiotherapy for bone metastases if bone pain has been refractory to analgesics. Another example is that a blood transfusion may be warranted for palliation of severe dyspnea in a patient with heart failure which has worsened because of the anemia. Some hospices may even cover the costs of short-term IV inotropic therapy with the goal to palliate severe fatigue secondary to advanced heart failure. In the scenarios discussed, the primary goal is always to relieve patient suffering and improve his/her quality of life.

#### PAIN AND SYMPTOM MANAGEMENT AT END-OF-LIFE

In persons facing serious life-limiting illness, effective management of pain and non-pain symptoms is often challenging due to multi-morbidities, patient fatigue, cognitive impairment, a complex and ever changing medication regimen, caregiver burden / burnout, and goals of care that change as death approaches and when an unexpected medical or emotional crisis occurs (either in the patient or family / caregiver). The prevalence of non-pain symptoms is often greater than that of pain, and that pain may be the most prevalent symptom in persons with end stage COPD, heart disease, or renal failure than non-pain symptoms.<sup>(17)</sup>

For *any* symptom experienced by patients on hospice, a reasonable approach can enable practitioners and the hospice interdisciplinary team to intervene in a timely and effective manner.<sup>(18)</sup>

- **First**, recognize the presence of each symptom, then proceed to:
- Establish its intensity, temporal pattern, any exacerbating/ relieving factors, location, and effect on function and cognition.
- Determine whether the symptom is acute, chronic or intermittent.
- Identify any associated symptoms.
- Assess its impact on quality of life, ADLs, cognition, decisional capacity, sleep, mood, appetite, and dignity.
- Review previous and current treatments for the symptom.
- Perform an appropriate, timely, and symptom-focused physical exam.
- Ascertain, if possible, the likely pathophysiology underlying the symptom.
- Consider whether any medication could be causing or aggravating the symptom.
- Identify potentially reversible causes.
- If necessary, use the least invasive diagnostic testing, if any, to minimize patient pain, discomfort, or suffering.
- Given the above considerations, determine the most likely diagnosis (if possible).
- Always evaluate for the presence of any psycho-emotional, spiritual, religious, social, or practical factors to the symptom.
- Initiate palliative and traditional treatment based upon the primary illness, phase of illness, prognosis, comorbidities, patient/family preferences for care, and care setting.
- Consider benefits and risks of all treatments as well as any complementary

and alternative therapies especially if requested by patients and families.

Remember that any patient symptom can be complex and multifaceted. First consider if any nonpharmacologic and / or practical intervention may alleviate the symptom before prescribing a medication. If known, the medical and/or pharmacologic treatment should be focused on the ***underlying pathophysiologic cause of each symptom***. One should be cognizant of the ***principle of double effect*** where any treatment's ***primary intent*** must be to achieve symptom alleviation, even though there remains a risk to unintentionally cause harm or hasten death. The intent to palliate can be misunderstood by many people, either family or healthcare professionals, as an intent to kill the patient (euthanasia) and this must be addressed and clarified.

In the case of severe or intractable physical symptoms or intolerable existential, religious, spiritual or psychological suffering ***palliative sedation***, either intermittent or continuous, may be an option with the primary goal to maintain patient personhood and dignity.

### **PRACTICAL, NONPHARMACOLOGIC, AND PHARMACOLOGIC TREATMENT**

Though patients may present with a myriad constellation of distressful and concomitant symptoms, the following will review ***practical, nonpharmacologic and pharmacologic considerations*** for non-pain symptoms. Studies have shown that grouping of several symptoms may occur. For example, symptoms of fatigue, anorexia, and delirium may be manifestation of constipation without the patient feeling constipated. Several excellent resources have contributed to his review.<sup>(8,19,20,21,22,23)</sup>

**Disclaimer:** Note that many of the medications suggested to palliate symptoms are not FDA approved and yet have been found either empirically or through research to have been of some benefit. Practitioners should refer to usual medication pharmacopeia resources for dose information.

### ANOREXIA, CACHEXIA, LOSS OF APPETITE

Practical considerations:

- Consider anorexigenic effects of medication and treatments: chemotherapy, radiotherapy, digoxin, anticholinergics.
- Evaluate for presence of associated symptoms such as nausea, vomiting, constipation or pain.
- Assess for potentially reversible conditions such as urinary retention, fecal impaction, GERD, oral /esophageal candidiasis, xerostomia, pain, depression.

Nonpharmacologic considerations:

- Encourage small, frequent meals; try a variety and different tastes of food and sucking on hard candy to mask bad tastes. Consider cold or semi-frozen liquid nutritional supplements.
- Educate patient/ family/ caregiver that these symptoms are often associated and expected with progressive chronic illness and will only partially respond to interventions.
- Discuss lack of effectiveness and potential adverse effects of parenteral nutrition in advanced life-limiting illness.
- Address personal, cultural, ethical and legal aspects or conflict concerning nutrition and hydration at end-of-life, and acknowledge and address potential health care professional conflict.

Palliative pharmacotherapy considerations (appetite stimulants):

- Corticosteroids : dexamethasone, methylprednisolone, prednisone
- Progestin : megestrol (short term trial of 4-8 weeks)
- Other : dronabinol (usually limited by side effects): olanzapine (be aware of FDA black box warning) : omega-3 fish oil : thalidomide : mirtazapine

Corticosteroids may have a temporary effect for up to 4 to 8 weeks and are often administered in the morning to help prevent insomnia. Be aware that corticosteroids can worsen hypertension and hyperglycemia, especially in diabetes, cause fluid retention to result in peripheral edema, exacerbate heart failure and precipitate delirium especially in the elderly.

Megestrol is best prescribed short term, 4 to 8 weeks, to minimize the increased risk of DVT and pulmonary embolus. It mainly increases weight through fluid retention and increased fat stores with no gain in lean muscle mass. And can cause significant peripheral edema at doses of 400 mg to 800 mg a day. Omega-3 fish oil may increase lean muscle mass in cancer patients but does not have enough evidence to justify its use, especially in hospice patients who have a limited life expectancy. Thalidomide may have some benefit in patients with HIV/AIDS. Dronabinol should be used with caution in the elderly due its high risk to cause confusion. Cyproheptadine is rarely used long-term yet may be considered if other treatments are not effective. Consider mirtazapine administered at bedtime if a patient has the triad of weight loss, insomnia and depression. Be aware of its increased risk for causing *serotonergic syndrome* if

patients are taking other serotonergic medication.

DYSPNEA (AIR HUNGER, BREATHLESSNESS)

Practical Considerations:

- Consider possible adverse effects of medication.
- Evaluate for associated signs and symptoms such as anxiety, panic, and feelings of impending doom.
- Consider potentially reversible causes: aspiration, excess respiratory secretions, pneumonia, heart failure, pulmonary embolus, pleural effusion and /or anemia; if present optimize their medical management if benefit outweighs risk.

Nonpharmacologic Considerations:

- Use a fan blowing on face (trigeminal nerve V2); ensure a comfortable ambient room temperature and eliminate respiratory irritants (dust, pet odors, smoke, perfumes, strong meal odors, cleansers).
- Try re-positioning; if orthopnea use pillows, raise head of bed; encourage pursed lip breathing if COPD.
- Ensure patient is close to and has easy access to medication to relieve dyspnea and oxygen, if hypoxic.

Palliative Pharmacotherapy Considerations:

- Opioids : morphine, oxycodone, hydromorphone, (codeine)
- Bronchodilators : beta-2-agonists
- Anxiolytics : benzodiazepines

- Guaifenesin : Mucolytic
- Anticholinergics : glycopyrrolate; scopolamine, atropine O.S.(administered orally and sublingually)
- Oxygen therapy (?): only if hypoxemia is present

***Opioids are considered first-line treatment for palliation of non-anxiety triggered dyspnea.*** For mild dyspnea and to minimize the risk of respiratory dyspnea in an ***opioid-naïve*** patient, start with low dose of liquid morphine sulfate 20mg/ml at 0.125 ml (2.5 mg) or 0.25 ml (5mg) administered buccally or sublingually every 3 to 4 hours as needed (PRN) for episodic dyspnea or routine if symptoms are chronic. ***Note that an “opioid-tolerate” patient is one who has been tolerating a daily oral morphine equivalent dose of 60 mg for more than 7 to 10 days.*** Other opioids have similar benefit and should be prescribed at an Equianalgesic dose to morphine (see TABLE 5 on opioid interconversion). If the initial dose of opioid is not relieving dyspnea, up-titrate the total daily dose of the opioid by 25% to 50% over a few days. It is prudent to aim for a safe respiratory rate between 14 to 20. Use of codeine is not recommended due to its very constipating side effects. On the rare occasion of refractory dyspnea, consider a trial of nebulized morphine (use IV grade morphine) of 2.5 mg in 2 to 4 ml of 0.9% sterile normal saline. If dyspnea is triggered by anxiety, consider addition of low dose benzodiazepine, preferably lorazepam, but use with caution if already taking an opioid due to the increased risk of respiratory depression.



**Table 5.** Oral Morphine Equianalgesic Dosing (mg)<sup>(27)</sup>

	<u>Oral</u>	<u>Parenteral</u>	<u>Epidural</u>	<u>Intrathecal</u>
Morphine	30 mg	10 mg (1/3 oral dose)	1	0.1
Oxycodone	20-30 mg	N/A		
Hydromorphone	7.5 mg	1.5 mg (1/5 oral dose)		
Meperidine	300 mg	75 mg (1/4 oral dose)		
Hydrocodone	30 mg	N/A		
Codeine	180-200 mg	N/A		

(25 microgram fentanyl patch has an equianalgesic effect of 50 mg oral morphine/24 hours for 3 days)

Adapted from: American Pain Society. Principles of Analgesic Use. 7<sup>th</sup> edition. 2016; p 27-36.

Bronchodilators, especially administered via nebulizer may be helpful. However, their potential adverse effects of causing tachycardia, tremulousness and anxiety may limit their use. Also, this author is of the opinion that nebulizer treatments will “push” fluid into the lungs and thus worsen cough and congestion. Remember that deep suction often stimulates increased secretions and thus worsen dyspnea. It is not uncommon to concomitantly prescribe guaifenesin and an anticholinergic agent, as the latter will decrease respiratory secretions while the former has a mucolytic effect on excess secretions.

**Use of OXYGEN:** though the use of oxygen may alleviate severe hypoxemia, *there is no evidence it is of benefit in relieving dyspnea in non-hypoxemic patients.* In fact, administration of oxygen may diminish respiratory drive and precipitate carbon dioxide retention to suppress breathing and cause premature death. However, it is not an uncommon situation where families perceive their loved one’s dyspnea as very distressful to themselves and request that oxygen be administered. If oxygen is administered, ensure that flow rate is set at a safe level

such as 1 to 2 liters/ minute, with gradual up or down titration while monitoring for decreased mental status or apnea. Note that hypoxemia is common during the last hours and days of life, with patients experiencing no acute distress, and that the administration of oxygen can prolong the natural dying phase, resulting in excessive caregiver distress. Use of non-invasive ventilatory support (e.g. CPAP, BiPAP) by be warranted in special circumstances such as late stage COPD or ALS, if consistent with goals of end-of-life care.

#### NAUSEA AND VOMITING

##### Practical Considerations:

- Consider potential emetogenic effects of medication: chemotherapy agents, digoxin, opioids, NSAIDs, SSRIs
- Evaluate for presence of associated symptoms such as pain, constipation, acid reflux, anxiety.
- Assess for reversible medical causes such as gastroparesis, ileus, bowel obstruction, constipation, UTI, urinary retention, hypercalcemia, and other metabolic disturbances (hyperkalemia, uremia, ketoacidosis).

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- Consider anticipatory anxiety related to upcoming chemotherapy or other interventions.

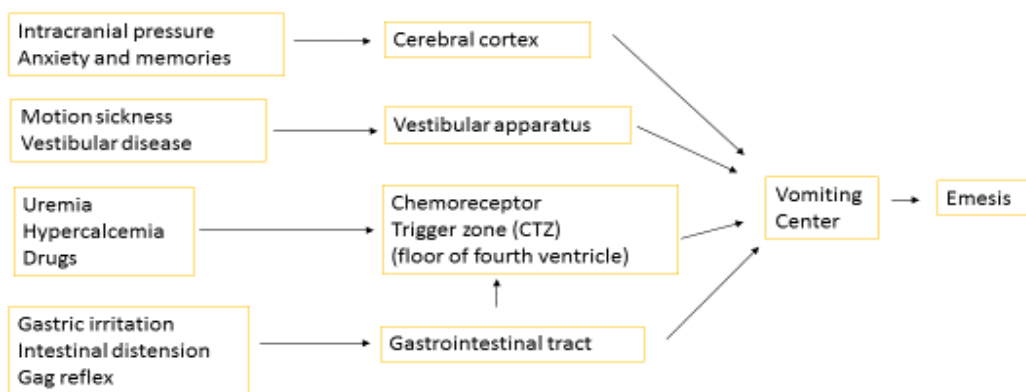
Nonpharmacologic Considerations:

- Offer smaller more frequent meals of bland food.
- Appropriate body positioning while eating and after or when being fed by PEG tube.
- Relaxation techniques.
- Reduce strong odors and visual stimuli.
- Improve air circulation and tolerable ambient room temperature.
- Lessen oral intake to that preferred by the patient or reduce feeding rate through a PEG tube and consider continuous rather than bolus PEG feeding.
- Evaluate effects on patient and family as it relates to mood, social interactions, and psychological impact.

Palliative Pharmacotherapy Considerations:

In determining the cause and most appropriate treatment for nausea and vomiting it is essential to understand the four different pathways that can lead to these symptoms and the neurotransmitters involved. (See TABLE 6). Nausea and vomiting involves the vomiting center in the medulla and the chemoreceptor zone located at the floor of the 4<sup>th</sup> ventricle and involves several neurotransmitters: serotonin, dopamine, acetylcholine and histamine. Thus anti-serotonergic, anti-dopaminergic, anti-cholinergic and anti-histaminic drugs can be effective either alone or in combination, especially if N/V has multiple causes or is refractory to treatment. In such a scenario, a combination of dexamethasone, metoclopramide and a low dose antipsychotic such as haloperidol or olanzapine may be considered. All these medications have CNS anti-emetic effects.

**Table 6.** Pathophysiology of Nausea and Vomiting<sup>(20)</sup>



Note: vomiting center is located in the medulla (brain stem)  
: CTZ stimulates vomiting center through serotonin, dopamine, acetylcholine and histamine.

Adapted from: AAHPM.UNIPAC 4,2017

1

Be aware of the potential side effects of serotonin receptor antagonists such as ondansetron (headache, constipation, fatigue, xerostomia), as well as anticholinergics and antihistamines (drowsiness, fatigue, confusion, dry mouth, constipation, urinary retention, blurred vision). Metoclopramide can induce extra pyramidal syndrome (EPS), dystonia and tardive dyskinesia. Low dose haloperidol (0.5-2mg) or olanzapine (2.5-7.5 mg) may be useful in alleviating nausea/vomiting, though not FDA approved for N/V.

Dronabinol can have an antiemetic effect though poor evidence of efficacy (start at 2.5 mg twice a day to maximum of 20 mg/day). Common adverse effects include somnolence, asthenia, paranoia, nausea, and vomiting. Opioid-induced nausea/vomiting may require either a dose reduction of the opioid or rotation to another opioid. If N/V is due to bowel obstruction, consider the addition of octreotide which acts to decrease intestinal secretions.

### CONSTIPATION

*Constipation should be considered the 6<sup>th</sup> vital sign* and its recognition and prevention is paramount when caring for hospice patients. As such, a thorough history and physical exam including a digital rectal exam is necessary. A KUB x-ray may be warranted in order to evaluate intestinal stool burden. Constipation is often unrecognized due to the presence of vague symptoms such as malaise, anorexia, altered mental status or a decline in functional status. Constipation can occur due to a combination of poor fluid intake, low dietary fiber, impaired mobility and constipating effects of drugs (including opioids) as well as advanced disease state.

### Practical Considerations:

- Consider constipating effects of medication: Opioids, anticholinergic muscle relaxants, iron or calcium supplements, calcium channel blockers, clonidine.
- Evaluate for associated symptoms.
- Assess for potentially reversible causes such as rectal fecal impaction, ileus or metabolic disturbances (hyperkalemia, hypothyroidism).
- Remember that a rectal fecal impaction can cause urinary retention and be the only manifestation of constipation.

### Nonpharmacologic Considerations:

- Ensure accessible toilets/establish a toileting routine.
- Encourage increased fluid intake, if tolerated.
- Consider a natural laxative such as prunes, prune juice, if tolerated.
- Address personal and cultural issues related to caregiver assistance or resistance to providing hands on care for fecal incontinence.

### Palliative Pharmacotherapy Considerations:

A stepped approach is suggested in *preventing* and treating constipation (see TABLE 7). Treatment should include, if possible, a reduction in the *anticholinergic load* caused by many medications such as calcium channel blockers, clonidine, tricyclics, antipsychotics, beta blockers, some diuretics and anticholinergic drugs prescribed for an overactive urinary bladder. Even ranitidine and warfarin have anticholinergic effects! Bulk-forming laxatives are usually *not* recommended because they can exacerbate constipation in patients who have poor fluid intake, as is often the case in hospice, and may cause or worsen bloating, nausea or

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vomiting. A reduction in the dose of the opioid may not be feasible.

Remember to prevent and recognize opioid-induced constipation: *as the dose of the opioid is increased, so must the laxative*

*regimen also be increased.* Stimulant laxatives such as senna are most effective for opioid-induced constipation. If severe constipation, consider oral lubiprostone or subcutaneous methylnaltrexone, though these are expensive. Prevention is best.

**Table 7.** Stepwise Regimen to Prevent or Treat Constipation *“The Sixth Vital Sign”*<sup>(18)</sup>

1. Begin with:	Senna with/without docusate	1-2 tabs/cap qd-bid
2. Titrate up to:	Senna	3-4 tabs bid
3. If needed <i>add</i> :	Sorbitol or lactulose Or Polyethylene glycol	17 g in 8 oz. water qd-bid
4. Consider, <i>in addition</i> :	Glycerin rectal suppository with/without bisacodyl rectal suppository	Scheduled qd-qod
5. If needed:	Mineral oil or soapsuds enema	
6. If rectal impaction:	May need digital disimpaction*	

\*Consider radiologic administration of a gastrografin enema if refractory to pharmacologic and manual disimpaction.

Stool softeners are considered to have poor effectiveness but can be initially prescribed in some patients when initiating their bowel regimen, i.e., the ‘laxative ladder’. Remember that some patients may also require concomitant use of a rectally administered lubricating agent (glycerin) and/or stimulant (bisacodyl) to ensure adequate rectal elimination of stool. Noted that a rectal fecal impaction can cause “paradoxical” diarrhea or urinary retention, either of which may not be evident. This often requires manual disimpaction, though a polyethylene glycol solution taken orally may be effective. In the rare case of a severe, refractory rectal fecal impaction, a gastrografin enema may be tried. This is radiologic procedure.

***Malignant bowel obstruction*** commonly occurs in the presence of metastatic ovarian or colon cancer, usually during the last weeks or days of life. Obstruction may resolve spontaneously with conservative management: NPO, NG suction, analgesics and fluids administered IV or SC (hypodermoclysis), the latter if congruent with the patient’s advance directives, goals of care, site of care and the hospice agency’s capability to do so. Consider an anticholinergic such as glycopyrrolate or scopolamine to lessen intestinal secretions and cramps; a steroid such as dexamethasone to reduce bowel edema and inflammation; an opioid to reduce pain; and an anti-emetic to control N/V; as well as octreotide to reduce intestinal secretions.

DELIRIUM

Delirium is an acute or subacute confusional state that is characterized by a fluctuating course through the day/night, inattention, disorganized thinking and speech, altered perceptions (delusions, hallucinations), emotional lability, worsened memory as well as psychomotor agitation or retardation. Delirium may manifest as **hyperactive, hypoactive, or mixed**. Keep in mind that any acute illness, medication or change in the patient's physical or "people" environment can potentially precipitate or be a contributing factor to the onset of delirium, especially in frail patients with advanced illness. Suggestions to the management of delirium include:

## Practical Considerations:

- Consider potential adverse effects of medication: opioids, anticholinergics, benzodiazepines, antipsychotics, steroids, marijuana.
- Evaluate for the presence of associated symptoms: fever, insomnia, pain.
- Have a high level of suspicion as to undetected potentially reversible conditions such as infection, constipation, pain, urinary retention and metabolic disorders.
- Assess for possible **medication withdrawal syndrome** from opioids, benzodiazepines, alcohol.

## Nonpharmacologic Considerations:

- Familiarize the patient to the physical and people environment and ensure a quiet environment.
- Speak in simple short sentences/questions.
- Attempt to focus the patient's attention to the present, but do not contradict what the patient believes or says.
- Improve night time sleep and if possible the patient's sleep-wake cycle.

- Optimize hearing and eyesight (hearing aids "in", ensuring batteries are charged, and eyeglasses "on" with clean lenses).
- Encourage oral fluids and liquid nutritional supplements.
- Reduce immobility by removing physical restraints, that can even include a Foley catheter, oxygen tubing or use of continuous oxygen pulse oximetry!

## Palliative Pharmacotherapy Considerations:

Pharmacologic treatment of delirium can be challenging due to altered pharmacokinetics and pharmacodynamics of drugs due to the presence of impaired GI drug absorption and circulatory distribution and deterioration of liver metabolism and renal excretion. Pivotal to the management of delirium is to treat the symptoms of delirium side-by-side with treating the medical condition(s) that have led to the delirium. Delirium should be considered an emergency that can compromise patient safety and as well the safety of the family/caregiver and the hospice staff, and compromise the patient's dignity.

If delirium persists despite practical and nonpharmacologic interventions, then pharmacologic intervention is warranted.

- Consider treatment with low-dose haloperidol; **no more than a total daily dose of 2 to 3 milligrams; OR**
- A **low dose benzodiazepine**, usually lorazepam liquid concentrate 0.5 to 1.0 mg PO/SL every 6 to 8 hours as needed or scheduled, **OR**
- Valproic acid 125 to 250 mg po every 8 to 12 hours, often upon awakening, early to mid-afternoon and evening / bedtime.
- Concomitant use of haloperidol and lorazepam is often warranted, but can cause excessive sedation.

A not uncommon cause of delirium is *opioid toxicity*. Both haloperidol and lorazepam can cause *paradoxical agitation* in which case their dose should be *decreased*, not increased, or discontinued. Remember that antipsychotics have a **FDA black box warning** as to increased risk of death especially when prescribed to persons afflicted with dementia.

Occasionally 10% to 30% of patients follow a *“difficult road”* to death and experience a *terminal hyperactive delirium* manifested by confusion, restlessness, hallucinations and myoclonic jerks and possible seizures and eventual comatose state. The remaining 70% to 90% follow the *“usual road”* with onset of sleepiness that progresses through lethargy, obtundation, to a semi-comatose / comatose state and death. Terminal delirium is a true crisis that requires timely recognition and treatment, and may be potentially preventable with judicious use of those medications just discussed.

*Note that opioid toxicity can mimic a terminal delirium* and should be suspected if onset of myoclonic jerks of the torso and extremities. In this author’s experience this has occurred several times. With careful down-titration of the opioid, the myoclonic jerks and the delirium may resolve and avoid premature death. In some cases of a terminal delirium practitioners may not be able to decrease the opioid dose without losing good pain control. In such a situation clonazepam may be effective to treat the myoclonic jerks.

#### WEAKNESS/ FATIGUE/ LOSS OF ENERGY

These symptoms commonly occur in patients with advanced illness and worsen during the last 6 months of life for patients on hospice care. As discussed in previous sections, it is important to consider the

adverse effects of medication as a contributing factor, to elucidate associated clinical signs and symptoms, and to treat potentially reversible conditions. These symptoms often present with increasing daytime sleepiness/ sleep with the patient eventually becoming bed ridden.

#### Nonpharmacologic and Practical Considerations:

- Provide realistic prognostication and education to patient and family that these symptoms are in keeping with expected course in the advanced / terminal phase of his/her illness.
- Encourage the patient to better conserve energy by pacing activities and limiting social/ family visits if contributing to their exhaustion, be it physical, emotional and / or spiritual/ religious.
- Consider psychosocial interventions or therapy.
- Encourage good sleep hygiene, nutrition and pain control.
- Consider short-term physical therapy specially to improve safety of transfers and ambulation and to prevent falls.

#### Palliative Pharmacotherapy Considerations:

Once reversible etiologies of fatigue have been ruled out consider methylphenidate or modafinil, though the majority of trials have demonstrated little or no efficacy. However, under certain situations a trial may be reasonable, but with careful monitoring as to potential side effects.

- Methylphenidate: start with low dose of 2.5 mg twice daily to be administered in the early and late morning; if tolerated, may increase to 5 mg twice daily, but not a higher dose (author’s recommendation). Discontinue if no improvement in 1 to 2 weeks. Prudent

use is advised in patients with heart disease or hypertension.

- Modafinil: limited research: expensive so unlikely to have costs covered by hospice.
- Consider caffeinated beverages.

### ANXIETY / DEPRESSION

At end of life patients commonly suffer from anxiety and depression related to psychiatric, psychological and spiritual religious distress. These symptoms are thoroughly discussed in UNIPAC 2 published by the American Academy of Hospice and Palliative Medicine. As the use of anxiolytics and antidepressants is well known to practitioners this will not be discussed in this review. However, several factors can contribute to these symptoms. These include patient burden of non-pain and pain symptoms, degree of connectedness to family and community, dignity, finding meaning to one's life and leaving a legacy (or not), being forgiven or not by family and others. The hospice must aim to balance a sense of hope (*"hope for the best"*) while helping the patient to transition through the last months, weeks and days of life (*"prepare for the worst"*).

#### Practical Considerations:

- Provide empathic listening and supportive counselling to patient, family, and caregivers. It is the responsibility of all members of the hospice interdisciplinary team to do so, including volunteers, practitioners and not uncommonly the patient's community religious or spiritual leader.
- It is imperative to address the severity of depression and any suicidal ideation, as well as patient's access to means to commit suicide and to remove accessibility to these means. Psychiatric consultation, possibly inpatient evaluation, may be necessary.

- Encourage patient in life review, meaning of life and the search for meaning in dying.
- Facilitate social interaction and if tolerated, engage in recreational and distracting activities that provide individual patient meaning and satisfaction to every day.
- Consider holistic interventions such as guided imagery, aromatherapy, massage, sand therapy and dignity therapy.
- Support family and caregivers in adopting positive coping skills.

### PAIN MANAGEMENT AT END-OF-LIFE

Effective pain management is the *cornerstone* to the provision of high quality palliative and end-of-life hospice care. It is essential for nurses and practitioners to recognize that pain is often an underlying factor to other distressful symptoms experienced by patients. The primary goals of the treatment of pain are:

- To relieve pain and suffering
- To prevent both loss of function and onset of disability
- To maintain decision making capacity
- And to preserve dignity

The International Association for Study of Pain has defined pain as "an unpleasant sensory or emotional experience associated with actual or potential tissue damage". The literature on pain management is extensive so readers of this article are encouraged to access excellent up-to-date resources, such as Geriatrics at Your Finger Tips, published annually by the American Geriatrics Society (AGS)<sup>(21)</sup>; and UNIPAC 3, Pain Assessment and Management, 5<sup>th</sup> edition, published by the American Academy of Hospice and Palliative Medicine in 2017.<sup>(19)</sup> Other informative resources are the AGS guidelines on the pharmacologic management of persistent pain in older

persons<sup>(26)</sup> and Principles of Analgesic Use, 7<sup>th</sup> edition (2016) published by the American Pain Society<sup>(27)</sup> Thus this article will more briefly review key components to the assessment and treatment of pain to include indications to prescribing nonopioid analgesics and the judicious and safe use of opioids at end-of-life.

Key components to the *evaluation* of pain include:

- Perform a focused history and physical exam, with particular attention to those body regions or organ systems related to the pain.
- Inquire as to any associated signs and symptoms.
- Assess the need for any diagnostic testing.
- Review previous and current treatments and their effectiveness in relieving the pain, including complementary and alternative medicine treatments.
- **Prevent** the occurrence of pain. For example, prescribing a steroid in an attempt to lessen the likelihood of post-herpetic neuralgia.
- **Anticipate** the occurrence of pain. Examples include postsurgical incisional pain, onset of peripheral neuropathy in diabetics or those receiving chemotherapy, or bone pain in cancer patients who have known or likely to develop bone metastases.
- Observe for **nonverbal cues** of pain such as guarding with movement or repositioning, rubbing, grimacing, agitation, restlessness, insomnia, irritably, withdrawing behavior, decreased mobility.
- Establish the pain's location(s), intensity, temporal pattern, any exacerbating or relieving factors, and effects on function and cognition, consider using a pain assessment scale.

Many scales are available and most can be converted to a numerical scale from "0" to "10".

- Determine whether the pain is **acute** or **chronic** (duration of 1 month or more), intermittent or **breakthrough** pain, and whether multiple sources and causes of pain are present.
- Clarify whether the pain is **nociceptive**, **neuropathic** or **inflammatory** in nature.
- Assess "**total pain**" i.e. its physical, psycho-emotional, social and religious / spiritual dimensions, as well as the person's cultural beliefs as to the meaning of pain and the manner of expressing and enduring pain.
- **Finally**, determine the most probable cause(s) for the myriad types of pain the patient is experiencing. Always evaluate for potentially reversible causes.

**Remember** that conditions such as headache, bladder spasms, contractures, improper positioning, pressure skin ulcers, muscle strain, oral thrush, urinary retention, fecal impaction, and a DVT can all cause pain. Thus pain must not be treated for pain's sake but its underlying cause be determined in a timely manner and appropriately treated.

Key components to the *treatment* of pain include:

- Determine treatment options taking into account the patient's current health status, prognosis, and any known advance directives for health care, including DNR status.
- Conduct a thorough discussion to ensure informed choice(s) by the patient, family and/or caregiver.
- Establish an interdisciplinary treatment plan appropriate to the patient's setting of care (i.e. home, nursing facility, residential/ assisted living, or hospital)



- *Set personal goals for pain relief*, to include desired and acceptable severity of pain, self-care, mobility, desired personal and recreational activities, improved sleep, mood, and cognition. A patient may accept a certain level of sedation from opioids in order to achieve adequate relief of pain.

Up to 90% of patients can have their pain adequately controlled with orally administered analgesics using the World Health Organization (WHO) *Three-stepped Analgesic Ladder* (see TABLE 8). The *five guiding principles* to the administration of analgesics are hereby reviewed. Administer analgesics:

**Table 8.** The WHO 3-Step Analgesic Ladder

		<b>3. Severe</b>
	<b>2. Moderate</b>	Morphine
<b>1. Mild</b>	A/Codeine	Hydromorphone
ASA	A/hydrocodone	Methadone
Acetaminophen	A/Oxycodone	Levorphanol
NSAIDs	A/Dihydrocodeine	Fentanyl
	Tramadol/apap	Oxycodone
+Adjuvants	+Adjuvants	+Adjuvants

Adapted from: Technical Report Series 804. Geneva: WHO. 1990

Note: an adjuvant analgesic may be prescribed at any level of pain.

- By mouth: whenever possible prescribe an oral analgesic. Avoid IM injections as they can be painful; subcutaneous injections are less painful. Opioids in a concentrated liquid form can be administered sublingually or transbuccally.
- Around the clock: scheduled dosing for continuous pain and to minimize breakthrough pain.
- According to the ladder: the initial choice of analgesic and use of adjuvants is based on the severity of the pain. Using a numerical pain scale, 1-3 can be considered mild pain; 4-6 moderate pain; 7-9 severe pain; and 10 excruciating pain or the most severe pain.
- Adapted to the individual: the choice of analgesic should be based upon the patient's condition, comorbidities (such as liver and kidney failure; coexistent dementia or delirium), drug safety and

toxicity profile, ease of administration, and goals of both pain relief and the overall desired outcome. (i.e. acceptable level of pain).

- With attention to detail: ensure correct dosing: consider drug pharmacokinetics and pharmacodynamics; make appropriate dose adjustments in timely manner, always monitor benefit versus potential harm and adverse effects.

Effective management of pain entails prescribing the most appropriate analgesics based upon diagnoses, the pathophysiologic mechanism underlying the pain (see TABLE 9): on Selection of First and Second Line Analgesic Based on the Type of Pain), pain severity, the potential adverse effects of each medication and treatment modality and the patient's individual organ function that can alter each drug's pharmacokinetics and

pharmacodynamics (especially renal and hepatic, as well as GI absorption or malabsorption).

**Table 9.** Select First and Second Line Analgesics Based on Type of Pain<sup>(19)</sup>

Type of Pain	Consider First Line	Consider Second Line
Nociceptive pain	WHO step 1 or 2 drug	WHO step 3 drug
Neuropathic Pain	TCA's, anticonvulsants	WHO step 2 or 3 drug
Bone Pain	NSAIDs, corticosteroids	WHO step 2 or 3 drug
Intracranial Pain	Corticosteroids	WHO step 2 or 3 drug
Visceral Pain	Anticholinergic, opioid	Steroids, opioids

Source: UNIPAC Three. AAHPM. 2017

Helpful caveats to ensure effective pharmacologic management of pain:

- In most patients, prescribe at least one analgesic as scheduled, i.e., administered routinely, rather than just as needed (i.e. PRN).
- Choose an appropriate analgesic and dose for breakthrough pain.
- Most types of pain respond, at least partially, to an opioid.
- The maximum dose of acetaminophen is 3000-4000 mg/day, but 2000 mg/day may be prudent if renal or hepatic insufficiency is present.
- Care must be used when prescribing an opioid/acetaminophen combination as the recommended ceiling dose of acetaminophen (no more than 4000 mg) may be reached before pain is adequately controlled.
- The maximum dose of tramadol is 300 mg/24 h: it may precipitate confusion, seizures, and serotonin syndrome.
- Conventional nonselective NSAIDs (e.g., ibuprofen, naproxen) should only be used short term, that is days to 3-4 weeks; precautions include risk for gastrointestinal bleeding, renal impairment, platelet dysfunction, worsened edema, increased blood pressure, or worsened heart failure.
- Selective COX-2 inhibitors (e.g., celecoxib) still have a significant risk of GI bleeding and renal insufficiency.
- Consider discontinuing aspirin chemoprophylaxis when administering a NSAID or COX-2 inhibitor.
- Consider concomitant proton pump inhibitor therapy in patients at increased risk for GI bleeding when prescribing a NSAID or those taking aspirin.
- Never prescribe a NSAID if the patient is taking warfarin as the risk for GI bleeding is high.
- Consider use of topical analgesic such as capsaicin cream, diclofenac gel or a

lidocaine patch for persons with one or two localized areas of musculoskeletal, arthritic or neuropathic pain.

- Remember use of the lidocaine patch it is to be applied for only 12 hours each 24-hr period, off the remaining 12 hr, and applying no more than three patches at a time.
- Avoid use of meperidine due to its potential for causing undesirable CNS side effects such as confusion or seizures.
- Partial opioid agonists such as butorphanol, pentazocine, buprenorphine and nalbuphine are *not* recommended because of their analgesic ceiling effects and ability to counteract the analgesic effect of pure agonist opioids. These medications can either precipitate an opioid-withdrawal pain crisis or lessen the analgesic effects of other opioids.

#### SAFE USE OF OPIOIDS AT END OF LIFE

Judicious prescribing of opioids can provide effective control of moderate to severe pain and dyspnea for patients at end-of-life. Caution must be taken to avoid abruptly reducing or discontinuing an opioid as this can result in severe withdrawal symptoms. Practitioners also need to be

cautious as some patients may have an *opioid use disorder* and/or *other substance use disorder*. Opioid diversion can also occur. The hospice interdisciplinary team is often aware of these issues and must take steps to address them.

#### GUIDELINES TO PRESCRIBING OPIOIDS

- For acute pain: start by prescribing an immediate-release opioid.
- For chronic pain: consider prescribing a sustained-released opioid with a sufficient dose of an immediate release opioid for breakthrough pain.
- Remember that the total dose of a mixed opioid (i.e., an opioid with acetaminophen) is limited by its 24 h dose of acetaminophen.
- Once the total daily dose of an immediate release opioid has been able to adequately control the patient's pain, consider converting it to an equivalent dose of a sustained release opioid.
- Note that the duration of analgesic action for all immediate-release morphine preparations is 3-4 h whether administered PO, SL, SC, or IV. Though the onset of action and peak analgesic effect do vary (see Table 10).

**Table 10.** Pharmacodynamics of Immediate Release Morphine

Administered	Peak analgesic effect (min)	Duration of analgesia (h)
Oral/sublingual	45-60	3-4
Subcutaneous	15-30	3-4
Intravenous	5-15	3-4

Note: Irrespective of route of administration of morphine, duration of analgesia is 3-4 hours.

- The opioid dose for breakthrough pain is 10-15% of the total daily opioid dose, administered as often as every 1-2 h if needed.
- One can usually safely daily uptitrate the total 24 h dose of an opioid 25-50% for mild to moderate pain and 50-100% for moderate to severe pain.
- When starting a patient on an opioid, **ALWAYS start the patient on a prophylactic bowel regimen to prevent constipation.** A stimulant and/or osmotic agent are preferable.
- The use of an **adjuvant analgesic** can often allow a lower dose of opioid to be used and thus lessen the likelihood of opioid adverse effects.
- Monitor for the development of common and less common side effects of opioids (see Table 11)
- Adverse effects to an opioid may require “rotating” to another opioid, especially if adequate pain relief is not achieved despite increasing doses of the opioid (see Table 5 on the equianalgesic dosing of opioids).
- It is **NOT** recommended to use three or more different opioids because of the potential for adverse drug-drug or opioid receptor interactions. Different opioids interact to different degrees at the **mu, delta and kappa opioid receptors.**
- Avoid the use of meperidine due to its high potential to cause CNS toxicity, and codeine is too constipating.
- For a patient on a transdermal Fentanyl patch, use an immediate release opioid for break-through pain, either as an oral tablet or a sublingual concentrate of morphine or oxycodone.
- Transmucosal oral fentanyl (i.e. Actiq®) is **only** indicated for severe **breakthrough cancer pain.**
- **Scheduled doses of methadone can be used to treat chronic pain but should never be given PRN for breakthrough pain due to high risk for respiratory depression.**

**Table 11.** Common and Less Common Side Effects of Opioids<sup>(18)</sup>

Common	Less Common
Constipation	Hypotension
Somnolescence	Diaphoresis
Nausea/ Vomiting	Urinary retention
Dizziness	Confusion, delirium
Sweating	Bradycardia
Dry mouth	Seizures
Asthenia	Respiratory depression, apnea
Dysesthesias	Paralytic ileus
Pruritus	Paresthesia, hyperesthesia, hyperalgesia
Falls	Shock, cardiac arrest
	Osteopenia, hypogonadism

INTERCONVERSION OF OPIOIDS

Circumstances may occur that require a patient be converted from one opioid to another. These include inadequate pain relief despite increasing doses of the opioid (tolerance), adverse opioid side effects, formulary coverage or non-availability, or suspected opioid diversion. Also, morphine may require conversion to another opioid in the presence of renal or hepatic insufficiency due to potential accumulation of its active metabolites resulting in toxicity. In such a case hydromorphone or oxycodone may be considered. Note that both methadone and fentanyl have inactive metabolites, but special knowledge is required to ensure their safe use and is best prescribed under the guidance of the hospice medical director or a palliative or pain care specialist.

*General guidelines to ensure the safe conversion from one opioid to another* include the following:

- The dose of each opioid is based on its estimated equal analgesic effect as compared to the analgesic effect of 30 mg of oral morphine. For example, oral hydromorphone 7.5 mg has an analgesic equivalent dose as oral morphine 30 mg.
- Due to *incomplete cross-tolerance* the relative conversion for the total daily dose of the new opioid should be **reduced by 25% to 50%.**
- When converting from one opioid to another it may be prudent to do so over 2 to 3 days with down titration of the opioid being discontinued, coupled with up titration of the newly prescribed opioid.

The dosing regimen in the conversion Table 5 is based on the premise to prevent opioid overdosing or underdosing when converting from one opioid to another.

Caution is warranted when using conversion calculators available on the Internet as errors can easily occur. If the latter are used, it is strongly recommended that the conversion table in this article be used as a quick check as to the correctness of the opioid conversion. The hospice medical director and nurse case manager should be knowledgeable on the opioid conversion guidelines. Further discussion is beyond the scope of this article. However, Mary McPherson Pharm D has written an excellent book on opioid conversion calculations<sup>(28)</sup>.

HOSPICE CARE DURING THE LAST WEEKS/DAYS OF LIFE

Irrespective of where the patient resides, it is essential to maintain patient hope, dignity and quality of life until death. Eventually, the continuation of life-sustaining treatments such as PEG tube feeding, antibiotics, pacemakers, ICDs, and hemodialysis can become burdensome, causing more harm, pain and suffering than benefit. The physiologic process of dying and its accompanying symptoms are at times complex and challenging and can be effectively managed by practitioners and the hospice. Palliative drugs, equipment and supplies should be readily available in anticipation of symptoms that are likely to occur or worsen.

As death approaches, patients and families should be advised that fatigue and weakness will increase while the desire for food and fluid intake is reduced. Reduced cardiac output and intravascular volume depletion result in tachycardia, hypotension, peripheral cooling, cyanosis, and mottling. Urine output will diminish with eventual anuria. Neurologic dysfunction will occur, leading to decreased level of consciousness and eventual coma. Ten percent of patients

may experience an agitated delirium during the last days of life.

Practical interventions to maintain patient comfort include periodic repositioning; decreasing food and fluid intake to prevent choking or aspiration; maintaining a moist oral mucosa; and providing moisture and lubricating agents to the conjunctiva and lips. Family members should be encouraged to participate in this care as it can often provide them with a sense of fulfillment in having helped to comfort their loved one at end of life.

Nonessential drugs (e.g. aspirin, multivitamins, calcium supplements, lipid lowering agents) should be discontinued. Practitioners should also consider the benefits and risks of continuing any medications not needed to maintain the patients comfort such as antidepressants, antihypertensives, warfarin, and thyroid replacement. Other drugs, such as diuretics, ACE inhibitors and hypoglycemic agents (even insulin) may require a dosage reduction or even discontinuation. Reduced hepatic function and renal perfusion can precipitate an opioid-induced terminal delirium. If this occurs, consider reducing the opioid dosage while ensuring that pain is still adequately controlled. During the last few days of life judicious, medication management is essential to avoid polypharmacy and its potential sequelae, especially as “comfort medications” are administered to manage pain and distressful symptoms and suffering. Remember that a ***peaceful death is just as important to the family*** as to the patient, perhaps even more so.

General guidelines on the use of comfort-focused pharmacologic interventions during the last of life hours and days include:

- ***For tachypnea or breathlessness***: use an immediate release opioid or liquid concentrate with or without a benzodiazepine, each administered sublingually or transbuccally.
- ***For excessive respiratory or oral secretions***: consider an anticholinergic agent administered sublingually (e.g., hyoscyamine or an ophthalmic solution of atropine) or topically (e.g., transdermal scopolamine patch). It is beneficial to educate the family and staff to avoid suction as it will stimulate the production of even more secretions.
- ***For pain***: use a concentrated liquid oral formulation of either morphine (e.g., 20 mg/cc) or oxycodone (20 mg/cc). Either can be administered sublingually or transbuccally and the pharmacist can provide in a higher concentration. Avoid IM or SC injections if possible as these can be painful.
- ***For anxiety***: use a benzodiazepine or an opioid, possibly an antipsychotic. Remember that these medications can cause *paradoxical agitation*.
- ***For terminal restlessness or delirium***: perform a careful medication review and rule out a rectal fecal impaction or urinary bladder retention. Ensure adequate pain control. Consider treatment with an antipsychotic, with or without a benzodiazepine.
- ***For fever***: if distressing to the patient, schedule doses of acetaminophen administered orally, per rectum or per PEG (if present).
- ***If excessive sweating***: Review medications, consider cooling the room or use a fan and consider an opioid dose reduction (as opioids can cause sweating).
- ***For urinary incontinence / retention***: consider placement of a Foley catheter to prevent skin breakdown or abdominal discomfort from a distended urinary

bladder. This is not an uncommon occurrence due to either a rectal fecal impaction or as an adverse drug effect from an opioids that can cause atonia of the bladder.

Compounded formulations applied topically on the skin may be effective for restlessness, though evidence is lacking. For example, ABH gel compound that contains a mixture of lorazepam, diphenhydramine, and haloperidol. Review of compounded topicals is beyond the scope of this chapter so practitioners are encouraged to contact their local compounding pharmacy and hospice agency.

### Summary

Practitioners must ensure that patients with serious life-limiting illness who have chosen to forgo disease modifying treatment (curative care), have access to high quality palliative care at end-of-life. As such, practitioners should establish familiarity with no more than 2 or 3 hospice agencies to whom to refer patients and, if possible to remain the physician of record as they best know the patients, families, and caregivers. The practitioner's trusting patient relationship and knowledge of patient values and preferences for care can be paramount to ensuring timely and effective care for patients enrolled in hospice. To do so requires practitioners to acquire knowledge, core skills, and both clinical and cultural competencies in hospice care and self-assurance to manage those pain and nonpain symptoms that patients experience during the last months, weeks, and days of life.

### Pearls for Practitioners

- Recognition of the **4 illness trajectories** that often lead to eventual death should encourage practitioners to initiate a discussion with patients and families to

determine goals of care when patients are confronted with serious life-limiting illness.

- **General indicators** and **clinical parameters** that may prognosticate the likelihood of death within 6 to 12 months can forewarn practitioners as to a patient's terminal condition.
- Be cognizant that a patient's **goals of life** may supersede and determine subsequent goals of care.
- Knowledge of the **disease-specific eligibility guidelines for hospice** can help practitioners recognize that a patient likely has a prognosis of less than 6 months to live if the patient's condition follows its natural and anticipated progression; and to recognize that a patient is in a "pre-hospice" phase of illness that still could benefit from non-hospice palliative care.
- Practitioners' understanding of the **four levels of care** provided by the Medicare Hospice Benefit can ensure patients receive the intensity of hospice service required to alleviate distressful symptoms in order to ensure death with dignity.
- Ensure that **hospice myths** believed by patients, family members, and health care professionals are recognized and dispelled as these myths can delay timely referral (or no referral) to needed hospice and palliative care.
- Know the **role of the hospice medical director** as to the certification of hospice eligibility, face-to-face visits, and the overall administrative and clinical responsibilities related to the hospice

patient's overall supervision and coordination of care.

- The **first two certification periods** for hospice are each of 90 days duration and all subsequent periods 60 days duration; with each 60 day period requiring a face-to-face visit to verify continued eligibility that can only be performed by either the hospice medical director or a nurse practitioner, the latter either contracted or employed by the hospice.
- Similar to home health and hospital admissions, *the costs of hospice is reimbursed under Medicare Part A*; while practitioner rendered services are billed under Medicare Part B. Note that if the hospice medical director is the hospice attending of record, then he/she should directly bill the hospice.
- All *specialist care and specialist-related procedures related to the treatment of the terminal hospice diagnosis* should be directly billed to the hospice, not Medicare Part B. This often requires the specialist to have an agreement with the hospice as to appropriateness and coverage of these costs.
- *Core* and *non-core* services provided under the Medicare Hospice Benefit are explained to patients and the patients' representatives upon admission to hospice. As such, practitioners should also be cognizant of these services and any *non-covered services*.
- The *costs of any laboratory test or X-rays*, for example, that are warranted for practitioners to *treat the terminal diagnosis* should be covered by the hospice, especially in those persons who are home bound or residing at an assisted living or nursing facility.
- When managing distressful symptoms, it is vital that both the hospice and practitioner *consider practical, non-pharmacologic and pharmacologic interventions*, in addition to judicious determination of inherent risks and burdens verses desired and anticipated benefits.
- *Note that many medications may not be FDA-approved* for the conditions being treated by the hospice, yet are appropriate to palliate patient symptoms.
- There is no evidence that administration oxygen is of patient benefit in relieving dyspnea in *non-hypoxemic patients*, but may actually hasten death due to a decrease in respiratory drive as a result of carbon dioxide retention.
- *Conversely, administration of oxygen during the last days of life can prolong dying and eventual death* and this can be very distressful to families.
- *When prescribing an opioid, remember to always prescribe a bowel regimen* to prevent constipation and to intensify the bowel regimen as the dose of the opioid is increased.
- Remember the *mode of action* of each medication prescribed to prevent/treat constipation; a stool softener, stimulant and an osmotic agent are often necessary and should not be considered as duplicative therapy, but synergistic.
- *Use of fentanyl and methadone* for the treatment of pain is best prescribed and monitored by the hospice medical director or a palliative care specialist.



- ***Only the cost of medication prescribed to treat the hospice terminal diagnosis*** and significant contributing conditions are required to be covered by the hospice. In addition, ***analgesics are usually covered*** in order to provide patient comfort irrespective of the terminal diagnosis.
- The hospice may consider ***intermittent or continuous palliative sedation*** or ***patient controlled analgesia*** to alleviate intractable pain or emotional existential or spiritual suffering that persists despite aggressive palliative treatment.
- ***Become proficient in the safe interconversion from one opioid to another***, remembering that ***cross-tolerance*** often requires the daily calculated opioid dose to be reduced by 25% to 50%.
- Lastly, remember ***practitioner's self-care*** is imperative to prevent professional and personal burnout.

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