

# **ETHICS FOR END-OF-LIFE CARE**

**"If we know that severe pain and suffering can be alleviated and we do nothing about it, then we ourselves become the tormentors."**

**Primo Levi, cancer patient & Auschwitz survivor**

**"Hope is an orientation of the Spirit, an orientation of the heart. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out."**

**Vaclav Havel**

**"Our prime aim in helping a dying person is to put them at ease."**

**The Dalai Lama**

**"Tell them not to be afraid of the dying. It's very simple. The dying need tender loving, nothing more."**

**Mother Teresa**

**"If we could remember to treat the living well, we wouldn't need to remember the rights of the dying; we would meet their needs naturally."**

**Elisabeth Kubler-Ross**

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# ETHICS FOR END-OF-LIFE CARE

- Objectives:
  - Explain the hospice philosophy of care
  - Identify the ethics of end-of-life care
  - Cite and negate hospice myths
  - Recognize barriers to hospice care
  
- Course outline based on Objectives:
  - Describe a brief history of the development of hospice care
    - Latin, *hospes*, which served double-duty in referring both to guests & hosts; root word for "hospital, hospice, hostel, & hospitality"
      - First hospices are believed to have originated around 1065 when for the first time the incurable ill were permitted into places dedicated to treatment by Crusaders
      - 14<sup>th</sup> century, order of the Knights Hospitaller of St. John of Jerusalem opened first hospice in Rhodes
      - Hospices flourished in the Middle Ages, but languished as religious orders were dispersed
      - St. Camillus de Lellis; 1550 – 1614; Hospital for Incurables; order: Fathers of a Good Death
      - 17<sup>th</sup> century in France by Daughters of Charity of Saint Vincent de Paul
      - 1843 the hospice of L'Association des Dames du Calvaire, founded by Jeanne Garnier
      - Six other hospice followed before 1900
    - Dame Cicely Saunders, MD
      - "You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die."
      - 1905 the Irish Sisters of Charity opened St. Joseph's Hospice in London. It was there in the 1950's that Dame Saunders developed many of the foundational principles of modern hospice care.
      - She was a registered nurse whose chronic health problems had forced her to pursue a career in medical social work.
      - The relationship she developed with a dying Polish refugee helped solidify her ideas that terminally ill patients needed compassionate care to help address their fears & concerns as well as palliative comfort for physical symptoms.
      - After his death, Saunders began volunteering at St. Luke's Home for the Dying Poor, where a physician told her that she could best influence the treatment of the terminally ill as a physician.
      - She entered medical school while continuing her volunteer work at St. Joseph's. When she achieved her degree in 1957, she took a position there.
      - Because of her experiences as a registered nurse, medical social worker, and physician, she launched the hospice movement on a multidisciplinary platform.
      - **Total Pain** – formulated the idea of total pain as incorporating physical, psychological, social, emotion, and spiritual elements.
        - Willingness to acknowledge the spiritual suffering of the patient and to see this in relation to physical problems. In my opinion, addressing spiritual pain is the least addressed aspect.
        - Crucially, total pain was tied to a sense of narrative and biography, emphasizing the importance of listening to the

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- patient's story and of understanding the experience of suffering in a multifaceted way.
- This was an approach that saw pain as a key to unlocking other problems and as something requiring multiple interventions for its resolution.
- St. Christopher's Hospice – 1967 – birthplace of modern hospice movement
  - Dame Saunders died at St. Christopher's July 14, 2005
- Elizabeth Kubler-Ross, MD; On Death and Dying – 1969
  - On the Fear of Death
    - "Let me not pray to be sheltered from dangers but to be fearless in facing them. Let me not beg for the stilling of my pain but for the heart to conquer it. Let me not look for allies in life's battlefield but to my own strength. Let me not crave in anxious fear to be saved but hope for the patience to win my freedom. Grant me that I may not be a coward, feeling your mercy in my success alone; but let me find the grasp of your hand in my failure". Rabindranath Tagore, *Fruit-Gathering*
  - Attitudes Toward Death and Dying
    - "Men are cruel, but Man is kind". Tagore, *Stray Birds*.
  - First Stage: Denial and Isolation
    - "Man barricades against himself". Tagore, *Stray Birds*.
  - Second Stage: Anger
    - "We read the world wrong and say that it deceives us". Tagore, *Stray Birds*.
  - Third Stage: Bargaining
    - "The woodcutter's axe begged for its handle from the tree. The tree gave it". Tagore, *Stray Birds*.
  - Fourth Stage: Depression
    - "The world rushes on over the strings of the lingering heart making the music of sadness". Tagore, *Stray Birds*.
  - Fifth Stage: Acceptance
    - "I have got my leave. Bid me farewell, my brothers! I bow to you all and take my departure. Here I give back the keys of my door – and I give up all claims to my house. I only ask for last kind words from you. We were neighbours for long, but I received more than I could give. Now the day has dawned and the lamp that lit my dark corner is out. A summons has come and I am ready for my journey". Tagore, *Gitanjali*.
  - Hope
    - "In desperate hope I go and search for her in all the corners of my room; I find her not. My house is small and what once has gone from it can never be regained. But infinite is thy mansion, my lord, and seeking her I have come to thy door. I stand under the golden canopy of thine evening sky and I lift my eager eyes to thy face. I have come to the brink of eternity from which nothing can vanish – no hope, no happiness, no vision of a face seen through tears. Oh, dip my emptied life into the ocean, plunge it into the deepest fullness. Let me for once feel that lost sweet touch in the allness of the universe". Tagore, *Gitanjali*.

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- Connecticut Hospice Care Inc.
  - First hospice in United States – 1974
  - Florence Wald, RN – Dean of Yale’s School of Nursing
    - Dame Saunders consulted on-site at the request of Ms. Wald
    - Took a year sabbatical to study with Dame Saunders at St. Christopher’s
    - She died at the hospice in 2008 at the age of 91
- Hospice Plus
  - Largest hospice in Metroplex
    - Average daily census 900+, cover 14,000 square miles
    - Bryan White, MD is Medical Director
    - Joint Commission Certified with Deemed Status
  - Opened 2005
  - Curo Health Services is parent corporation
- Hospice Legislation (“History of Hospice Care” – The National Hospice & Palliative Care Organization)
  - 1972: Dr. Kubler-Ross testifies at the first national hearings on the subject of death with dignity, which are conducted by the U.S. Senate Special Committee on Aging.
  - 1974: The first hospice legislation is introduced by Senators Frank Church and Frank Moss to provide federal funds for hospice programs. The legislation is not enacted.
  - 1978: A. U.S. Department of Health, Education, and Welfare task force reports that “the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which olds out a means of providing more humane care for Americans dying of terminal illness while possible reducing costs. As such, it is the proper subject of federal support.”
  - 1979: The Health Care Financing Administration (HCFA) initiates demonstration programs at 26 hospices across the country to assess the cost effectiveness of hospice care and to help determine what a hospice is and what it should provide.
  - 1980: The W.K. Kellogg Foundation awards a grant to the Joint Commission on Accreditation of Hospitals (JCAHO) to investigate the status of hospice and to develop stands for hospice accreditation.
  - 1984: JCAHO initiates hospice accreditation.
  - 1986: The Medicare Hospice Benefit is made permanent by Congress. States are given the option of including hospice in their Medicaid programs. Hospice care is now available to terminally ill nursing home residents.
  - 1993: Hospice is included as a nationally guaranteed benefit under President Clinton’s health care reform proposal. Hospice is now an accepted part of the health care continuum.
  - Hospice is the only entity for which Medicare pays 100% of services provided
- Describe the hospice philosophy of care
  - Holistic concept
    - Emotional, physical, social, and spiritual comfort

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- Family unit
  - The dying person & his/her family as the unit of care
- Palliative care
  - Emphasis on comfort not cure; benefit vs. burden; Quality of Life ("majority of patients are over treated with technology but pain is under treated")
  - W.H.O. definition: compassionate care directed at improving quality of life for people with life-limiting illness not responding to curative treatment; encompasses last 2 – 2.5 years of life (hospice care – usually refers to last 6 months of a person's life)
- Affirms life and prepares for death
  - Regards dying as a normal process
  - Supports the natural dying process.
  - Allows nature to take its course.
  - "Death belongs to life as birth does. The walk is in the raising of the foot as in the laying of it down". Tagore, *Stray Birds*.
- Describe the ethics of end-of-life care (David Kessler)
  - The right/need to be treated as a living human being.
  - The right/need to maintain a sense of hopefulness, however changing its focus may be.
  - The right/need to be cared for by those who can maintain a sense of hopefulness, however changing this may be.
  - The right/need to express feelings and emotions about death in one's own way.
  - The right/need to participate in all decisions concerning one's care.
  - The right/need to be cared for by compassionate, sensitive, knowledgeable people who will attempt to understand one's needs.
  - The right/need to expect continuing medical care, even though the goals may change from "cure" to "comfort" goals.
  - The right/need to have all questions answered honestly and fully.
  - The right/need to seek spirituality.
  - The right/need to be free of physical pain.
  - The right/need to express feelings and emotions about pain in one's own way.
  - The right/need of children to participate in death.
  - The right/need to understand the process of death.
  - The right/need to die.
  - The right/need to die in peace and dignity.
  - The right/need not to die alone.
  - The right/need to expect that the sanctity of the body will be respected after death.
- Describe the referral process
  - Patient/family
    - Physician discusses hospice with pt/family
    - Pt/family wishes to further pursue hospice options
  - Physician
    - Writes Order for hospice consult in Care Connect CPOE
      - Either "hospice consult" with any narrative;
      - Or "social work consult" with narrative for hospice consult
    - Order sent to social worker per hospital policy
  - Social worker

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- Confirms pt/family wishes to pursue hospice services
- Provides hospice agency options
- Notifies hospice agency chosen by pt/family
- Nurse
  - Provides additional support to pt/family
  - Assists with discharge planning
- Hospice agency
  - Completes evaluation and intake process
  - Meets with pt/family to discuss hospice services
  - Plans and assists with discharge;
  - Or, coordinates general inpatient admission
- Describe hospice services
  - Criteria for admission
    - Terminal diagnosis
    - Life expectancy of less than 6 months
    - Desire to have treatment focused on comfort rather than curative interventions
    - Safe environment to receive care
  - Cancer and non-cancer diagnoses
    - Cancer diagnosis with life expectancy of less than 6 months
    - General Guidelines (Failure to Thrive or General Debility)
    - End-stage AIDS
    - Amyotrophic Lateral Sclerosis (ALS)
    - CVA and Coma
    - End-stage Dementia
    - End-stage Cardiopulmonary Disease (ES Cardiac & ES Lung recently combined into one category by Medicare)
    - End-stage Liver Disease
    - End-stage Renal Disease
  - Symptom control
    - Physical – pain, respiratory distress, fever, nausea and vomiting, hemorrhage, oropharyngeal secretions, etc.
    - Emotional – anxiety, fear, restlessness, agitation, denial, depression, etc
    - Spiritual – lack of or faltering spiritual aspect of life, need for reassurance, reconnect with spiritual community, arrange funeral services, etc.
    - Social – unresolved issues, need to make amends, life reviews, “still grandma”
  - 4 Levels of Care
    - Routine home care, wherever the patient lives
      - Home
      - Assisted living facilities
      - Nursing home
      - Residential home
    - General Inpatient care
      - Patient is actively dying; comatose; less than a week to live and cannot be cared for in a lower level of care
      - Acute symptom management
      - If patient stabilizes, must move to another level of care
    - Respite care, in a contracted nursing home facility
      - To provide a break or rest for the family and/or caregiver

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- Medicaid covers a total of 5 days for entire time patient is on hospice
  - Continuous home care, wherever the patient lives
    - Crisis care for acute symptom management
    - For other crisis within the home
- Ancillary services
  - Medications related to hospice diagnosis and symptom control
  - Durable medical equipment
  - Medical supplies
  - Specialty and therapy services needed for symptom control
    - OT, PT, ST, RD
- Interdisciplinary Team
  - Provided by professional team primarily in the home setting
  - Personalized, comprehensive services based on patients and family's individual needs
  - Team members:
    - Patient and family
    - Physician
    - Registered nurse
    - Medical social worker
    - Spiritual Care coordinator
    - Hospice aide
    - Volunteers
    - Bereavement coordinator
- Pain Management
  - "Pain is what the experience the person says it is, existing whenever he or she says it does." Margo McCaffery, RN, Pioneer in Pain Management
  - **The patient's report must be accepted!**
  - "At the end of your life, I cannot prevent you from dying. But with your permission, I can prevent you from suffering." Mildred McAfee, MD, formerly physician with M.D. On Call Hospitalist
  - "If you haven't been scammed occasionally by a patient requesting pain medications, you've more frequently been under-medicating." Tiffany Sun, M.D., Intern THD 2008.
  - Hospice Philosophy: "If you hurt, take more; when you stop hurting, stop taking it." Medicate at a 3/10 and keep as close to 0 as possible; severe impact to quality of life when pain is 5/10.
  - PAINAD scale for the unresponsive. See attached.
  - Ethical Imperative: The Principal of Double Effect recognizes that one's actions may have multiple effects, and that the primary intent of an act is determinative. For example, it is considered medically appropriate to administer morphine to relieve pain and respiratory distress to a terminally ill patient. Knowing that the accompanying secondary effect may be slight decrease in respiration and provide a state of comfort that allows the patient to die peacefully. The primary intent should always be symptom control.
  - Important Definitions:
    - **Pain**, according to the IASP (International Association for the Study of Pain), is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. In 2001, the following was added: the inability to communicate

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verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment.

- **Addiction:** addiction is a primary, chronic, neurobiologic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm and craving.
- **Tolerance:** tolerance is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time.
- **Physical Dependence:** physical dependence is a state of adaptation that is manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug and/or administration of an antagonist.
- **Opioid "pseudo-addiction":** an iatrogenic syndrome in which patients develop certain behavioral characteristics of psychological dependence as a consequence of inadequate pain treatment. Patients with this syndrome must continually demonstrate their need for analgesics and are often described as difficult patients, chronic complainers, drug seekers and/or "addicts." Patients will often resort to bizarre or dramatic behavior (acting out) in an attempt to prove their pain is real so analgesics are provided.
- **W.H.O. Pain Ladder:**
  - Step 1 – Non-opioid: aspirin, acetaminophen, NSAIDs
  - Step 2 – Weaker opioid: tramadol, codeine, hydrocodone; *new literature is suggesting to replace this step with lower doses of medications from Step 3*
  - Step 3 – Stronger opioid: morphine, hydromorphone, oxycodone, fentanyl
  - Adjuvants: antidepressants, anticonvulsants, steroids, muscle relaxants, massage therapy, music therapy, pet therapy, acupuncture, etc.
- **Morphine-Dilaudid Equianalgesic Table:**

	<b>IV</b>	<b>PO</b>
<b>Morphine</b>	10	30
<b>Dilaudid</b>	1.5	7.5

- Routine general inpatient hospice (GIP) orders:



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- Admit to General Inpatient Hospice for Faith Presbyterian Hospice per services of *John Doe, MD* with diagnosis of *End Stage CHF*
  - DNR (some new terminology: "DNAR" = Do Not Attempt Resuscitation & "AND" = Allow Natural Death)
  - Diet: NPO
  - O2 protocol; No O2 sats, nasal cannula only please
  - No lab draws, diagnostics, procedures, and/or consults.
  - If they have a morphine or dilaudid drip, "Continue morphine drip at *(the current rate)* and titrate to comfort"
  - Morphine 1 – 5 mg IVP q2h prn pain/respiratory distress and titrate to comfort
  - Or – Dilaudid 1 – 2 mg IVP q2h prn . . . . .
  - Fentanyl transdermal patches work best if pt has adequate subcutaneous tissue for appropriate absorption and release
  - Ativan 1 – 2 mg IVP q4h prn restlessness/agitation and titrate to comfort (or, substitute haldol [same dosage and frequency] if ativan isn't effective; or, may need both in extreme cases of terminal restlessness)
  - Phenergan 12.5 mg IVP or 25 mg supp q4h prn n/v; or, Zofran 4 mg IVP q4h prn n/v
  - Tylenol 650 mg supp, 1 PR q4h prn fever
  - Atropine 1% Ophthalmic Drops - 2 drops SL q2h prn oropharyngeal secretions
  - Scopolamine Patch 1 TD behind ear and change q72h
  - If they have a peripheral IV site that we might lose or if they do not have an IV site, "Roxanol 20mg/ml, 5 – 20 mg SL q2h prn pain/respiratory distress and titrate to comfort"; "Lorazepam Intensol 2mg/ml, 1 – 2 mg SL q3h prn restlessness/agitation and titrate to comfort," and "Dilaudid 3mg Supp, 1 – 2 supp PR q2h prn pain/respiratory distress and titrate to comfort"
  - If they have IVF's, slow them to a TKO of 10 ml/hr
  - If they have PEG or DHT feedings, for the family's emotional sake, slow them to ½ of current rate and then DC the following day
  - Please call Hospice Plus with any change in condition and when patient expires 214-343-7900.
- Describe reimbursement in hospice care
    - Per diem
    - Medicare
    - Medicaid
    - Commercial Insurance
    - Unfunded
  - Recognize hospice myths
    - Hospice is for cancer patients.
      - Fact - Hospice is for any end-stage disease
    - Hospice is just for the last few weeks of life.
      - Fact – The longer someone is on service, the more opportunities for quality of life at the end of life – life review, complementary therapies, and the building of trust through relationships.
    - Hospice provides 24-hour custodial care.
      - Fact – Routine Hospice Care is intermittent care provided by an entire interdisciplinary team. However, hospice staff is always

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available 24/7 if needed. If around-the-clock care is needed, hospice can provide a list of suitable organizations for hiring caregivers.

- Hospice is always a place.
  - Fact – Hospice is where they live. Hospice patients live in their own homes, in long term care facilities (nursing homes, assisted living facilities), and sometimes even in hospitals.
- Being admitted to hospice means you are giving up hope.
  - Fact – Hospice is a healthcare choice. It is appropriate for those who choose "quality of life" over aggressive treatment. When faced with a terminal illness, many patients and family members tend to dwell on the imminent loss of life rather than on making the most of the life that remains. Hospice helps patients reclaim the spirit of life. It helps them understand that even though death can lead to sadness, anger, and pain, it can also lead to opportunities for reminiscence, laughter, reunion, and hope. Often, with good pain and symptom management, patients who choose hospice care live longer than those who do not. Research has shown that, for the same disease process, patients on hospice live an average of 29 days longer.
- Hospice is expensive, patient needs Medicare or Medicaid to afford hospice care
  - Fact – Hospice expenses are covered 100% by Medicare and Medicaid. Most private insurance companies also offer a hospice benefit. In addition, through community contributions, memorial donations, and foundation gifts, many hospices are able to provide patients who lack sufficient payment with free services. Other programs charge patients in accordance with their ability to pay.
- You can only be on hospice for 6 months.
  - Fact – Hospice is available to everyone who has a life-limiting disease and a *prognosis* of six months or less to live. A doctor's order for hospice is required for admission. However, that does not mean that the person will die in six months. In fact, many patients improve with quality pain and symptom management and may come off of service for an extended prognosis. Others have remained on hospice much longer than six months, as long as they continue to meet hospice criteria.
- Everyone who is eligible goes on hospice.
  - Fact – only approximately 25% of those who are eligible for hospice actually receive services. Many people do not know about hospice or are afraid because of the myths and misconceptions. Many people believe that hospice means giving up hope, or that they will die sooner if they choose hospice care. Other people do not realize it is a healthcare choice and that they should ask their physician about it.
- Hospice "takes over" the patient's care.
  - Fact – The hospice team consists of the patient's primary care physician, hospice physician, nurse, social worker, chaplain, hospice aid, and volunteers. However, the team does not replace the attending/referring physician or pastor. The hospice team in an addition to the patient/family support system. One of the goals of hospice is to educate the family so that they may take good care of

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the patient. Hospice should never try to take away the patient's or the caregiver's autonomy.

- Hospice services for the patient and family end at the time of the patient's death.
  - Fact – Bereavement services are offered to the family for 13 months after the death. These services include, but are not limited to, phone calls, counseling, appropriate mailings, and community events, such as grief groups and memorial services.
- Hospice is only for the physical care of the patient.
  - Fact – not all pain is physical. Hospice care is holistic. It provided physical, emotional, and spiritual care for the patient and their loved ones.
- Hospice only provides visits by licensed staff.
  - Fact – While the actual hands-on care is provided by licensed staff, visits are also made by volunteers. The volunteers go through extensive training and perform a variety of services depending on patient and/or caregiver needs.
- All hospice programs are the same.
  - Fact – All licensed hospice programs must provide certain services, but the range of support services and programs may differ. In addition, hospice programs and operating styles may vary from state to state depending on state laws and regulations. Like other medical care providers, business models differ. Some programs are not-for-profit and some are for-profit.
- Hospice is just for the patient.
  - Fact – hospice focuses on comfort, dignity, and emotional support. The quality of life for the patient, and also family members and others who are caregivers, is the highest priority.
- A physician decides whether a patient should receive hospice care and which agency should provide that care.
  - The role of the physician is to recommend care, whether hospice or traditional curative care. It is the patient's right (or, in some cases the right of the person who holds power of attorney) and decision to determine when hospice is appropriate and which program suits his or her needs. Before entering a hospice, however, a physician must certify that a patient has been diagnosed with a terminal illness and has a life expectancy of six months or less.
- To be eligible for hospice care, a patient must already be bedridden.
  - Hospice care is appropriate at the time of the terminal prognosis, regardless of the patient's physical condition. Many of the patients served through hospice continue to lead productive and rewarding lives. Together, the patient, family, and physician determine when hospice services should begin.
- Recognize barriers to hospice care
  - Patient:
    - Lacks knowledge about hospice
    - Denies terminal status
    - Wishes to continue active treatment
    - Believes hospice means death
    - Myths listed above
    - Financial status
  - Hospice structure

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- Complicated admission criteria
- Drug restrictions
- Primary caregiver requirement
- Prognosis of 6 months or less
- Physician
  - Negative perceptions
    - Perceives hospice as inflexible
    - Views hospice as last resort
    - Lacks knowledge about and experience with hospice
    - Myths listed above
  - Discomfort communicating
    - Reluctant to give terminal diagnosis and prognosis
    - Fears being blamed for giving up
    - Uncomfortable talking about death
  - Instrumentalist perspective
    - Fears losing control of patient
    - Prefers active treatment to palliative care
    - Feels pressure from cure-oriented profession
  - Timing of discussion
    - Overestimates life expectancy
    - Wary of suggesting hospice
    - Waits until patient has no other options or is too fragile to transfer
    - "Would you be surprised if your patient died in the next 6 months."
- Dunn, Hank, *Hard Choices for Loving People*:
  - What really makes these decisions "hard choices" has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual.
  - When a person dies after the withholding or artificial food and fluids, the death is from the condition or disease that made the patient unable to eat, not from the removal of artificial feeding. Therefore, nothing is being introduced to "kill" the patient, but the natural process of dying is being allowed to progress.
  - The medical evidence is quite clear that dehydration in the end stage of a terminal illness is a very natural and compassionate way to die.
  - From moral, ethical, medical, and most religious viewpoints there is no difference between withholding and withdrawing. Emotionally, there is a world of difference.
  - There are three possible goals of medical care: 1) Cure; 2) Stabilization of function; 3) Preparing for a comfortable and dignified death.
  - At any point during an illness, patients and families need to prepare emotionally and spiritually for the possibility of death. This preparation can be accomplished even while aggressively treating symptoms.
  - Wherever hospice serves, emphasis is on management of pain and other symptoms and the quality of life rather than length of life.
  - Cure sometimes – comfort always.
  - The first step toward a comfortable and dignified death is accepting the terminal diagnosis. An earlier recognition of the prognosis contributes to a more peaceful death.
  - The permanent inability to take in food or water is a terminal condition.
  - Curiously, many cultures see stopping eating as a sign of dying not its cause. They never even consider the use of a feeding tube.

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- I believe we are on dangerous ground thinking we get a clear divine message that someone with advanced end-stage cancer will not die when the death expectancy rate for all of us is 100 percent.
- The dying patient's perspective:
  - AIDS patient: "I have finally learned the difference between giving up and letting go."
  - 83-year-old patient: "Let me tell you, Doctor, dying is the experience of a lifetime." What she meant by these splendid words remains, like the fabric of life itself, a mystery.
  - Lillian Preston's final letter from St. Christopher's Hospice: "I was meant to come here so that at last, I could experience joy."
  - Elderly blind gentleman of St. Joseph's Hospice in London: "I never knew how to live until I came here to die."
- Final Quotes:
  - Ryan's Rule: "Do what brings you comfort."
  - "We have little time to make a difference." & "We must be a chameleon; we have to be what they need us to be." Trudy Rand, R.N., CHPN, Hospice of Metro Denver
  - "People die they way they lived." Gail Meyer, LCSW, VNA Hospice
  - "People who are dying are still living." David Kuhl, M.D.
  - "The ultimate tragedy is depersonalization . . . dying in an alien and sterile arena, separated from the spiritual nourishment what comes from being able to reach out to a loving hand." Norman Cousins
  - "It sounds paradoxical: by excluding death from our life we cannot live a full life, and by admitting death into our life we enlarge it." Etty Hillesum
  - "Death is not the ending of anything. I believe all of us are only energy that becomes matter. When the matter goes away, the energy still exists. You can't destroy it. It never dies. It manifests itself somewhere else. We are never alone. Even by ourselves, we are not alone. Death is just a door opening to somewhere else. Someday we'll know what that door opens to. I believe that. I really do." Willie Nelson
  - "After flying so many missions in the war, I'm not afraid of dying. But is sure is boring waiting around." Former patient.
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