

# Death as a Part of Life

## PART I: INTRODUCTION

From the moment we are born, we begin dying. It's a fact of life, but one that nobody wants to be reminded of. However, as health care providers, it is imperative that we understand our own perceptions of death and dying, as well as assist the transition from life to death for those we care for and ease the pain this transition causes to their loved ones by providing end-of-life care that is compassionate and complies with the standards of care established by the medical community. End-of-life care refers to health care for a person with a terminal condition that has become advanced, progressive, and/or incurable. This course will explore issues affecting end-of-life care decisions: culture, health literacy, family dynamics, medical advances, ethics and the dichotomy of prolonging life vs. quality of life. Hospice, Advance Directives, palliative care as well as current health insurance issues will be explored. To best meet the needs of the individuals being cared for, health care providers must be familiar with, and comfortable with, end-of-life care.

## PART II: DEFINITIONS

To clarify and ensure an understanding of the information contained in this module, participants must become familiar with the definition of the following terms:

- **ACCOUNTABLE CARE ORGANIZATION (ACO)** is a health care model consisting of a network of doctors and hospitals that share financial and medical responsibility for providing coordinated care to patients in hopes of limiting unnecessary treatments and spending.
- **ADVANCE DIRECTIVES** inform a health care team what kind of care an individual would like to have, no matter how ill, if the person becomes unable to make medical decisions (loses mental capacity). It can also inform the health care team what type of treatment a person doesn't want. It is completed by the patient. Laws about Advance Directives (i.e. Living Will, Advanced Health Care Directive, Durable Power of Attorney for Health Care) are different in each state and health care workers should be familiar with the laws in the states they practice in.
- **ASSISTED LIVING FACILITY (ALF)** is a housing facility for people who cannot safely live independently.

- **CARE COORDINATION** involves bringing together various providers and information systems to coordinate health services, patient needs, and information to help better achieve treatment and care goals.
- **CASE MANAGEMENT** is a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates options and services required to meet a patient's health and human service needs.
- **CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)** is the administrative body that administers Medicare, a national health insurance program for Americans aged 65 or older as well as some younger people with certain illnesses or disability status. It also administers Medicaid, a federal and state program for people of all ages whose income and resources are insufficient to pay for health care.
- **CULTURAL COMPETENCE** is the ability to understand, communicate with, and effectively interact with people of different cultural backgrounds.
- **CULTURE** is the way of life of a particular people, especially as shown in their ordinary behavior and habits, their attitudes toward each other, and their moral and religious beliefs.
- **DEATH** has two phases – clinical and biological. Clinical Death occurs when the heart stops beating and the blood stops flowing and can be reversible with intervention. Biological Death is the permanent cessation of all biological functions that sustain a living organism and is irreversible.
- **DEATH WITH DIGNITY LAWS** allow qualified terminally ill adults to voluntarily request and receive a prescription medication to hasten their death.
- **DURABLE POWER OF ATTORNEY FOR ASSET MANAGEMENT** is a legal document that allows an individual to appoint another person to act for them in financial matters and cannot be used to make health care decisions.
- **END-OF-LIFE CARE** refers to health care for a person with a terminal condition that has become advanced, progressive, and/or incurable.
- **ETHICS** is universally accepted as a set of recognized and accepted standards of what is considered right and wrong that are codified into a formal set of rules which are adopted by a group of people.

- **ETHNICITY** is the fact or state of belonging to a social group that has a common national or cultural tradition.
- **ETHNOCENTRISM** is the act of judging another culture based on the values and standards of one's own culture.
- **EUTHANASIA** is the act of assisting people with their death in order to end their suffering, but without the backing of a controlling legal authority.
- **FEE-FOR-SERVICE** is a health care model in which a health care provider is paid a fee for each particular service rendered, regardless of the outcome.
- **HEALTH LITERACY** is the ability to read, understand and act on health care information.
- **HOME HEALTH CARE** is the provision of services in the home that are appropriate to a patient's need and are performed by licensed professionals.
- **HOSPICE**, also called "**comfort care**," focuses on managing pain and keeping a patient comfortable at the end of life.
- **NURSING HOME** is a residential facility providing a high level of long term personal or nursing care for people who are unable to care for themselves properly.
- **PALLIATIVE CARE** focuses on providing relief from symptoms, including pain, and physical and mental stress at any stage of illness.
- **PATIENT-CONTROLLED ANALGESIA PUMP (PCA)** is a computerized machine that gives a drug for pain through a tube placed in a patient's vein to enable the patient to control pain by pressing a button.
- **PHYSICIAN-ASSISTED SUICIDE (PAS)** occurs when a physician facilitates a patient's death by providing necessary means and/or information to enable the patient to perform the life-ending act.
- **PHYSICIANS ORDERS FOR LIFE SUSTAINING TREATMENT (POLST)** is a more detailed and specific Do Not Resuscitate (DNR) order. This form is filled out with a patient's physician and once signed, all medical and emergency personnel must honor the instructions on the form.

- **RELIGION** is an organized system of beliefs, ceremonies, and rules used to worship a superhuman controlling power, especially a personal God or gods.
- **SELF AUTHORIZATION FOR CREMATION** is a legal document signed by someone who is doing a prearrangement for themselves to be cremated after death.
- **SUPPORT SYSTEM** is a network of people who provide a patient with practical or emotional support. This can be formal (health care providers) or informal (family, friends, etc.).

### **PART III: END-OF-LIFE CARE DECISIONS**

Even though modern medicine has prolonged life by turning many once fatal illnesses into chronic ones, death is inevitable. Many people are reluctant to deal with and/or discuss end-of life care for numerous reasons. This is significant because a study published in the January 2014 edition of “The American Journal of Preventive Medicine” surveyed adults in the United states and found that of the 7,900 respondents, only 26.3% had advance directives, regardless of age or health. This indicates that individuals have not documented their end-of-life care preferences.

When an individual loses mental capacity and has not made end-of-life care choices known, others must take over the decision-making process for the individual. Due to a lack of advance planning, who can make these decisions is often not clear and can lead to problems, especially among family members. The process of documenting an individual’s desires can be done through an Advance Directive. Laws about Advance Directives are different in each state and all health care providers should be aware of the laws in the states they practice in.

A Living Will is one type of Advance Directive. It is a written, legal document that describes the kind of medical treatments or life-sustaining treatments individuals would or would not want if they were seriously or terminally ill. A Living Will doesn’t identify someone to make decisions for them if they are unable to make these types of decisions for themselves. Another type of Advance Directive is the assignment of a Health Care Proxy (also known as a Durable Power of Attorney for Health Care, Medical Power of Attorney, or Appointment of a Healthcare Agent). This document allows individuals to appoint another person (a proxy or agent) to express their wishes and make health care decisions for them if they are unable to do so by themselves. A Do Not Resuscitate (DNR) order is another kind of Advance Directive. A DNR is a request not to have Cardiopulmonary Resuscitation (CPR) if a person’s heart stops or if he/she stops breathing. Unless given other instructions, medical staff will try to help any individual whose heart has

stopped or who has stopped breathing. Doctors and hospitals in all states accept DNR orders. A more comprehensive DNR is the Physicians Orders for Life Sustaining Treatment (POLST). Most of the Advance Directives can be done by the patient alone, but the POLST is written by the physician with the patient's input. Since emergency personnel are legally mandated to provide life saving measures to all individuals, this form legally alleviates the problem of the initiation of unwanted emergency procedures.

Although these forms are readily available, for the reasons previously identified, many people do not complete Advance Directives. To overcome the most prevalent reason for not having advance directives, which has been attributed to a lack of awareness of them, several initiatives have been developed.

A primary initiative is providing payments to physicians for discussions relating to end-of-life care by the Centers for Medicare and Medicaid (CMS) and insurance companies.

One specific initiative is The Conversation Project which was launched in 2011 in collaboration with the Institute for Healthcare Improvement (IHI). IHI is a not-for-profit organization that helps lead improvement of health and health care throughout the world. The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care and to make sure that everyone's wishes are expressed & respected. The Conversation Project ([theconversationproject.org](http://theconversationproject.org)), provides a Conversation Starter Kit for guidance about how to help talk with individuals about their wishes for end-of-life care. After the conversation, a "Conversation Starter Kit Summary Sheet" can be used to record the wishes.

Another initiative is "Five Wishes". Five Wishes is used in all 50 states and in countries around the world. It meets the legal requirements for an Advance Directive in 42 U.S. states and the District of Columbia. In the other eight states a completed Five Wishes form can be attached to a state's required form. Five Wishes can be used in any part of the world as a helpful guide and documentation of an individual's wishes for end-of-life care. It is available in 28 languages. Five Wishes is America's most popular Living Will because it's written in everyday language and helps people express their wishes in areas that matter most — the personal and spiritual in addition to the medical and legal. It also helps individuals describe what good care means to them, whether they are seriously ill or not. The Five Wishes lets others know:

1. Who the patients want to make health care decisions for them when they can't make them for themselves.
2. The kind of medical treatment they want or don't want.
3. How comfortable they want to be (palliative care).
4. How they want people to treat them.
5. What they want their loved ones to know.

These Advance Directives are extremely helpful in ensuring that individual end-of-life care preferences are honored.

Mrs. Smith, age 80, has stage 4 Pancreatic Cancer. She is being given continuous controlled sedation for her intractable pain. Her physician wants to insert a feeding tube because she is unable to be fed orally due to the sedation. Mrs. Smith has an Advance Directive in the form of a Living Will which states that she does not want life-sustaining measures taken if she has a terminal illness with no chance of recovery. The physician must abide by her mandated health care decision not to prolong her life with this life-sustaining measure that will not alleviate her pain nor be curative.

#### **PART IV: EFFECT OF POOR HEALTH LITERACY AND COMMUNICATION ON END-OF-LIFE CARE DECISIONS**

Poor health literacy can impede end-of-life care and the decisions made for that care. Health literacy is the ability to read, understand, and act on health care information. Educational levels may be one cause of poor health literacy as well as having English as a second language (ESL). The National Assessment of Adult Literacy (NAAL) found that in 2005, over 30 million American adults were functionally illiterate and could not read above the 3<sup>rd</sup> grade level. Only 12% of American adults had proficient health literacy. This is especially important to the elderly, as they tend to have lower health literacy than other adults. Poor health literacy may cause individuals to be unable to read and fill out an Advance Directive form. They may also not understand what the terminology means during the decision-making process, be embarrassed to admit to this and allow others to decide for them, even if it is not what the individuals want. To get an Informed Consent for healthcare decisions, patients must understand all the care options available, including end-of-life care, and what effect their decisions will have on them. Most informed consent forms are written at high school level or higher. The average American reads at the eighth-to-ninth (8<sup>th</sup> – 9<sup>th</sup>) grade level, so it is easy to understand how people could have trouble comprehending this information. Informed consent is not only a medical issue. It is also a legal issue and federal law mandates that every individual or health care proxy must have the knowledge and information to understand what the doctor plans to do and agrees to have it done.

Often healthcare providers do not realize that patients cannot understand them. Low health literacy is often hard to deal with, since many patients may have developed coping skills to cover up the fact that they have poor literacy skills. They may feel shame because they feel “dumb”. Other people may feel intimidated by authority figures and the medical language they hear. They don’t want to ask questions and have the healthcare provider think they’re stupid or they don’t want to waste the healthcare worker’s time. This can cause a breakdown in communication between the patients and their healthcare providers.

Besides poor health literacy, language and physical handicaps such as poor vision or hearing can also be potent barriers to communication. However, it is a health care provider’s responsibility to ensure that effective communication occurs, so the functional health literacy of an individual is improved, resulting in clearer understanding of what is being said.

There are many ways communication can be improved. Following are some recommendations:

- Ascertain English proficiency or get an interpreter.
- Determine if hearing, vision, or cognition is impaired and account for this in the discussion.
- Remove as many distractions as possible (quiet environment, electronic devices/TV off, etc.).
- Ensure the patient's/caregiver's attention is focused on the discussion.
- Don't overwhelm the patient/caregiver with too much information at once; break the discussion into several parts if necessary.
- Use non-print materials or other adaptors as needed (video/audio tools, pictographs, etc.).
- Get feedback for understanding and clarification.
- Encourage patient/caregiver to ask questions.
- Rephrase the information given using different words if the patient/caregiver doesn't seem to comprehend what is being said.
- Be mindful of nonverbal (body language) and verbal (word choice, not using medical terminology/acronyms, etc.) communication.
- Be a good listener and convey empathy.
- Give supplemental written material to augment the discussion if appropriate.
- Be patient and calm during the discussion; allow the patient/caregiver time to process the information given.

Being aware of potential barriers to communication and understanding how health literacy can impede informed consent issues will help mitigate any breakdowns in communication and can reinforce the bond and trust between patients/caregivers and healthcare providers as well as increase patient satisfaction.

## **PART V: EFFECT OF CULTURE, ETHNICITY, AND RELIGION ON END-OF-LIFE CARE**

Death and dying are universal human experiences throughout the world, but individuals' beliefs, feelings, and practices relating to this experience vary widely between different religions and cultures. To provide quality of care, health care personnel must give culturally appropriate care to patients from diverse cultures as well as respecting their religious needs. This requires that providers become familiar with the norms of various populations they may provide service to. It also requires the providers to understand their own cultural and religious beliefs and not allow these to influence their judgement or treatment of their patients. Ethnocentrism will hinder the development of sensitivity to unique religious and/or cultural needs of patients.

As important as it is to understand various cultures, it is important to not generalize or assume that all people from the same cultural or religious backgrounds are alike. Within many ethnic

populations, such as Hispanics/Latinos, there is a great deal of diversity in terms of cultural practices and geographic origin. When dealing with various cultural populations, it is also important to realize if the patients recently came to America or are first, or second, generation immigrants. If English is not their primary language and they are not proficient in it, health care providers must be determined how best to communicate with them.

Health care providers cannot possibly know the mourning ceremonies and traditions of each culture but understanding some basics about how different cultures prepare for and view death is important. Patients and their families should be consulted about the cultural rituals for coping with dying, the final arrangements for honoring the deceased body, and what their beliefs are concerning what happens after death.

Certain general customs and beliefs can be attributed to religious and/or cultural groups. For example:

- Monotheistic religions such as Christians, Jews, and Muslims believe that death is a transition to a more glorious place and in a single supreme being (God/Allah). They all believe in an afterlife. However, traditions around death and dying differ across all three major monotheistic religions as well as within different branches of each faith. Some key rituals and practices that differ include the preparation of the deceased person's body, the permissibility of organ donation, and the choosing of cremation vs. burial. For example, Jews believe burial should be done within 24 hours after death and Eastern Orthodox Christians prohibit cremation.
- Buddhism and Hinduism believe in reincarnation and do not pray to a single God. They both are a set of philosophies and ways of life. Death is not seen as the end of life but is merely the end of the body a person inhabits in this life; the spirit will be born again as a result of his/her past life. The transition of a soul to a new life is very important so the handling of the body and rituals at the time of dying are significant. Hindus believe the body must be treated in a specific way and cremated before the next sunrise, while the corpse of a Buddhist should not be touched for 3-8 hours after breathing has stopped.
- Collectivist cultures feel the good of the individual is enmeshed with the good of the family or group and they should have a greater say in health care decisions than the patient does in certain circumstances. For example, some cultures believe that physicians should not reveal bad news directly to the patients. This is in direct conflict with the Patient Self-Determination Act. To be in accordance with this cultural belief and the law, patients should be asked who they want to be told about test results or diagnoses.
- Cultural expressions of grief vary from very demonstrative, including wailing, to being restrained in public. For example, in Japan, it is extremely important not to show grief because the Japanese feel they should bear up under misfortune with strength and acceptance. In Latino cultures, it may be appropriate for women to wail, but men are not expected to show overt emotion due to "machismo".

These are just a few illustrations of the types of death and dying rituals followed by various cultural, ethnic, and religions that health care providers should be aware of at end-of-life care.



For health care providers, providing culturally sensitive bereavement/end-of-life care can be uncomfortable. Language and cultural barriers compound the challenges of being professionally appropriate and compassionate. Religious practices may interfere with how health care providers handle end-of-life care. However, familiarizing themselves about the beliefs and customs of their patients, as well as acknowledging their own belief systems, will enable them to provide the most appropriate end-of-life care.

## **PART VI: ROLE OF FAMILY DYNAMICS AT END-OF-LIFE**

Death in a family, though inevitable, can significantly disrupt and upset a family system. Fortunately, most families bond together with the impending passing of a loved one and the giving of emotional support and effective communication between families and health care providers is beneficial to them. However, unresolved issues within a family may impact the behaviors of family members and cause dissension. Some of these issues may be:

- Family members with a warm, loving relationship vs. others harboring dislike, anger, or grudges.
- Family members who accept the approaching death vs. others denying that the patient is dying.
- Family members who are willing to stop life-extending treatment vs. others not willing to do this.
- Family members distressed at the deterioration of a loved one and distancing themselves vs. others who are present and resentful of the lack of their presence.
- Sibling rivalry surfacing and dividing loyalties.
- Family members living at a distance feeling guilty at not being present.
- Family members caring for the patient feeling overwhelmed and resentful of others for not “pulling their weight”.
- Family members who do not want to tell the patient of an impending death vs. those who believe the patient should be informed to enable him/her to prepare for this.
- Advance Directives not made and family members not in agreement as to end-of-life decisions.
- Health Care Proxy’s selection/decisions not accepted by other family members.
- Unresolved death preparation (i.e. Last Will and Testament), especially involving potential heirs from blended families.

The family members may also cause issues with the health care providers. For example:

- Some may act with anger when asked to choose hospice care, not willing to accept the patient’s pending death.
- Others may insist on aggressive treatment, even though the patient is terminal, and this type of treatment may increase distress to the patient.
- Excessive expressions of sadness and grief at the bedside may upset the patient and cause disruption with the care provider’s ministrations.

Although these issues may cause discord, most of the family members feel they are acting in the patient's best interests. Health care providers must be aware of these potential conflicts and try to mitigate their impact on the patient's care.

The type of death of a loved one may strongly impact a family's reaction and/or acceptance. The death of an elderly loved one may be sad but is more readily accepted than a young person's death. Suicide or a drug overdose death may be tragic to the family but may also be a source of shame and/or cause religious distress. A sudden death is usually more traumatic than one that is caused by a prolonged illness. What was extremely traumatic to Americans was the sudden death of thousands of people on 9/11. Someone suddenly dying from a gunshot or traffic accident is incomprehensible to the average person. The family doesn't have time to "say goodbye" and may have problems and issues that can never be resolved as a result of the sudden death. If someone dies after a prolonged illness, the family has time to process and more easily accept the death. Some may even be relieved to see their loved one at peace and no longer suffering.

The role of the dying patients may have significant impact on families. Some things for health care providers to acknowledge are that the loss of authority figures may leave families with no leadership and impair decision-making. The loss of a parent may severely impact dependent children. Besides losing a loved one, the death of a breadwinner and potential loss of a family's standard of living can be doubly devastating. The importance of understanding these stressors on families must be taken into consideration when providing end-of-life care.

A care management approach taking into consideration the physical and emotional status of the patient as well as the family needs can lessen the impact of any negative family behavior. A care management approach views the family as part of the care team and must work to resolve end-of-life care decisions with everyone's input. Effective communication and the assistance of professionals other than medical (i.e. religious advisors, trusted support systems, support groups, etc.) could also help in this process.

Mrs. Chang, a 75-year-old Chinese American widow, does not speak English. She has two sons, does not have an Advance Directive, and was diagnosed with lung cancer the previous year. At her sons' request, she has been told she has a "lung disease". Despite her declining health, the sons insist that she not be told of her diagnosis or prognosis. The health care team is increasingly frustrated with the fact that Mrs. Chang is not able to fully participate in decisions about her care. However, culturally her sons are the decision-makers and their culture must be respected

## **PART VII: EFFECT OF MEDICAL INTERVENTIONS ON END-OF-LIFE CARE**

Advances in healthcare have given medical personnel tools to enable them to prolong life to patients who have illnesses that were once fatal. Some forms of Cancer, AIDS, Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), Insulin Dependent Diabetes Mellitus (IDDM), Myocardial Infarction/Heart Attack (MI), Cerebrovascular Accident/Stroke (CVA), and Pulmonary Embolism (PE) are just some of the illnesses that are now able to be cured

or to become chronic rather than fatal. Life saving procedures such as organ transplants and stem cell/bone marrow transplants, targeted therapy for specific cancers, genetic testing for early diagnosis, improved medications (chemotherapy, antibiotics, etc.), minimally invasive (stents vs. open heart surgery) and robotic techniques, technology improvements (i.e. MRI, IV, ventilators, stents, etc.), and improved therapies to treat chronic conditions (i.e. Asthma, Atherosclerosis, etc.) are just some of the advances to prolong life.

The health care provider's role in end-of-life care must be considered to provide optimum end-of-life care. It should be remembered that medical personnel are trained to cure people. Their educational curriculum is based on this. Therefore, they want to treat patients aggressively to prevent death using the latest medical technology. Even when death is inevitable, medical practitioners fear that by discussing death and dying, patients may lose hope, give up and die or go into a serious depression, commit suicide or become non-compliant. They may also be unsure of their own feelings about death and dying. Medical personnel often view death as a failure and try to circumvent it as long as possible.

Health care providers, as well as medical facilities, may also be wary of medical liability issues. Due to the internet, non-medical individuals can research current treatment modalities and claim medical malpractice if "everything possible isn't done". Sometimes the families just can't accept the death and want to "blame someone" and file a malpractice claim. These types of claims take time if a practitioner or facility representative must go for depositions or to court. They also cost money for the practitioner who must be away from the practice during depositions and court appearances as well as possibly having his malpractice insurance premiums raised. Likewise, it may cost the medical facility if its liability rates go up. The reputation of a medical practitioner may be at risk. Medical databases track malpractice claims against practitioners and are accessible to others. Facilities are also monitored by licensing bodies such as the Agency for Health Care Administration (AHCA), The Centers for Medicare and Medicaid Services (CMS), as well as state Departments of Health (DOH). Medical practitioners and health care facilities do everything in their power to avoid malpractice claims.

Other factors can affect medical interventions in end-of-life care. One such factor is insurance reimbursement. The fee-for-service insurance model pays for each service the medical practitioner performs. Therefore, the more services provided, the more earnings the practitioner gets. It serves no medical purpose to provide treatments to terminally ill patients unless they contribute to longevity or better quality of life. Newer payment modalities are beginning to change this reimbursement factor. Medicare, under the Affordable Care Act, has developed Accountable Care Organizations (ACO). An Affordable Care Organization is a group of doctors, hospitals, and other health care providers that come together to give coordinated high-quality care to Medicare patients. Its goal is to have patients get the right care at the right time, avoid unnecessary duplications of services, and prevent medical errors. Another result of this model has been increased patient satisfaction. This model has proven to be successful and other health insurance agencies are beginning to adopt this payment model.

The Accountable Care Organization is outcomes and value-based driven. Various standards are used to measure desired outcomes. Coordination of care and case management has proven effective for value-based care. Care coordination involves bringing together various providers and information systems to coordinate health services, patient needs, and information to help better achieve treatment and care goals. This coordination is achieved through case management. Case management is a collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates options and services required to meet a patient's health and human service needs.

Another positive step for improved medical end-of-life care is the increase in the utilization of palliative and hospice care. Palliative care is not only for end-of-life care, but its goal is similar to hospice care, in that both focus on pain management and comfort. Hospice is a type of care and philosophy that focuses on the palliation of terminally ill patients' pain and symptoms and attending to their emotional and spiritual needs. To be eligible for hospice, patients must have a prognosis of six months or less to live as certified by their primary care physician as well as the hospice medical director. A certified hospice program provides services by a treatment team comprised of doctors, nurses, social workers, home health aides, chaplains and volunteers. It provides any and all services needed to keep patients comfortable, including prescriptions for pain and durable medical equipment (DME) necessary to assist in their health care management. Hospice care can be provided in a hospital, nursing home, assisted living facility, and in a patient's home. It is provided by Medicare, Medicaid, and private insurance companies based on Medicare's hospice model. It generally requires little or no deductibles or coinsurance. Its focus is on quality of life vs. longevity.

Other aspects of medical end-of-care provision has to do with legal issues. As of 2019, eight states and the District of Columbia have Death With Dignity Laws. These laws are also called Physician Assisted Suicide. They are not the same as Euthanasia, as that assistance does not have legal sanction. Besides the District of Columbia, the states that have enacted the Death With Dignity Laws are:

1. California
2. Colorado
3. Hawaii
4. Maine
5. New Jersey
6. Oregon
7. Vermont
8. Washington.

The requirements of the Death With Dignity Act are:

- The patient must be certified as terminally ill by a medical doctor.
- The patient must be within six months of death.
- The patient must be the one to initiate the request.
- Any physician, pharmacist, or healthcare provider may refuse to participate.
- The request must be confirmed by two witnesses who may not be:

1. the patient's physician.
  2. a relative.
  3. someone who is in the employ of a health care facility caring for the patient.
  4. anyone entitled to a portion of the patient's estate.
- After the request is made, another physician must examine the patient's medical records and confirm the diagnosis.
  - The patient must be determined to be free of a mental condition that could impair judgement.
  - The patient must wait fifteen days and make a second oral request before the prescription may be written.
  - The patient has the right to rescind the request at any time.

As mentioned previously, patients may have completed Advance Directives and medical personnel must follow those directives as well as abide by the designated health care proxy's decisions, even if they don't agree with those mandates. All these legal and moral issues must be accounted for in end-of-life care by health care providers.

## **PART VIII: ETHICS AND END-OF-LIFE CARE**

Family dynamics, desires of health care providers for continuation of treatments, enrolling in medical trials, and insurance coverage denials among other issues can all create conflicts. These conflicts must be ethically and legally resolved. If the conflict is determined by legal standards, the health care team must abide by the ruling. However, other conflicts can create an ethical dilemma.

Every profession has its own specific set of ethical guidelines, but the principles contained in them are similar. They are often referred to as Codes of Conduct, a codified set of standards adopted by a group of people for ethical behavior. They guide the behaviors and decisions made by individuals. These principles can be summarized by the following seven concepts:

- Autonomy – The duty to preserve the patient's right to self-determination.
- Privacy – The duty to maintain client confidentiality.
- Veracity – The duty to tell the truth.
- Beneficence – The duty to do good.
- Non-Maleficence – The duty to avoid harm.
- Justice – The duty to treat everyone equally.
- Fidelity – The duty to honor commitments.

Although the various codes of conduct can serve as a guide when ethical dilemmas occur, they do not provide a set of rules that mandate how health care providers should act in all situations. Specific applications of these codes must take into consideration the context of the dilemma presented and the conflict/s that may occur among values, principles, and standards set forth in the codes.

- a. James, the 17-year-old only child of Mr. & Mrs. Johnson has a severe Traumatic Brain Injury (TBI) due to a Motor Vehicle Accident (MVA). His medical team has informed his parents that he is in an Irreversible Vegetative State with minimum brain activity. He is on a ventilator and is being fed through a feeding tube. His mother wants all life sustaining measures taken while the father feels James has no chance of recovery. He is ready to stop heroic measures and would like to donate James' organs. The principles of Non-Maleficence and Fidelity conflict with the principles of Justice and Beneficence.
- b. Mr. Jones is an 88-year-old male who lives in a private home with his 85-year-old wife. They have no children and no surviving relatives nearby. He is in poor health with diagnoses of Obesity, Early Onset Alzheimer's Disease (AL), End-Stage Renal Disease (ESRD), Hypertension (HTN), and Chronic Obstructive Pulmonary Disease (COPD). His health is deteriorating. He has had numerous falls in the previous six months and has been hospitalized three times within the same time period. He uses a cane to assist ambulation. His ability to care for himself has declined. He wants to remain in his home, but his wife is frail with health issues of her own. Mr. Jones has refused home care. Although Mr. Jones has some cognition decline, he is still mentally competent to make health care decisions for himself. The principles of Autonomy and Fidelity conflict with Non-Maleficence and Beneficence.

Some factors that can contribute to ethical dilemmas arising in end-of-life care are:

- The terminally ill may develop physical and/or mental declines (lacking capacity), necessitating interventions by others in the provision of their care. Depending on Advance Directives, or lack thereof, difficulties in care decisions may develop.
- Family functioning may not be cohesive, with different members wanting different treatments/outcomes.
- The issues of quality of life vs. prolongation of life, even if the treatment cannot be curative, can be interpreted differently by the patient/family.
- The patient/family beliefs regarding the viewpoint of what constitutes "life" – equating life to just biological functioning or something more – can differ.
- Religious and/or cultural beliefs relating to end-of-life care can impact care decisions.
- The cost of care may inhibit care choices.
- Lack of knowledge of a disease process may blur the ability to make informed decisions relating to care.
- Emotions may interfere with the facts of the situation.
- Fear of litigation by the medical profession/health care facilities can create dilemmas.
- Research protocols may impact ethical principles.
- Laws and facility/agency policies are often involved in complex cases, and health care providers are often legally obligated to take a particular course of action.

These factors can cause a dichotomy of choices affecting a health care provider's interpretation of his/her professional ethical code. For example:

- The patient may develop a lack of autonomy if he/she loses capacity.
- If the patient/family is not given enough information about the treatment options and outcomes of the disease process, Informed Consent cannot be obtained.
- Health care providers must respect the individual's cultural and/or religious beliefs, even if they do not agree with evidence-based scientific medical knowledge.
- Usage of resources for a terminally ill patient may result in other patients not having the resources to treat their problems, causing a breach of the code for justice (providing equal care for all).
- Health care providers must treat patients as a whole and respect the concept that patients are members of families and communities, even though family members may differ in their choices.
- Facility policies and procedures, or the lack of them, may set up a situation resulting in an ethical dilemma.
- Laws may allow physician assisted suicide which may conflict with codes of conduct relating to non-maleficence.
- The need for appropriate research can conflict with issues of non-maleficence and autonomy.

These are just a few of the types of ethical dilemmas health care providers face. To deal with these dilemmas, an ethical decision-making process should be used.

When working through an ethical dilemma, the situation first needs to be examined to determine if it meets the criteria of a dilemma which is that a decision must be made, there must be different courses of action to choose from, and some ethical principle would be compromised by the decision. Once it is determined to be an ethical dilemma, it is helpful to be able to work through the steps of an ethical decision-making model and to assess which of the moral principles may be in conflict. There are numerous models, but all of them contain similar steps. They include:

- Identifying the Problem. Determining who is affected (the patient and/or the patient's significant others, the institution/agency and their policies and procedures, or applicable laws) as well as what ethical principles are involved.
- Gathering as much information as possible to clarify the situation. Medical, family systems, social, cultural, economic, community involvement, and legal information should be gathered. Staff input as well as patient preferences should also be ascertained. It is important to be as specific and objective as possible while doing this.
- Identifying the core ethical principles and competing issues involved.
- Reviewing all relevant codes of ethics.
- Reviewing applicable laws and regulations. If it is a legal question, legal professionals' advice should be sought. If it relates to the institution/agency, the facility's policies may provide guidelines to resolve the dilemma.

- Consulting with colleagues, supervisors and/or legal experts to be sure the health care provider's actions are not biased by his/her own values and interpretations. An Ethics Panel at a facility may be consulted if this is available.
- Reviewing relevant professional literature to ensure that the most current professional thinking is being applied in the decision-making process.
- Consulting state or national professional associations to see if they can offer guidance with the dilemma.
- Generating possible courses of action to be taken and the consequences of the various options available. Being creative and brainstorming as many courses of action as possible will assist in generating options. Comparing the benefits and burdens for or against a specific course of action should help with a decision.
- Making a decision for an action plan. Developing a strategy for effectively implementing the plan, building support for the decision by making sure all parties involved in the decision recognize and understand the reasons for the plan.
- Implementing the plan of action.
- Evaluating the selected course of action and the results to determine whether the intended outcome was achieved. If the course of action selected seems to present new ethical issues, re-evaluating of the entire decision-making process needs to be conducted.
- Documenting the entire decision-making process. Carefully documenting the input and considerations taken into account at each phase of the process will demonstrate that critical thinking was used, and the decision was non-biased.

The Ethical Decision-Making Model at a glance:

- Identify the problem.
- Gather information.
- Identify the ethical principles involved.
- Review Codes of Conduct and applicable laws/regulations.
- Consult other professionals and literature.
- Generate courses of actions.
- Select a course of action after a benefit/burden analysis is done.
- Implement the course of action.
- Evaluate the course of action.
- Document the decision-making process.

When a health care provider is attempting to determine if an ethical dilemma exists and then manage it, certain questions may help the process:

- What conflicting principles are involved in the situation?
- What are the pros/cons of various courses of action?
- What guidelines are applicable in resolving the dilemma?
- What resources are needed to be consulted to help determine an ethical course of action?



It is important to recognize that different professionals may prefer different courses of action in the same situation. There is rarely one right answer to a complex ethical dilemma. That is why it is important to reach a consensus on the best course of action in a particular situation, always remembering that at the core of any care, advocacy for the patient is of prime importance. However, if a systematic decision-making process is followed, a professional rationale for the course of action chosen is demonstrated to be the result of critical thinking and not biased or randomly selected. Dealing with end-of-life care decisions can be stressful for everyone involved. However, by coming to a consensus and respecting everyone's input, conflicts can be resolved.

## **PART IX: CONCLUSION**

Death is part of the life cycle. Even though a person's survival instinct is a powerful primal force, death cannot be forestalled forever. There are many issues that are part of the dying process that health care providers must consider in order to provide optimum end-of-life care and maximize a patient's quality of life. Religious and cultural traditions, health literacy, family dynamics, and the potential conflicts these may cause all have to be understood and addressed. Helping patients and their loved ones prepare for the inevitable death is also a part of end-of-life care. To best meet the needs of the individuals being cared for, health care providers must be familiar with, and comfortable with, end-of-life care.

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