

## **IMPROVING CARE AT END OF LIFE: Essential Issues**

### **Self-Study Packet & Test**

*A Professional Education Training Program for **Two** Contact Hours from:*

Baptist Health South Florida

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## **IMPROVING CARE AT END OF LIFE: Essential Issues**

### **Instructions for completion of this self-study.**

1. Please read the complete Self-Study Guide educational course material.
2. Answer the questions on the Post-Test.
3. The passing score is 80% on the Post-Test.
4. A continuing education certificate will be issued upon successful completion of the Post-Test.

### Objectives

- Participants will demonstrate core knowledge of palliative care
- Participants will recognize the critical role healthcare providers play in end of life/palliative care and its benefits to patient and families
- Participants will be able to understand legal and ethical issues related to palliative care/end of life.

## IMPROVING CARE AT END OF LIFE: Essential Issues

*In our system, it is easier to get open-heart surgery than Meals on Wheels, easier to get antibiotics than eyeglasses, and certainly easier to get emergency care aimed at rescue than to get sustaining, supportive care.* Joanne Lynn from *Travels in the Valley of the Shadow*

### INTRODUCTION

Regarding care at end of life, there is good news and bad news. The good news is that the medical community is giving the issue greater attention. Many public and professional organizations are working to improve palliative/end-of-life care, and increasing numbers of medical and nursing schools now include the topic in their curriculums. The Joint Commission (TJC) has also devised guidelines for end-of-life care that benefit both patients and the medical professionals who care for them (Table 1). In 2009, TJC implemented the *Palliative Care Certificate Program* which will be similar to programs for diabetes and stroke care.<sup>31</sup>

The bad news is that many people suffer at the end of their lives. In the hour or so it takes the reader to read this self-study, hundreds of people in this country will have died a horrible death. For some, the circumstances surrounding their death, such as being in an accident or being the victim of a homicide, precluded the possibility of preventing suffering. Many others, however, left this world experiencing psychosocial, spiritual, and/or physical distress that could have been alleviated.

The purpose of this self-study is to provide the reader with the latest information about palliative/end-of-life care and to stimulate personal reflection. Furthermore, the authors and reviewers hope that the study will encourage the reader to help improve palliative/end-of-life care for patients at his or her institution. The resources listed at the end of this study will prove very helpful for readers looking to take steps in this direction.

### CORE PRINCIPLES

Discussions about palliative/end-of-life care should focus on several core principles:

- autonomy (self-determination)
- beneficence (doing good)
- nonmaleficence (avoiding harm)
- veracity (truth-telling)
- confidentiality (respecting privileged information)
- fidelity (keeping promises)
- justice (treating people fairly)

While providers should attempt to honor all of the principles, it should be noted that reinforcing one principle may unintentionally violate another. Sometimes this cannot be avoided. Nor does it mean that the “moral compass” in a particular palliative/end-of-life scenario has gone askew.

For example, truth telling can be a point of tension among patients, families and caregivers, yet patients also have the right to refuse to be told information. Likewise, the principle of double effect invokes the principles of beneficence, yet has the potential to violate the principle of nonmaleficence. This does not negate the morally positive aspects of such an act. As one source has noted, “the increasing titration of medication to achieve adequate symptom control (beneficence), even at the expense of life (doing harm), thus hastening death secondarily, is ethically justified.”<sup>2</sup>

Over the years many groups have adopted policy statements and guidelines that embrace core principles regarding palliative/end-of-life care. In 2006, the National Consensus for Quality Palliative Care established Clinical Practice Guidelines through consensus of five major United States palliative care organizations which supports to improve clinical practice throughout the continuum of care in all health care settings, during all stages of debilitating chronic or life-threatening illness or injury. The National Quality Forum (NQF) identified palliative care and hospice care as national priority areas for healthcare quality improvement and endorsed preferred practices that focus on improving palliative and hospice care across the Institute of Medicine's six dimensions of quality - safe, effective, timely, patient-centered, efficient and equitable. The **thirty-eight** preferred practices mark a crucial step towards standardization of palliative care and hospice (Table 2).<sup>24</sup>

**Table 1. 2013 TJC Standards Related to End-of-Life Care**<sup>30</sup>

**Standard PC.02.02.13**

**The patients comfort and dignity receive priority end-of-life care**

**Introduction to Standard PC.02.02.13:** Patients who are near or at the end of their lives need to receive care that addresses their psychosocial, emotional, and spiritual needs. To provide care that meets these needs, staff involved in patients care require, education about the unique needs of dying patients and their families.

**Rationale:** N/A

**Elements of Performance:**

1. To the extent possible, the hospital provides care and services that accommodate the patient's and his or her family's comfort, dignity, psychosocial, emotional, and spiritual **end-of-life** needs.
2. The hospital provides staff with education about the unique needs of dying patients and their families

**Standard LD.04.02.03**

Ethical Principles guide the hospitals business practices

**Elements of Performance for LD .04.02.03**

1. The hospital has a process that allows staff, patients, and families to address **ethical** issues or issues prone to conflict.
2. The hospital uses its process to address **ethical** issues or issues prone to conflict.
3. The hospital follows **ethical** practices for marketing and billing.
4. Marketing materials accurately represent the hospital and address the care, treatment, and services that the hospital provides either directly or by contractual arrangement.
5. Care, treatment, and services are provided based on patient needs, regardless of compensation or financial risk-sharing with those who work in the hospital, including staff and licensed independent practitioners.
6. When leaders excuse staff members from a job responsibility, care, treatment, and services are not affected in a negative way.
7. Patients receive information about charges for which they will be responsible.

**Standard RI.01.01.10**

The hospital respects protects and promotes the patients rights

1. The hospital has written policies on advance directives, forgoing or withdrawing life-sustaining treatment, and withholding resuscitative services, in accordance with law and regulation.
4. For outpatient hospital settings: The hospital's written advance directive policies specify whether the hospital will honor advance directives. Note: It is up to the hospital to determine in which of its outpatient settings, if any, it will honor advance directives.
5. The hospital implements its advance directive policies.
6. The hospital provides patients with written information about advance directives, forgoing or withdrawing life-sustaining treatment, and withholding resuscitative services.
8. Upon admission, the hospital provides the patient with information on the extent to which the hospital is able, unable, or unwilling to honor advance directives.
9. The hospital documents whether or not the patient has an advance directive.
10. Upon request, the hospital refers the patient to resources for assistance in formulating advance directives.
11. Staff and licensed independent practitioners who are **involved in** the patient's care, treatment, and services are aware of whether or not the patient has an advance directive. (See also RC.02.01.01, EP 4)
12. The hospital honors the patient's right to formulate or review and revise his or her advance directives.
13. The hospital honors advance directives, **in** accordance with law and regulation and the hospital's capabilities.
15. The hospital documents the patient's wishes concerning **in** organ donation when he or she makes such wishes known to the hospital or when required by the hospital's policy, **in** accordance with law and regulation.
16. The hospital honors the patient's wishes concerning **in** organ donation with **in** the limits of the hospital's capability and **in** accordance with law and regulation.
17. The existence or lack of an advance directive does not **determine** the patient's right to access care, treatment, and services.
19. For outpatient hospital settings: The hospital communicates its policy on advance directives upon request or when warranted by the care, treatment, and services provided.
20. For outpatient hospital settings: Upon request, the hospital refers patients to resources for assistance with formulating **in** advance directives.
21. For hospitals that use **Joint** Commission accreditation for deemed status purposes: The hospital **defines** how it obtains **in** and documents permission to perform an autopsy.

**Standard RI.01.05.01**

The hospital address patient decisions about care, treatment, and services received at the end of life.

**Elements of Performance for RI.01.05.01**

**Table 2:**

**National Quality Forum (NQF) Preferred Practices for Palliative and Hospice Care <sup>24</sup>**

1. Provide palliative and hospice care by an **interdisciplinary team** of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professions(s).
2. Provide access to palliative and hospice care that is responsive to the patient and family **24 hours a day, 7 days a week.**
3. Provide **continuing education** to all healthcare professionals on the domains of palliative care and hospice care.
4. Provide adequate **training and clinical support** to assure that professional staff is confident in their ability to provide palliative care for patients.
5. Hospice care and specialized palliative care professionals should be appropriately **trained, credentialed, and/or certified** in their area of expertise.
6. Formulate, utilize and regularly review a **timely care plan** based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.
7. Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values and clinical information so that **continuity of care and seamless follow-up** are assured.

**Table 2 continued:**  
**National Quality Forum (NQF) Preferred Practices for Palliative and Hospice Care**<sup>24</sup>

8. Healthcare professionals should present **hospice as an option** to all patients and families when death, within a year would not be surprising and should reintroduce the hospice option as the patient declines.
9. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare **professionals' ability to discuss hospice** as an option.
10. **Enable patients to make informed decisions** about their care by educating them on the process of their disease, prognosis and the benefits and burdens of potential interventions.
11. Provide **education and support to families** and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.
12. Measure and **document pain, dyspnea, constipation and other symptoms** using available standardized scales.
13. Assess and **manage symptoms and side effects** in a timely, safe, and effective manner to level that is acceptable to the patient and family.
14. Measure and **document anxiety, depression, delirium, behavioral disturbances** and other common psychological symptoms using available standardized scales.
15. **Manage anxiety, depression, delirium behavioral disturbances** and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
16. Assess and **manage the psychological reactions** of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.
17. Develop and offer a **grief and bereavement care plan** to provide services to patients and families prior to and for at least 13 months after death of the patient.
18. Conduct regular **patient and family care conferences** with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis and advance care planning, and to offer support.
19. Develop and implement a comprehensive **social care plan** that addresses the social, practical, and legal needs of the patient and caregivers, including but not limited to relationships, communications, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
20. Develop and document a plan based on an assessment of **religious, spiritual, and existential concerns** using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
21. Provide information about the **availability of spiritual care services**, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
22. Specialized palliative and hospice care teams should include **spiritual care professionals** appropriately trained and certified in palliative care.
23. Specialized palliative and hospice spiritual care professionals should build **partnership with community clergy** and provide education and counseling related to end-of-life care.
24. Incorporate **cultural assessment** as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complimentary and alternative medicine, perspectives on death, suffering, and grieving, and funeral/burial rituals.
25. Provide professional **interpreter services** and culturally sensitive materials in the patient's and family's preferred language.
26. Recognize and document **the transition to the active dying phase**, and communicate to the patient, family, and staff the expectation of imminent death.
27. **Educate the family on a timely basis regarding the signs and symptoms of imminent death** in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
28. As part of the ongoing care planning process, routinely ascertain and **document patient and family wishes** about the care setting off the site of death, and fulfill patient and family preferences when possible.
29. Provide **adequate dosage of analgesics and sedatives** as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using narcotics and of analgesics hastening death.

**Table 2 continued:  
National Quality Forum (NQF) Preferred Practices for Palliative and Hospice Care<sup>24</sup>**

30. **Treat the body after death with respect** according to the cultural and religious practices of the family and in accordance with the law.
31. Facilitate effective grieving by implementing in a timely manner a **bereavement care plan** after the patient's death, when the family remains the focus of care.
32. **Document the designated surrogate/decision maker** in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
33. **Document the patient/surrogate preferences for goals of care**, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.
34. **Convert the patient treatment goals into medical orders**, and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.
35. **Make advance directives and surrogate designations available across care settings**, while protecting patient privacy and adherence to HIPPA regulations, for example, by using Internet-based registries or electronic personal health records.
36. Develop healthcare and community collaborations to **promote advance care planning** and the completion of advance directives for all individuals, for example, the Respecting Choice and Community Conversations on Compassionate Care programs.
37. Establish or have access to **ethics committees or ethics consultation** across care settings to address ethical conflicts at the end-of-life.
38. **For minors with decision making capacity, document the child's views and preferences** for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision maker.

## DEFINING PALLIATIVE CARE

Palliative care refers to the comprehensive management of the physical, psychosocial, social, spiritual, cultural, and existential needs of persons of all ages experiencing a debilitating, chronic or life-threatening illness, condition or injury. Palliative care ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues through cure, or until death, and into the family's bereavement period. The goal is to prevent and relieve suffering and to support the best possible quality of life for patients, their families and significant others, regardless of the stage of the disease or the need for other therapies. Palliative care can be provided at the same time as life-prolonging care. Care should be based on the core principles discussed at the beginning of this document. It should be clinically excellent, ethically based, culturally sensitive, and available to all who require it.<sup>23, 24</sup>

## LEGAL AND ETHICAL ISSUES

Legal and ethical issues at end of life are separate but related topics. Undoubtedly the most high-profile entanglement of the two is physician-assisted suicide, a subject of great debate in the

United States. Physician-assisted suicide is illegal in this country, with the exception of the state of Oregon and Washington. In the state of Montana the *Baxter vs Montana* (2009) court decision *Palliative Care, Baptist Health South Florida 2013*

created a defense for physicians who are prosecuted should he/she be charged in assisting suicide. There are those who claim that mercy killings are unethical; others contend that if a patient suffering great pain requests euthanasia, it is more ethical to end his suffering than to allow it to persist. No doubt, debate over the ethics of physician-assisted suicide and euthanasia will continue long into the future. The goal when caring for persons at end of life is to provide humane care while acting in an ethically responsible manner and within the law of the country and state.

### **Aspects That Complicate End-of Life Care**

A whole host of issues adds to the complexity of care at end of life. Some of these issues have considerable legal and/or ethical implications for both provider and patient. Changes in society and accelerating technological developments further complicate the picture. Concerns to consider include:

- advances in medical technology;
- America's aging population;
- lack of available family and community caregivers;
- the professional-patient relationship;
- consent, confidentiality, disclosure, and research;
- applying and defining the concept of medical futility;
- the rise in litigation and attendant fears among medical professionals;
- lack of knowledge about appropriate treatment for end-of-life;
- control of pain and difficult symptoms;
- prolongation of life and quality of life;
- withdrawing, withholding and/or refusal of treatment;
- legalization of assisted suicide;
- access to hospice service;
- legal and bureaucratic obstacles to the practice of palliative care;
- reimbursement for end-of-life care;
- advent of managed care;
- rising costs of health care; and
- allocation of health care resources.<sup>6</sup>

### **Concerns and Desires Regarding Dying**

People who contemplate their eventual dying often worry about suffering from pain or other terrible symptoms; being hooked up to machines; causing a financial drain on family resources; and becoming a burden to others. As one patient remarked, "I'm not worried about death. I'm worried about the dying part."

In a recent nationwide survey, seriously ill patients, recently bereaved family members, physicians, and other care providers (nurses, social workers, chaplains, and hospice volunteers) rated the most important attributes of quality care at end of life. More than 70% of those surveyed (n=1462) agreed that the following attributes are paramount at the end of life:



- be kept clean;
- name a decision maker;
- have a nurse with whom one feels comfortable;
- know what to expect about one's physical condition;
- have someone who will listen;
- maintain one's dignity;
- trust one's physician;
- have financial affairs in order;
- be free of pain;
- maintain sense of humor;
- say goodbye to important people;
- be free of shortness of breath;
- be free of anxiety;
- have a physician who knows one as a whole person;
- resolve unfinished business with family or friends;
- have physical touch;
- know that one's physician is comfortable talking about death and dying;
- share time with close friends;
- believe family is prepared for one's death;
- feel prepared to die;
- have family present;
- have treatment preference in writing;
- not die alone;
- remember personal accomplishments; and
- receive care from personal physician.

When presented with nine preselected attributes and asked to rank them in order of importance, survey participants yielded the following list, ranked from most important to least important:

- be free from pain;
- be at peace with God;
- have family present;
- be mentally aware;
- have treatment choices followed;
- have finances in order;
- feel that life was meaningful;
- resolve conflicts; and
- die at home.<sup>30</sup>

### **Rights of Patient to Self Determination and Decision Making**

The Florida Statutes (Health Care Advance Directives) states that every competent adult has the fundamental right of self-determination regarding decisions pertaining to his own health. This statute also states that a health care facility will provide to each patient *written* information concerning advanced directives.<sup>7</sup> Similarly, the Patient Self-Determination Act, a federal law which was implemented in 1991 as part of the Omnibus Budget Reconciliation Act of 1990,

mandates that all health care institutions that receive reimbursement from Medicare and Medicaid develop and implement a system to educate patients, staff, and the public about health care advanced directives.<sup>13</sup> This does not mean that patients must possess or fill out an advance directive, rather it means that they have to be educated about them in accordance with existing state law. An advance directive completed in another state, in compliance with the other state's law, can be honored in Florida.

### Advance Directives

An advance directive is a general term that refers to orally and preferably, written instructions about future medical care, in the event that one becomes unable to speak for oneself. Florida law recognizes the following advance directive documents: the designation of a health care surrogate, the living will, the durable power of attorney, and the decision to make an anatomical gift.

**The Florida Designation of Health Care Surrogate:** Enables an individual to name someone else to make decisions about his or her medical care (at any time, not just at the end of life) in the event that the individual can no longer speak for himself/herself.

**The Florida Living Will:** Allows a person to state his or her wishes about medical care in the event that he or she can no longer make medical decisions. The living will becomes effective when the individual has a terminal or end-stage condition, or is in a persistently vegetative state. The state recognizes several forms, including the Five Wishes document, as a legitimate living will.

**Durable Power of Attorney:** Allows an individual to delegate to an agent the authority to handle all aspects of his or her affairs, financial and personal. If the power is to include making healthcare decisions, this must be specifically stated in the document. The document must be a durable power of attorney rather than an ordinary power of attorney because the "durability" makes it valid even if the donor of the power becomes mentally incapacitated. Durable power of attorney is a good planning tool and can sidestep having a court-appointed guardian. An attorney must be involved when one creates a power of attorney document.

**Organ Donor Card:** Enables a person to express his/her wishes relative to organ donation.

### **ORGAN DONATION COLLABORATIVE** <sup>8</sup>

As mandated by State and federal regulations, all deaths, imminent deaths, including fetal demises after 20 weeks, are reported to the Organ Procurement Organization (OPO) Life Alliance Organ Recovery Agency (LAORA) at 1-800-255-GIVE (4483), for identification and referral of potential organ, tissue and eye donors, 24 hours a day, 7 days a week.

In accordance with hospital policy, state and federal regulations hospitals are required to call Life Alliance **within one hour** of any of the following clinical triggers being met:

#### **Imminent death triggers include:**

- Glasgow Coma Scale (GCS) equal to or less than 5/ventilator-dependent
- Brain death testing to be initiated
- Prior to withdrawal of ventilator
- Cardiac death/Asystole

Donation requests are facilitated by LAORA coordinators. The approach to the process of requesting permission for donation will be ethically based, and culturally sensitive to the circumstances, individual beliefs, and desires of potential donors, surrogates and proxies.

The ***Do Not Resuscitate Order (DNRO) Form 1896*** (Available through the Florida Division of Emergency Medical Services, <http://www.doh.state.fl.us/demo/trauma/dnro.html> or 850-245-4440) allows a person or his/her surrogate, durable power of attorney, proxy, or court appointed guardian to direct that cardiopulmonary resuscitation be withheld or withdrawn in the event of cardiac or respiratory arrest. The individual's physician must sign the form. The form is yellow and if copied, must be copied onto yellow paper. When the person is living at home, the form should be placed where it can be easily seen, such as on the refrigerator, in the event that emergency medical services are called. A miniature version is available for travel purposes.

The act of signing a Living Will does not necessarily mean that a person has opted for a treatment plan free of heroics. Quite the contrary: Some individuals direct that they want aggressive treatment, even if they have a terminal condition. Such directives often lead to conflicts among the caregivers, the patient, and the patient's family. Similarly, despite the fact that physicians are not mandated to provide life-sustaining treatments in futile situations, they often feel compelled to continue them.

A person's wishes regarding what type of life and limitations he or she would be willing to tolerate often change over time. This is why people should be encouraged to discuss these issues periodically and to regularly update their living wills. Furthermore, even if someone has a living will stating that he wants no life-sustaining treatment, as long as the person is competent, the living will is not enforceable should he have a change of mind and verbally or otherwise request life-sustaining treatment. The actual format of many living wills leaves numerous questions unresolved. Most living wills simply ask for a yes or no response to a couple of questions and do not address every medical scenario possible. Ideally, advance directives should contain explicit details for a wide range of scenarios, rather than black-or-white choices such as "do or do not attempt resuscitation" or "do or do not intubate." Some groups have designed more comprehensive directives about care at end of life. For example, the Florida Commission on Aging with Dignity developed the *Five Wishes* booklet that can be used instead of the one-page living will document. *Fives Wishes* prompts the individual to choose his or her health care proxy, what medical treatments are wanted or not wanted, desired level of comfort, and what he or she wants family to know.<sup>1</sup>

### Withholding, Withdrawing and Refusal of Treatment

Patients do have the right to refuse treatment or request that it be withheld or withdrawn. According to the American Nurses Association (ANA), "Honoring the refusal of treatments that a patient does not desire, that are disproportionately burdensome to the patient, or that will not benefit the patient can be ethically and legally permissible. Within this context, withholding or withdrawing life-sustaining therapies or risking the hastening of death through treatments aimed at alleviating suffering and/or controlling symptoms are ethically acceptable and do not constitute assisted suicide or active euthanasia. There is no ethical or legal distinction between

withholding and withdrawing treatments, though the latter may create more emotional distress for the nurse and others involved.”<sup>3</sup> A competent patient can refuse any life-sustaining treatment. This applies to whether the action is withholding a treatment or withdrawing a treatment in progress.

The courts have concluded that refusing life-sustaining treatment is not suicide; it is simply asserting the fundamental right to tell other people to keep out of one’s body.

#### Do-Not-Resuscitate (Allow Natural Death), No CPR, No Code and Similar Orders

These orders can be conflicting or confusing when the patient’s wishes are either not known or not respected by the health care team. For example, many nurses have cared for patients whose deaths were imminent and any heroic care including cardiopulmonary resuscitation (CPR) would be futile or, at the least, would prolong their inevitable deaths. Yet, in these situations, whether it be at the physician’s or family’s urging, CPR is ordered. Written or inferred stipulations, may be attached to a CPR order such as “chemical code only” or “slow code”; however, use of these qualifications is not recommended and using them further clouds the issues and creates ethical and legal questions. The inappropriate use of CPR and other heroic measures contribute to the suffering of patients at end of life and causes morale problems among health care providers.

The term do not resuscitate has been replaced by **allow natural death** (AND). Institutions need to clarify “do not resuscitate” or the new term “allow natural death” and similar orders. Ideally, the decision to resuscitate or not, should be made by the patient and reviewed with him or her at appropriate intervals. Having a living will to guide caregivers certainly helps, but unfortunately, people often sign one without fully understanding its meaning and implications. On occasion, a family member or rarely, the patient, will insist that CPR be done even though it is clear that doing so will only prolong the inevitable and probably cause more suffering for the patient. A request like this is usually a maladaptive response of the requesting individual to the situation and requires intervention by a clinical social worker, psychologist, psychiatrist and/or a spiritual advisor and the institution’s ethics committee.

“No CPR” or “No Code” does not mean “No Care.” On the contrary: Caring for these patients is an involved and often demanding process that requires great skill and sensitivity. Whenever possible, the patient and family should be involved in decisions about care and consulted regarding the benefits and burdens of these activities. Caregivers do need to make it clear to the patient, family and loved ones that withholding life-sustaining treatment is not withholding caring.

The ultimate goal is for patients and their loved ones to make fully informed decisions. This requires that patients know as much as possible about their options and what their potential consequences might be.

### **PSYCHOLOGICAL DIMENSION**

Psychosocial factors are those factors that affect patients psychologically or socially or both. They are often overlooked in spite of strong empirical evidence of the correlation between psychosocial factors and medical problems. In recognition of this association the clinical practice

guidelines of the Agency for Health Care Policy and Research suggest the clinicians consider psychological and social factors in their interactions with patients and in their patient management strategies (U.S. Department of Health and Human Services, 1994a). The relative importance of these factors may vary with each patient and circumstance as every person is different. However, some common feelings and concerns may be present as patients and families attempt to deal with these factors and their effect on end of life and palliation issues.

Understanding how people of different ages view death and dying may assist you in understanding psychological and social concerns in your work with end of life care. In general, children prior to the age of two lack understanding of the concept of death. At ages two to seven children perceive death as a reversible sleep-like state. Between the ages of seven to eleven children begin to understand the concept of death and view death as irreversible and become anxious at the death of loved ones. It is important for us to understand that children of all ages respond to death in a unique way. Children need support and, in particular, someone who will listen to their thoughts and provide reassurance to alleviate their fears.

Both young adults and adults fear death. However, fear of death peaks during the middle years. With the middle age adult, a change of time perspective occurs from time of birth to time until death. The elderly adult is more cognizant of death and spends more time talking about death. However, is less fearful of death than younger adults. There is also literature which supports that past experiences with death contribute to our own concept of death.

Social and psychological sources of distress may include such aspects as socioeconomic status, mobility, ethnicity and culture, cognition, personality, gender, stress, social support system, illness behavior, anger/hostility, belief system or access to professional help. Most of these sources of distress are neither intrinsically good nor bad. A certain level of stress may be motivational and assist you in accomplishing goals. However, research does suggest that consistent levels of stress are harmful. Dealing with end of life issues is a consistent level of stress. As such it has serious implications which may present as anxiety, depression and family needs.

Anxiety and depression are common responses when confronted with the prospect of death and may be exacerbated by physical symptoms such as pain or dyspnea. Anxiety is the apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension. Depression in this context refers to the range of feelings associated with a depressed mood and a loss of interest or pleasure in life.

Clinical depression is difficult to diagnose in the terminally ill as many of the symptoms may also be manifestations of the illness.<sup>25</sup>

Both pharmacologic and non-pharmacologic interventions may be considered in dealing with anxiety and depression. Empirical evidence suggests a combination of both interventions is associated with increased positive outcomes. Supportive interventions include psychological counseling, spiritual counseling, social work services and encouraging the patient and loved ones to verbalize their fears of the dying process. When pharmacologic interventions are needed anxiety may respond to a selective serotonin reuptake inhibitor or to benzodiazepines. Though the latter may be beneficial there is an increased risk of falls and delirium with their use. Pharmacologic interventions associated with depression may include anti depressants or psycho stimulants.<sup>25</sup>

Family needs may refer to unresolved feelings, financial issues, burial arrangements,

existential questions, grief and other family or environmental concerns.

Grief is always present when you are dealing with your own death or the death of a loved one. It is a fluid natural process for patients and their loved ones. Kubler Ross has identified five stages of grief that people experience when dealing with death. These are denial, anger, bargaining, depression and acceptance. The stages do not necessarily present in order and persons move in and out of the stages depending upon their own personality and circumstance. For survivors the acceptance may take years.<sup>18</sup>

Closely associated with the psychosocial factors present in grief and death is a range of emotions. Research investigators agree that certain emotions are universal and form the basic components of more complex emotions. Universal means they may be present regardless of cultural variables. These emotions include anger, fear, joy, sadness, hope, surprise, disgust, love, shame and interest. Of these universal emotions research has shown the importance of hope inspiration in maintaining the quality of life of people who are dying.

To summarize there is empirical evidence which supports the psychosocial aspects or the non-physical factors of patient care in diagnosis and treatment. Do take this into consideration as you participate in end of life patient care planning.

## **SOCIAL DIMENSION**

Typically in the trajectory of an illness or condition, an individual can no longer maintain his or her role in the family, on the job, or in the community. Role changes can have a significant impact on self-esteem, sexuality, finances, rearing minor children, and so forth. Along with fearing role changes, an individual may dread becoming a burden on others. Caregivers can help people maintain a sense of worth and self-esteem by keeping them involved in their lives as much as they are capable and willing. For example, a terminally ill mother may not be able to dress her young children, but she can decide what they will wear. A gardening aficionado may not be able to plant the garden, but he can design the layout and choose what flowers and vegetables are to be planted.

### **Family Issues**

Caring for terminally ill people is usually a family-centered effort and it is the family who carries most of the burdens of giving care. The support of family and other loved ones at the end of life can significantly help a person to experience a good death. These individuals should be recognized and valued for the services they provide and the cost-savings to society.

Medical caregivers can support families in a number of practical ways, by giving them:

- understandable and timely information;
- education on how to care for the patient's physical and emotional requirements; and
- legal advice and financial counseling.<sup>11</sup>

In a study of 475 family informants who had been involved in caring for the patient in the last month of life, the following behaviors of health care providers were mentioned as most helpful:

- treating the patient as a unique individual;
- caring attitudes and behaviors;
- information and education;
- emotional support for the family; and
- provider responsiveness.

In contrast, families singled out the following behaviors as being among the most difficult to endure:

- communication difficulties with providers and between providers;
- inadequate information about the prognosis;
- uncaring attitudes and behaviors on the part of physicians; and
- dissatisfaction with aspects of the medical care.<sup>32</sup>

Table 3 lists some strategies for communicating and partnering with families and other loved ones.

One of the important roles of health care professionals is to facilitate the wishes of the patient and loved-ones. If the patient is in a hospital, policies should be flexible enough to accommodate these wishes as long as good judgment is used, no one is harmed, and the requests meet ethical and legal standards.

## **CULTURAL DIMENSION**

Culture determines the way people respond to end of life issues: Specifically, it governs the way people interact with each other and the health care system, how they behave when they or their loved ones are sick, how decisions are made in the family, and what rituals are used during end-of-life care and how the family grieves. Culture shapes how an individual makes meaning out of illness, suffering and death.<sup>21</sup> While end-of-life care needs to be improved across all cultures; there is evidence that individuals in minority groups are underserved by current palliative care models. Little research has been done to understand the health and caring perspectives of different cultural groups. This type of research can be very challenging due to the vulnerability of the population to be studied, the quickly changing nature of the patient's illness and the complexities of the phenomena to be studied.<sup>9</sup>

In order to improve care at end of life, healthcare providers must recognize, appreciate and respect people from all cultures. Cultural competence requires that health care professionals learn to communicate across cultures. Moreover, providers should avoid stereotyping people and predicting behavior based on a surname, appearance, or national origin. While it is helpful to learn about different cultures as a whole, healthcare providers should assess each patient and family individually to learn their preferences. The health care provider can partner with the patient and family to ensure that patient and family values, beliefs and practices guide the plan of care.<sup>21</sup>

**Table 3. Strategies for Communicating and Partnering with Families and Other Loved Ones**<sup>29</sup>

- ◆ Listen.
- ◆ Imagine what it must be like to be in this situation.
- ◆ Engage family members and loved ones as partners with health care professionals.
- ◆ Treat family members and loved ones with compassion and respect.
- ◆ Answer questions honestly.
- ◆ Ask what information is needed.
- ◆ Ask what he/she understands about the patient's condition.
- ◆ Allow family members and loved ones to visit as needed and to participate in care if desired. Restricting visitation is appropriate in only a few instances, e.g., patient preference, privacy and safety issues.
- ◆ Encourage family to bring inexpensive, personal items of comfort such as pictures (no heirlooms).
- ◆ Explain medical conditions and procedures using simple terms and examples.
- ◆ Provide written materials to support verbal education.
- ◆ Reinforce the importance of his/her role in the patient's care.
- ◆ Acknowledge the stress he/she may be feeling.
- ◆ Suggest taking time to care for himself/herself.
- ◆ Provide a comfortable environment (e.g., chairs, cot, and access to telephones and food).
- ◆ Listen.

### **SPIRITUAL DIMENSION**

The benefits of religious activity and spirituality to health are increasingly documented and supported by medical research. While the relationship is ancient, the modern American rediscovery perhaps began in 1971 when members of the White House Conference on Aging concluded that, "all persons are spiritual, even if they have no use for religious institutions and practice no personal pieties".<sup>22</sup>

Spirituality is that quality in human beings that longs for a meaningful life characterized by purpose and filled with meaning. This broad definition accentuates the universality of spirituality, for all people, religious and non-religious, typically possess this longing – the search for meaning and purpose; a quest for the good life. The term also implies a connection, or relationship, with that which is non-material and beyond space and time such as love, hope, peace and faith. Many aver that these are the gifts of a Supreme Being to the created order.

Nonetheless, in addition to a search for inner harmony, spirituality usually seeks inter-connectedness with other human beings, animals, nature, and God. Spirituality may, or may not, include religion and religious practices, but it usually does. Spirituality relates to the human concern with the ultimate questions: Who am I? Why am I here? Where am I going?

The Columbia Encyclopedia (Sixth Edition, 2004) defines *religion* as, "a system of thought, feeling, and action that is shared by a group and that gives the members an object of devotion; a code of behavior by which individuals may judge the personal and social consequences of their actions; and a frame of reference by which individuals may relate to their group and their universe." As its etymology implies, religion binds together. Religion calls for community; it gathers and unifies people around deeply shared beliefs, values and practices.



Religion provides a structure for spirituality via membership in a faith community, prayer, rituals, devotion and service. According to a survey of hospitalized patients, 88% of patients define themselves as both religious and spiritual, 7% as spiritual and not religious, 3% as religious but not spiritual and only 3% as neither.<sup>16</sup>

Several decades of studies in the area of spirituality, religion and health have been reviewed and summarized by a number of authors, and the impressive results include the following findings:

- People who regularly attend religious services have lower rates of illness and death than do infrequent attendees or non-attendees.
- People who report a religious affiliation have lower rates of heart disease, cancer, and high blood pressure.
- Older adults who participate in private and congregational religious activities have fewer symptoms, less disability, and lower rates of depression, anxiety and dementia.
- Religious participation is the strongest determinant of psychological well-being in African Americans.
- Actively religious people live longer, on average, than the nonreligious.<sup>20</sup>

A strong case for the importance of religion in the care of the dying is made by a recent study that concludes: “Religion, the role of the family, and social structures dominate end-of-life customs and practices.”<sup>27</sup>

Another author notes:

Dying patients have more than medical needs. In fact, what they feel most sharply, whether or not they are religious, are spiritual concerns. The Christian theological virtues of faith, hope, and charity, properly interpreted and translated to reflect the universal concerns with which they are connected, provide a starting point.<sup>10</sup>

John Hardwig challenged bioethicists to look more closely at spiritual care. At life's end, he observed, the dying usually return to long-neglected questions about what really counts in life. Many see little meaning in their narrowed and shortened future as they are forced to deal with friends and family in new and embarrassing ways. Where formerly they helped to lift burdens from the shoulders of others, they have now become a burden. They feel betrayed by their own bodies. They picture themselves as cast out from the society of the healthy. They can be overwhelmed by their feelings of isolation and abandonment, even self-hatred, fear, and anger.<sup>15</sup>

Therefore, the general consensus is that many dying patients shift most of their attention from physical and material concerns to spiritual questioning. Medicine can address how things happen, but questions about why things happen belong to religion and spirituality. It has been said that people can cope with the how if they understand the why.

In this manner medicine and religion can complement each other because good physical symptom management frees time and energy to work out these concerns that patients tend to think about in relationship to their health. Consequently they may welcome an opportunity to talk about religious and spiritual issues as they relate to their end of life experience.

Some common spiritual needs and questions that the dying may ponder, irrespective of religious commitment or belief are as follows:

### *Questions of Meaning and Purpose*

Has my life made a difference, and am I making a difference now? What is the meaning of life? Am I accomplishing my goals, my purpose? Is my life significant and valuable? Is there a purpose to my life? How do I want to spend the time that I have? Who am I, now that I am dying?

### *Questions of Hope and Significance*

Why is this happening to me? What is my future in this life and after death? Will my well-being and the well-being of my loved ones be persevered in the next twenty days or years, or forever?

### *Ultimate Questions about Love and Acceptance*

Am I loved and valued by others and God? Am I good enough? Am I being taken care of now, and will I be in the future? Am I forgiven? Must I forgive?

### *Questions about an Ultimate Spiritual Source*

Is God, or something greater than I, guiding and directing all things? Can I find peace, hope, joy and rest in this "Higher Person or Power"?

### *Questions Exploring the Need for Dignity*

Am I still human, still a person of worth, even if I lose control over many things – even if I become dependent on others for the simplest tasks of daily living? Will I still be me, even when I no longer look and act as I did before? Have I mattered, and will I still matter after no one remembers me? Do I matter right now?

As the research and the questions suggest, healthcare providers should include a spiritual history that can assist in screening for spiritual and religious needs when assessing a patient.

Dr. Christina Puchalski of the George Washington University and the National Institute for Healthcare Research has developed a questionnaire to teach doctors, nurses, social workers, and medical students how to take a spiritual history. The acronym for this screening tool is FICA:

- Faith or Beliefs
- Importance or Influence
- Community
- Addressing Issues

**This acronym FICA can help structure questions in taking a spiritual history by Healthcare Professionals.**

#### **F--Faith and Belief**

"Tell me about your beliefs. Do you have beliefs that help you cope with illness?" IF the patient responds "No," one can ask, "What gives your life meaning?"

**I--Importance**

"What importance does your faith or belief have in our life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?"

**C--Community**

"Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?" Communities such as churches, and temples, or a group of like-minded friends can serve as strong support systems for some patients.

**A--Address in Care**

"How would you like me, your healthcare provider, to address these issues in your healthcare?" <sup>28</sup>

Taking a spiritual history requires listening to a patient's stories, beliefs, fears, and hopes - this active listening for the values, concerns and sources of strength of patients helps to empower them in the midst of an otherwise disempowering experience. FICA is a guide to introduce the conversation about spirituality which can take less than two minutes, so it can be used in any setting. Of course, if deeper issues arise, the conversation may take longer. Asking patients about their spirituality is a way to help them tap into their own sense of hopefulness, and it is conducive to a deepening of the caring relationship. This method seems to be acceptable to physicians while promoting a conversation patients find helpful. To date, more than 60 medical schools are teaching the method, and many physicians have begun to use it.

Nurses and physicians can provide helpful psycho-spiritual support by being mindfully present, listening empathically, accepting the patient by emphasizing points of connection with what s/he says and using appropriate rapport building self-disclosure.

Additionally, this spiritual screening tool obtains preliminary spiritual information via a brief inquiry that can clarify if a referral to a clinical chaplain is needed. While this screening tool facilitates a meaningful conversation between a terminally ill patient and medical staff about the broader meaning of illness and life, a referral should be made to a certified chaplain when indicators of spiritual distress, and other needs, such as the following are in evidence:

- Illness and loss interrupt activities, plans and goals.
- Loss of hope that wellness will be sustained
- Inability to refocus hope as illness progresses.
- Loss of dignity and personhood; feeling dehumanized.
- Unresolved ethical issues; confusion over course of treatment and choices
- Lack of closure - not at peace with self, God and others
- Anxiety or fear of medical procedures, death and/or the dying process
- Expressed spiritual/religious needs
- A need for a patient/family care conference
- Also when staff is struggling with a case

The clinical chaplain is the specialist that can then make a thorough assessment and provide appropriate pastoral interventions that can have a comforting and healing affect on the patient; and obviously this is conducive to superior symptom management. A chaplain can provide a calming and healing presence to the terminally ill and their loved ones which can help to alleviate a plethora of maladies and complications and also help to lighten the psycho-spiritual burdens of the other staff members as they care for the dying.

Baptist Health has clinical chaplains on staff as part of the healthcare team at every facility and at the corporate level. Staff may need to explain to patients and loved ones what the program can offer them. Some patients are reluctant to call on hospital chaplains for fear of being preached at,

let patients know that all BHSF chaplains have special clinical training and certification, have no desire to impose beliefs on them, and can offer comfort, guidance, and practical resources to patients of any religious background as well as non-religious patients.

## **PHYSICAL DIMENSION**

There are any number of physical problems people have when they are experiencing life threatening illnesses or are at life's end. These symptoms may include pain, dyspnea, myoclonus, edema, cough, congestion, difficulty swallowing, diarrhea, constipation, anxiety, delirium, nausea and vomiting, among others. While in-depth discussion of these problems is beyond the scope of this self-study, readers who wish to delve deeper into these topics can find copious amounts of information in palliative care texts, on web sites and through other resources. Pain, dyspnea, myoclonus, and delirium will be discussed briefly because these are the most common distressing symptoms.

### **Pain Assessment and Management**

Many factors can cause pain at the end of life. Therefore, the key to reducing pain is to determine its cause if possible. Practitioners should not just assume that the report of pain is related to the underlying disease. Something as simple as a full bladder or constipation can cause extreme discomfort. Other common pain sources that are frequently overlooked are bone fractures, injured muscles, nerve compression, and arthritis-type pain. Regardless of whether or not a person is terminally ill, caregivers should advocate diagnostic testing to identify the cause of a treatable painful condition. Furthermore, surgery, antibiotics, radiation therapy and other "aggressive" therapies are appropriate in the palliative setting if the intent of such therapy is to reduce pain and suffering.

There are many pharmacological and nonpharmacological ways to manage pain. Treatment should be aggressive and tailored to the individual.

### Use of Opioids at End of Life

Opioids are one of the most powerful and effective ways to lessen pain among acutely and terminally ill patients. Yet many caregivers are not fully educated about their use and regard them with suspicion. Furthermore, the conventional literature is filled with misinformation about opioids, even when advocating their use. For example, the American Nurses Association (ANA) Position Statement on pain states that nurses "should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient. The increasing titration of medication to achieve adequate symptom control, even at the expense of life, thus hastening death secondarily, is ethically justified."<sup>2</sup> Although comforting, the ANA position statement further reinforces the paranoia about administering opioids to patients.

The belief that opioids shorten life when administered to actively dying patients is a pervasive myth. There is no evidence that properly titrated opioids hasten death. In fact, experts believe that unrelieved pain hastens death. Some studies demonstrate that patients with excellent symptom management at end of life may actually live longer than those who do not have pain and/or dyspnea adequately managed.<sup>33</sup>

Orders for analgesics should be clearly written with titration guidelines spelled out. For example: Morphine sulfate 5mg IV bolus may repeat an additional 5 mg IV in 10 min if needed for pain/dyspnea, then start Morphine sulfate drip @ \_\_\_\_\_ mg/hr. May titrate by 50% of the current rate every \_\_\_\_\_ PRN for ongoing pain/dyspnea, not to exceed \_\_\_\_\_ mg/hr. The nurse should titrate analgesics according to the patient's symptoms and document the rationale for dose increases and patient response. Nurses should notify the physician for higher or lower parameters as indicated by the patient's condition. An initial bolus of an opioid may be required to get the pain under control. Providers should note that there is not a perfect analgesic; nor is there a common dose for everyone. The right drug and dose are those that control pain with the fewest side effects.

Caregivers should continue to provide analgesics even if the patient is heavily sedated or becomes unconscious due to the natural dying process (unless, of course, the cause for the pain has been eliminated or resolved). This is an important fact to remember when administering sedatives, since these drugs are not analgesic. Otherwise, a patient could be experiencing pain, but be unable to communicate this fact because he or she is too sedated.

Occasionally, family members and loved ones may urge the staff to speed things along, claiming that the patient has "suffered enough." When caregivers are put in this position, they should determine the symptom that is most distressing to the patient/family/loved ones and aggressively treat it. Family members should be reminded that the patient is dying of a disease or condition and that the purpose of the analgesic and/or sedative is to reduce suffering, not hasten death. If symptoms become too difficult to manage, caregivers should consult with experts.

## Dyspnea

Dyspnea is a horrible and terrifying symptom that may result in panic. No patient should ever have to die gasping for breath. First-line therapy for irreversible dyspnea is morphine.<sup>29</sup> Rather than hastening death in dyspneic patients, studies suggest that early use of morphine or another opioid, may actually prolong survival by reducing physical and psychological distress and exhaustion.<sup>9</sup> Adding a benzodiazepine may help if morphine alone fails to relieve the symptom especially if the patient is anxious, as often seen with patients experiencing dyspnea.<sup>9</sup> Also, chlorpromazine (Thorazine) and promethazine (Phenergan) has been reported to help relieve dyspnea, particularly when combined with opioids.<sup>9</sup> Positioning (sitting up), increasing cool air movement across the face via a fan or open window, therapeutic breathing (pursed lips, diaphragmatic), and use of bedside relaxation techniques are all helpful. **For patients experiencing high levels of anxiety, physical "presence" (staying with the patient), speaking in a low, calm voice while reassuring the patient, and controlling environmental situation (low lights, calm environment) are all helpful.** In the imminently dying patient, discontinuing parenteral fluids is appropriate.<sup>5</sup>

## Myoclonus

The following conditions contribute to the development of myoclonus or abrupt muscle spasms: renal failure, hepatic failure, hyponatremia, hypercalcemia, cerebral edema, hypoxia, drug withdrawal, dopamine antagonists, and opioids. Experts suggest the following: treat the underlying cause if it is known and if feasible to do so; eliminate all unnecessary medications;

change to another opioid (meperidine is contraindicated) (if on morphine, change to hydromorphone (Dilaudid) or vice versa); give a benzodiazepine; add oxygen if cyanotic; and/or add fluids if patient is dehydrated.<sup>26</sup>

## Delirium

Delirium is a common psychiatric disorder in the terminally ill (See Fast Fact #1).<sup>4</sup> Although not always unpleasant, delirium can deeply disturb the patient and family, particularly if the patient is agitated (hyperactive delirium). Treatment is generally indicated in either a hyperactive or hypoactive delirium. Management options include identifying and treating the underlying cause, as well as symptomatic treatment through non-pharmacological and pharmacological interventions. Common reversible etiologies in advanced terminal illness include drug toxicity, infection, hypotension, hypoxia, hypoglycemia, hyponatremia, hypercalcemia, elevated ammonia, alcohol-sedative drug withdrawal, and sleep deprivation.<sup>19</sup> Terminal delirium, however, is distinct from those not actively dying and is considered by some to be the hallmark of death.<sup>19</sup>

Any number of medical conditions and medications (Table 4) can cause delirium at the end of life. Generally, patients are restless and may experience distressing hallucinations. On occasion, the hallucinations are pleasant. Patients may have periods of lucidity. Some of the causes can be eliminated or treated but many other causes, such as organ failure, are difficult, if not impossible, to treat.

### **With the exception of treating delirium due to drug withdrawal or anticholinergic excess, neuroleptics are the first-line pharmacological agents for symptomatic management.**

Benzodiazepines should be avoided unless the source of delirium is alcohol-sedative drug withdrawal or when severe agitation is not controlled by the neuroleptics. Benzodiazepines can cause “paradoxical” worsening of confusional states. The best studied neuroleptic, and the agent of choice for most patients, is haloperidol (Haldol), which has a favorable side effect profile and can be administered safely through oral and parenteral routes. Starting doses are 0.5 – 10 mg PO or IM/IV; titration can occur by 2.0 – 5.0 mg every 1 hour until a total daily requirement is established, which is then administered in 2-3 divided doses per day. Intravenous haloperidol may cause less extrapyramidal symptoms than oral haloperidol. Other neuroleptics are probably comparable to haloperidol in controlling delirium (and many are also good anti-emetics), but may have a higher incidence of side effects such as extrapyramidal reactions, sedation, and hypotension. Chlorpromazine (Thorazine) has been advocated for dying patients in whom sedation is desired, especially for terminal delirium. If agitation is refractory to high doses of neuroleptics consider adding Lorezapm 0.5mg- 2mg SQ/IV q 4 hrs. Titrate starting doses to optimal effect, consider opioid reduction or rotation.

Newer atypical neuroleptics, olanzapine (Zyprexa), quetiapine (Seroquel), and risperidone (Risperdal) may be helpful in the management of confusional states. Evidence supporting usage of atypical neuroleptics in delirium is scant, so they should not be considered a first-line treatment. However, these agents are associated with fewer drug-induced movement disorders than haloperidol, and may be agents of choice in patients with Parkinson’s disease and related neuromuscular disorders, as well as patients with a history of extrapyramidal reactions from neuroleptics.

The switch to an atypical neuroleptic may be made abruptly but it is probably wiser to taper off the typical agent slowly while titrating up the atypical agent. Atypical antipsychotics may not work as fast as conventional antipsychotics for acutely aggressive and agitated patients requiring onset of action within minutes. Quetiapine is the most sedating of the newer agents and has potential applicability in treating agitated delirium, especially at the end of life.<sup>19, 26</sup>

Family and loved ones will need even more attention and support during this very unpleasant time. Also, healthcare providers feel frustrated and need support when a patient appears to be suffering despite all efforts to provide comfort measures.

### Restlessness

Restlessness is a symptom of delirium, but it can also be attributed to any number of other problems such as unrelieved pain, distended bladder, fecal impaction, pruritus, body malposition, or hypoxia. Discovering the cause for restlessness can be a challenge especially when the patient is unresponsive or non-verbal. Nevertheless, careful assessment often yields the reason for the patient's distress. Recently, this writer assessed a restless patient who had a distended bladder. Catheterization produced 1000 ccs of urine thereby resolving her distress.

**Table 4. Possible Causes for Delirium**<sup>19, 29</sup>

Alcohol/drug withdrawal	Electrolyte/chemical imbalances
Brain tumors/central nervous system disease	Endocrine disorders
Dehydration	Hepatic failure
Depression/other psychological problems	Hypercalcemia
Drug-induced	Hypocalcemia
Anticholinergic drug	Hyponatremia
Benzodiazepine	Uremia
Central nervous system stimulant	Elimination problems
Chemotherapy	Hypoxia
Corticosteroid	Increased intracranial pressure
H <sub>2</sub> blockers	Infection/sepsis
Opioid	Nutritional abnormalities
Phenothiazine	Organ failure

### **Stress of the Professional Caregivers**

Nurses, nursing assistants, physicians and other professionals who care for patients at end of life also experience emotional upheavals. A person cannot work in this field without experiencing a wide range of positive and negative feelings. When patients die badly, which can happen despite the best of care and intentions, caregivers may feel defeated and discouraged. These feelings should be acknowledged and talked about to determine if things could have been done differently. Conversely, professionals should celebrate the successes as well, whether it is finally finding the solution to managing a difficult symptom, or knowing that a patient had a "good" death.

**CARING FOR THE CAREGIVER**<sup>12</sup> There are many different ways to take care of your own needs. The following ideas may be a healthy and helpful alternative.

1. Be gentle with yourself!
2. Remind yourself that you are not a magician. We cannot change anyone else-we can only change how we relate to them.
3. Find a hermit (quiet) spot. Use it daily.
4. Give support, encouragement and praise to peers and to management. Learn to accept it in return.
5. Remember that, in the light of all pain we see, we are bound to feel helpless at times. Admit it without shame. Caring and being there are sometimes more important than doing.
6. Change your routine often and your tasks when you can.
7. Learn to recognize the difference between complaining that relieves and complaining that reinforces negative stress.
8. On the way home, focus on a good thing that occurred during the day.
9. Be a resource to yourself! Get creative. Try new approaches. Be an artist as well as a technician.
10. Use supervision or the buddy system regularly as a source of support, assurance and re-direction.
11. Avoid “shop talk” during breaks and when socializing with colleagues.
12. Schedule “withdraw” periods during the week- limit interruptions. Say “I choose” rather than “I should, I ought to or I have to.” Say, “I won’t” rather than “I can’t.”
13. If you never say no-what is your “yes” worth?
14. Aloofness and indifference are far more harmful than admitting an inability to do more.
15. Laugh and play!



## CONCLUSION

The prospects of dying can have profound negative and/or positive effects on the psychological, social and spiritual dimensions of life. Certain aspects, such as personal relationships and the beauty of nature, are often more valued when one considers losing them. Health permitting, this may be a time when the individual does something he/she always wanted to do. For example, one of our patients had always wanted to learn how to draw; when faced with her impending death, she took this “opportunity” to develop her talent. Another terminally ill patient reported experiencing a tremendous spiritual growth as a result of having to face death. A surreal sense of peace seemed to surround him.

Similarly, healthcare teams have the opportunity to grow when working with patients who are at the end of life. The seemingly trivial aspects of life may take on more meaning: The sky is bluer, the grass is greener, and the flowers are more vibrant. One’s good health is never again taken for granted. Many healthcare professionals believe that it is a privilege to care for people at end of life, and know that they play a vital role in improving this care.

### **Definitions**

**Advance Directive**-- a witnessed written document or oral statement in which instructions are given by an individual or in which the individual's desires are expressed concerning any aspect of his/her health care, and includes, but is not limited to, the designation of a health care surrogate, a living will, or an anatomical gift.

**Artificial nutrition and hydration**--provision of nourishment and hydration by artificial means (e.g., through tubes inserted into the stomach, intestine, blood vessels, or under the skin).

**Cure**--to heal; to make well.

**Dying**--Defining dying is difficult.\* One definition suggests that a person is dying if he/she has an incurable illness with progressing disability that will lead to death sometime in the next few years. According to this definition, a lot of “dying” people are in the workforce. Furthermore, many people object to this term and suggest that we are “living” until we take our last breath. Interestingly, dying is not defined in Stedman’s Medical Dictionary. Webster’s defines dying as “about to die or come to an end.”

**End stage condition**-- a condition that is caused by injury, disease, or illness which has resulted in severe and permanent deterioration, indicated by incapacity and complete physical dependency, and for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.

**Euthanasia**--the act of someone, a physician or other medical team member, directly administering a drug with the intention to end a person's life who is suffering from a painful and prolonged illness or injury. This is sometimes called “mercy killing.” Voluntary euthanasia means that the patient consents to the act, involuntary euthanasia means the patient refuses to consent, and nonvoluntary euthanasia means that the patient is unable to consent.

**Incapacity**—is the term held when a patient has impaired judgment and reasoning to make informed decisions. This could be due to disease, major illness or administration of medications such as sedatives. Florida law and hospital policy requires that the attending physician assesses patients for incapacity. If the attending physician is unsure, he/she can ask another consultant to verify incapacity. A standard capacity form should be available on all patient care units to assist with this documentation. For the purposes of making an anatomical gift, the term also includes a patient who is deceased.

**Incompetent**—only a judge can declare a person to be incompetent.

**Informed consent**--consent voluntarily given by a person after a sufficient explanation and disclosure of the subject matter involved to enable that person to have a general understanding of the treatment or procedure and the medically acceptable alternatives, including the relevant risks, benefits and side effects inherent in the proposed treatment or procedures, including potential problems related to recuperations and to make a knowing health care decision without coercion or undue influence.

**Life-prolonging procedure**--any medical procedure, treatment, or intervention, including artificially provided sustenance and hydration, which sustains, restores, or supplants a spontaneous vital function. The term does not include the administration of medication or performance of medical procedure, when such medication or procedure is deemed necessary to provide comfort care or to alleviate pain.

**Living Will**-- A witnessed document in writing or a witnessed oral statement, voluntarily executed by the individual expressing the individual's instructions concerning life-prolonging procedures.

**Palliative**--To reduce the severity of; alleviate symptoms without curing the underlying disease.

**Palliative Care**—refers to the comprehensive management of the physical, psychosocial, social, spiritual, cultural and existential needs of persons of all ages experiencing a debilitating, chronic or life-threatening illness, condition or injury.

**Physician-Assisted suicide**--a physician prescribes the lethal dose of medication (medicines, poisons) for a person to kill himself or herself knowing the person's intent. Physician-assisted suicide is illegal in every state except Oregon.

**Proxy**-- a competent adult who has not been expressly designated to make health care decisions for a particular incapacitated individual, but who, nevertheless, is authorized pursuant to state law to make health care decisions for such individual.

**Suicide**--taking one's own life by his or her own hand.

**Surrogate**--any competent adult expressly designated by an individual to make health care decisions on behalf of the individual upon the individual's incapacity.

**Terminal illness**--a condition caused by injury, disease, or illness, from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death.

**Persistent vegetative state**-- a permanent and irreversible condition of unconsciousness in which there is the absence of voluntary action or cognitive behavior of any kind and an inability to communicate or interact purposefully with the environment.

\* "Society is... (facing) a number of inherited dysfunctional conceptual models and categories. Commonly people talk of the terminally ill or dying as if they were describing a separate kind of person discernible by prognosis...Most people, however, have ambiguous prognoses...on the day before death, the median prognosis for patients with heart failure is still a 50% chance to live 6 more months...a chronically ill patient can hold on for a long time..." J. Lynn, JAMA, 2000 284(19) 2509.

## **Website/Internet Resources**

Agency for Healthcare Policy and Research	<a href="http://www.ahrp.gov/">http://www.ahrp.gov/</a>
Aging with Dignity	<a href="http://www.agingwithdignity.org">http://www.agingwithdignity.org</a>
American Academy of Hospice and Palliative Medicine	<a href="http://www.aahpm.org">http://www.aahpm.org</a>
American Association of Retired Persons	<a href="http://www.aarp.com">http://www.aarp.com</a>
ABCD Americans for Better Care of the Dying	<a href="http://www.abcd-caring.org">http://www.abcd-caring.org</a>
American Hospice Foundation	<a href="http://www.americanhospice.org">http://www.americanhospice.org</a>
American Geriatrics Society	<a href="http://www.americangeriatrics.org">http://www.americangeriatrics.org</a>
American Medical Association	<a href="http://www.ama-assn.org">http://www.ama-assn.org</a>
American Nurses Association	<a href="http://www.ana.org">http://www.ana.org</a>
American Pain Society	<a href="http://www.ampainsoc.org">http://www.ampainsoc.org</a>
American Psychological Association (on-line)	<a href="http://www.apa.org/releases/mind.html">http://www.apa.org/releases/mind.html</a>
Before I Die: Medical Care and Personal Choices	<a href="http://www.wnet.org/archive/bid">http://www.wnet.org/archive/bid</a>
Center to Advance Palliative Care	<a href="http://www.capc.org">http://www.capc.org</a>
Decisions Near the End of Life	<a href="http://www.edc.org/CAE/Decisions">http://www.edc.org/CAE/Decisions</a>
Education for Physicians on End of Life Care (EPEC)	<a href="http://www.epec.net">http://www.epec.net</a>
End of Life Nursing Education Consortium	<a href="http://www.aacn.nche.edu/elnec">http://www.aacn.nche.edu/elnec</a>
End of Life Physician Education Resource Center	<a href="http://www.eperc.mcw.edu">http://www.eperc.mcw.edu</a>
Florida Department of Elder Affairs	<a href="http://elderaffairs.state.fl.us/">http://elderaffairs.state.fl.us/</a>
Florida Hospices and Palliative Care	1-850-878-2632; 1-800-282-6560
Hospice and Palliative Nurses Association	<a href="http://www.hpna.org">http://www.hpna.org</a>
Hospice Foundation of America	<a href="http://www.hospicefoundation.org">http://www.hospicefoundation.org</a>
Innovations in End of Life Care	<a href="http://www.edc.org/lastacts/">http://www.edc.org/lastacts/</a>
Institute for Healthcare Improvement	<a href="http://www.ihp.org">http://www.ihp.org</a>
Last Acts	<a href="http://www.lastacts.org">http://www.lastacts.org</a>
Mayday Pain Project	<a href="http://www.painandhealth.org">http://www.painandhealth.org</a>
National Association of Social Workers	<a href="http://www.socialworkers.org">http://www.socialworkers.org</a>
National Coalition on Health Care	<a href="http://www.nchc.org">http://www.nchc.org</a>
National Family Caregivers Association	<a href="http://www.nfcares.org/">http://www.nfcares.org/</a>
National Hospice and Palliative Care Organization	<a href="http://www.nhpco.org">http://www.nhpco.org</a>
On Our Own Terms (Moyers)	<a href="http://www.thirteen.org/onourown/terms">http://www.thirteen.org/onourown/terms</a>
Oncology Nursing Society	<a href="http://www.ons.org">http://www.ons.org</a>
Partnership for Caring: America's Voices for the Dying	<a href="http://www.partnershipforcaring.org">http://www.partnershipforcaring.org</a>
Project on Death in America	<a href="http://www.soros.org/death">http://www.soros.org/death</a>
Promoting Excellence in End-of-Life Care	<a href="http://www.promotingexcellence.org">http://www.promotingexcellence.org</a>
Society of Critical Care Medicine	<a href="http://www.sccm.org">http://www.sccm.org</a>
Stanford Cancer Center	<a href="http://cancer.stanford.edu/endoflife">http://cancer.stanford.edu/endoflife</a>
Supporters of Life-Affirming Care at End-of-Life(SOLACE)	<a href="http://www.hospiceonline.org">http://www.hospiceonline.org</a>
Supportive Care of the Dying	<a href="http://www.careofdying.org">http://www.careofdying.org</a>
The AGS Foundation for Health in Aging	<a href="http://www.healthinaging.org">http://www.healthinaging.org</a>
The Mayo Clinic	<a href="http://www.mayoclinic.com">http://www.mayoclinic.com</a>
The National Self-Help Clearing House	<a href="http://www.selfhelpweb.org">http://www.selfhelpweb.org</a>
University of Washington Ethics in Medicine	<a href="http://www.u.washington.edu">http://www.u.washington.edu</a>
University of Wisconsin Pain & Policy Studies Group	<a href="http://www.medsch.wis.edu/painpolicy">http://www.medsch.wis.edu/painpolicy</a>

## **Addendum**

**INSTITUTE OF MEDICINE**  
**Division of Health Care Services**  
**Report on Improving Care at The End of Life**  
**Christine Cassel, MD Committee Chair**  
**1997***(last funded published report)*

*Summary of Important Points Quoted from the Report*

### **Caring at End of Life: Dimensions and Deficiencies**

- Too many dying people suffer from pain and other distress that clinicians could prevent or relieve with existing knowledge and therapies.
- Significant organizational, economic, legal, and educational impediments to good care can be identified and, in varying degrees, remedied.
- Important gaps in scientific knowledge about the end of life need serious attention from biomedical, social science, and health services researchers.
- Strengthening accountability for the quality of care at the end of life will require better data and tools for evaluating the outcomes important to patients and families.

Further elaboration on the above points:

People suffer at end of life from both errors of omission (when caregivers fail to provide palliative and supportive care known to be effective) and from errors of commission (when caregivers do what is known to be ineffective or even harmful, e.g., performing inappropriate cardiopulmonary resuscitation or other painful, invasive procedures). Studies have repeatedly indicated that a significant proportion of dying patients and patients with advanced disease experience serious pain, despite the availability of effective pharmacological and other options for relieving most pain. In perverse counterpoint to the problem of undertreatment, the aggressive use of ineffectual and intrusive interventions may prolong and even dishonor the period of dying.

### **Recommendations and Future Directions**

- People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care. Health care organizations should adopt policies regarding information, education, and assistance related to end-of-life decisions and services.
- Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms.
- Because many problems in care stem from system problems, policy makers, consumer groups,

and purchasers of health care should work with health care practitioners, organizations and researchers to

1. strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them;
  2. develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life;
  3. revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and
  4. reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering.
- Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients.
  - Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.
  - The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care.
  - A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death.

For a full copy of the report, call 1-800-624-6242 or visit on-line at <http://www.nap.edu>

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