

End of Life Care: An Ethical Overview

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Introduction

As medical knowledge and technology increase, so do options for healthcare. When decisions arise concerning the treatment of dying patients, these options present complex ethical dilemmas. Many are faced with decisions about the best treatment to ease a patient's final suffering. Perhaps a decision will need to be made about whether to allow a patient's life to end by terminating treatment altogether. These decisions—regarding their own care or the care of a dying loved one—confront people from all walks of life.

Beginning with a definition of death in modern society and continuing all the way through post-death issues, *End of Life Care: An Ethical Overview* presents significant ethical issues related to death and dying. We focus on ethical considerations of subjects that include the benefits and drawbacks of various types of modern treatment, ending life through physician assistance or termination of treatment, options for preserving the individual autonomy of the patient, the special situation of terminally ill children, and conducting medical research. Each section includes key terminology sufficient to form a basic understanding of the issue and ethical arguments on both sides of the question. A list of further resources, as well as references throughout the paper, provide quick and easy access to further information on topics of particular interest.

With advances in modern medicine, people are living longer, and the number of elderly persons is increasing. As a result, the ethical issues surrounding end of life care continue to gain importance to all members of society. *End of Life Care: An Ethical Overview* offers a broad introduction to a number of these issues. Both basic and comprehensive, this overview will provide a starting place for those wishing to explore the complex subject of death and dying for any of a multitude of reasons.

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Part I

What is Death?

Causes of Death

Death often comes with advanced age or serious illness. More than half of all deaths in the United States can be attributed to heart disease and cancer.¹ Death is more likely to be violent or sudden in younger people. Causes of death for younger people include:²

- **Accidents** – primarily motor vehicle crashes – are the leading cause of death for people under age 45.
- **Homicide** is the second most common cause of death for ages 15-24 and the sixth leading cause for those 25-44.
- **Suicide** is the 3rd leading cause of death for 15-24 year olds and 4th for people ages 25-44.
- **Cancer and heart disease** rank 4th and 5th respectively as common causes of death in young people 15-24 years old. They rank 2nd and 3rd in the 25-44 age group.
- **HIV/AIDS** is the 5th leading cause of death in people aged 25-44 and the 7th in people ages 15-24.

WHO DIES?

In 2002, 2.45 million Americans died.

74% of deaths (1.8 million) occurred in individuals who were over 65 years old.

51% of deaths (1.25 million) were caused by either heart disease or cancer.

Kochanek, et al. 2002 National Vital Statistics Report, 11 Feb 2004. 52(13). Available on-line at: www.cdc.gov/nchs/

Globally, more than 6 million people die every year. The following were the worldwide leading causes of death in 1998:³

- | | |
|--------------------------------------|---|
| 1) Heart disease | 6) Diarrhea |
| 2) Stroke and blood vessel blockages | 7) Premature births, stillbirths, and neonatal deaths |
| 3) Lower respiratory infections | 8) Tuberculosis |
| 4) HIV / AIDS | 9) Lung cancer |
| 5) Chronic, obstructive lung disease | 10) Motor vehicle crashes |

Defining the End of Life and Declaring Death

Death is the point at which our vital physical functions cease. In past eras, human death was much easier to define than it is now. When our heart or lungs stopped working, we died. Sometimes our brain stopped before our heart and lungs did, sometimes after. But the cessation of these vital organs occurred close together in time.

With advances in life support, the line between who is alive and who is dead has become blurred.⁴ At accident scenes and in hospital rooms, cardiopulmonary resuscitation (CPR) treatments and technologies can re-start and maintain heart and lung functions. Life support technologies introduced in the 20th century have produced a new kind of patient, one whose brain does not function, but whose heart and lungs continue to work.

Thus, we need to define death in order to be able to declare a person physically and legally dead. The **Uniform Determination of Death Act (UDDA)**, written by the President's Commission on Bioethics in 1981, confronts the complexities concerning the declaration of death. The President's Commission determined that a uniform death policy would help eliminate confusion and also address problems associated with removing life support and organ donation.

How Does the Brain Work?

The human brain has two main divisions:

1. Cerebrum and Cerebellum

The cerebrum and cerebellum are the parts of the brain that think, move muscles, feel emotions and house human consciousness.



2. Brain Stem

The brain stem controls vital functions, including breathing, swallowing and heartbeat.



Since the cerebrum and cerebellum are separate from the brain stem, it is possible for a person to lack consciousness, but still live with a functioning brain stem and medical assistance.

Cancer Research UK website
www.cancerhelp.org.uk
Accessed 11/4/03.

The UDDA wording specifically states:⁵

“An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all the functions of the entire brain, including the brain stem, is dead.”

In other words, the UDDA states that a person can be declared dead when *either* the heart and lungs *or* the brain and brain stem stop functioning permanently.

The phrase “brain death” means that a person’s brain is not working and can never work again. The brain needs blood that carries oxygen to continue functioning. When blood stops flowing to the brain, oxygen can’t reach the brain cells. Without oxygen, the brain cells become damaged and cannot be repaired.

Doctors can determine brain death, or declare a person brain dead, by examining the following:⁶

Electrical activity– If no electrical activity is present in the brain, a person is declared brain dead. Electrical activity is determined by using an electroencephalogram (EEG).

Blood flow – Blood flow tests determine blood flow to the brain.

Clinical brain function – Involuntary reflexes include breathing and the pupil of the eye constricting in response to a bright light.

According to the National Conference of Commissioners on Uniform State Laws website, more than 40 states have adopted the UDDA either exactly as written or with “substantially similar” wording.⁷ However, controversy continues to surround this serious issue, as outlined in the table on the following page.^{8,9}

ARGUMENTS ABOUT THE UNIFORM DETERMINATION OF DEATH ACT

FOR	AGAINST
<p>Allows for consistent criteria for determining death across state lines.</p> <p>Helps reduce confusion and unnecessary delay for prompt retrieval of donated organs.</p> <p>Allows for accurate time of death declarations.</p> <p>Focuses on the human organism as a whole, and recognizes the brain's role in the functioning of the body as a complete organism.</p>	<p>Intention is to increase the number of organs for transplant.</p> <p>May lead to misdiagnosis of brain death.</p> <p>Brain death should be used over and above cessation of heart and lung function.</p> <p>Irreversible loss of vital organ functioning (heart, lungs, brain) depends upon whether or not a person can be revived. Revival depends upon the availability of CPR treatments and technologies, which can vary from location to location, and the decision made by those present about whether to use them.</p> <p>The loss of brain stem function is an unnecessary requirement for brain death. A person dies when there is a loss of personhood, which comes from the functioning of the higher brain—the cerebrum and cerebellum—and not the brain stem.</p>

Determination of death can be further complicated by the process of organ donation. For more information, see the next section on Non-Heart-Beating Organ Donation.

Non-Heart-Beating Organ Donation

The number of patients on the waiting list for organ donation far exceeds the number of available donors. For example, in early September 2004, 86,000 people were on the waiting list for a transplant, while only 13,000 transplant operations had been performed since January of that same year.¹⁰

To increase the number of organs available for transplant, organs can be taken from non-heart-beating donors (NHBD), hospital policy permitting. However, the procedure is controversial.

In a typical scenario, life support is withdrawn from a patient who has unrecoverable brain damage but does not meet the criteria for brain death. Then, when circulation and respiration cease, organs are retrieved for transplant. (If the patient resumes breathing, he or she is no longer a potential donor.) Staff must wait 2-5 minutes—depending on hospital policy—after the heart stops beating, before attempting organ retrieval. The time limit raises questions because patients in cardiac arrest have been resuscitated successfully after 5 minutes.¹¹

However, the organs in the body deteriorate very quickly without good blood flow and rapidly become useless for donation unless retrieved quickly.

Thus, honoring the dignity and sacredness of the patient's end of life, usually done without haste, may seem to be compromised by the attempt to save the life of another through organ donation, which requires fast organ retrieval after circulation ceases.

The U. S. Uniform Determination of Death Act of 1983 (UDDA) says that death may be declared when a person sustains “either (1) irreversible cessation of circulatory and respiratory function, or (2) irreversible cessation of all functions of the entire brain, including the brain stem.”

According to the Institute of Medicine (IOM), non-heart-beating donation “has the potential to contribute substantially to the supply of organs and tissues for transplantation.” The IOM recommends that: “All organ procurement organizations (OPOs) should explore the option of non-heart-beating organ transplantation, in cooperation with local hospitals, health care professionals and communities.”¹²

A Good Death

Improving the end of life and advocating for a “good death” has become the mission of many dedicated individuals and organizations, and is also a frequent subject of research and focus for policy improvements.¹³

“...too many Americans die unnecessarily bad deaths—deaths with inadequate palliative support, inadequate compassion, and inadequate human presence and witness. Deaths preceded by a dying marked by fear, anxiety, loneliness, and isolation. Deaths that efface dignity and deny individual self-control and choice.”

(Jennings B, Rundes T, D’Onofrio C, et al. Access to Hospice Care: Expanding Boundaries, Overcoming Barriers. The Hastings Center Report, 2003;33 (2):S3-4).

Advocates working to improve care for dying patients try to determine what elements are necessary for a “good death” to take place. Publications on the subject include books and peer-reviewed journal articles that survey patients, health care professionals, and family caregivers. Common elements of a good death have been identified as the following:^{14,15,16}

- Adequate pain and symptom management.
- Avoiding a prolonged dying process.
- Clear communication about decisions by patient, family and physician.
- Adequate preparation for death, for both patient and loved ones.
- Feeling a sense of control.
- Finding a spiritual or emotional sense of completion.
- Affirming the patient as a unique and worthy person.
- Strengthening relationships with loved ones.
- Not being alone.

For further information on end of life advocacy and good death, see the list of text and online resources at the end of Part I.

Further Resources

Books on Good Death

A Good Death: Challenges Choices and Care Options

Charles Meyer (1998)

The Good Death : The New American Search to Reshape the End of Life

Marilyn Webb (1999)

Final Choices: Seeking the Good Death

Michael Vitez et al.(1998)

The Good Death Guide: Everything You Wanted to Know but Were Afraid to Ask

Michael Dunn (2000)

A Good Death: A Guide to Life's Last Voyage

Diana J. Ingram (2003)

Books on Death and Dying

Death, Society, and Human Experience

Robert J. Kastenbaum (2003)

Death and Bereavement Across Cultures

Colin M. Parkes, Pittu Laungani and Bill Young, editors (1996)

The Denial of Death

Ernest Becker (1974)

How Different Religions View Death & Afterlife

Christopher J. Johnson and Marsha G. McGee, editors (1998)

On Death and Dying

Elizabeth Kubler-Ross (1997)

End of Life Advocacy Organizations

Americans for Better Care of the Dying on the internet at www.abcd-caring.org.

Last Acts Partnership on the internet at www.partnershipforcaring.org.

Minnesota Palliative Care Partnership on the internet at

<http://www.minnesotapartnership.org>. Their website includes “**The Commission on End Of Life Care Final Report,**” produced in collaboration with the Minnesota Department of Health.

Part II

Common Approaches to End of Life Care

Hospice Care

Dying patients may choose hospice care. A holistic and philosophical approach to end of life care, hospice brings doctors, nurses, social workers and other professionals together as a care team. The hospice team's goal is to make the patient as comfortable as possible during his or her final days. Hospice emphasizes pain control, symptom management, natural death, and quality of life to comfort the patient's physical body.¹⁷

Nearly all definitions of a "good death" respect the principle of autonomy and encourage helping an individual choose and participate in decisions about medical options at the end of life. (Autonomy is an individual's ability to control situations and circumstances). Part of the philosophy of hospice involves restoring and supporting both the patient and his or her family's control over the circumstances of death.

The hospice team cares for the dying patient wherever that patient is: at home, in a nursing home, in a hospital, or in a separate hospice facility. In addition to medical care, the hospice team may provide emotional and spiritual support, social services, nutrition counseling, and grief counseling for both the patient and loved ones.

Palliative Care

Palliative care works to achieve one of the primary goals of healthcare—relief of symptoms. Palliative care is an option for patients who are seriously or terminally ill. It focuses on achieving the best possible quality of life for a patient by emphasizing total and comprehensive care for all a patient's needs: pain and symptom management, spiritual, social, psychological, and emotional well being.¹⁸

Palliative care is similar to that of hospice care. However, palliative care is not restricted to patients near the end of life and can be used in both acute and long term care settings. One striking similarity between hospice and palliative care is the use of an interdisciplinary team of professionals including doctors, nurses, social workers, psychologists, chaplains, and others to provide comprehensive care.

Traditional American medical practice focuses primarily on curing illnesses and healing injuries. Symptom relief is often a secondary focus.¹⁹ Therefore, many curative treatments for terminal illnesses do not relieve physical suffering, and may not address emotional, spiritual, and psychological suffering at all. Palliative care supporters believe that failing to address the suffering of a patient with a terminal illness violates two of the main ethical principles behind health care:²⁰

- 1) Providing help or benefit to a patient (beneficence) – Failing to relieve pain and other symptoms does not help the dying patient.
- 2) Not harming a patient (non-maleficence) – Failing to relieve pain and other symptoms can actually harm a patient and the patient's loved ones.

For dying patients, palliative treatment provides relief of suffering from pain and other symptoms.

Most Common Symptoms in Dying Patients

Dying patients frequently experience significant suffering from difficulty breathing, pain, and depression:

Difficulty breathing: Nearly 75% of people who are imminently dying experience dyspnea, or “air hunger.”²¹

Pain: Research finds that the number of seriously ill patients who experience *substantial* pain ranges from 36% to 75%.²²

Depression: In a representative study, about 1 in 4 patients admitted to a palliative care unit name depression as a significant symptom .²³

Drug Treatment for Pain and Other Symptoms

Health care professionals must choose among available treatments to provide relief for pain, air hunger and other respiratory problems and depression. Many times drugs are the treatment of choice for these symptoms, often combined with non-drug treatments.

Drugs like morphine and sedatives can have negative consequences for patients who take them. The chemical reactions that allow drugs to relieve unwanted symptoms like pain or shortness of breath can also cause unwanted side effects like nausea, drowsiness, delirium, diarrhea, vomiting, and unconsciousness.²⁴ Alternatively, treating pain can actually extend life for some patients.²⁵ Ideally, patients and their families are fully aware of these side effects as they participate in making decision.

While addiction and drug abuse are considered hazardous because of the undesirable effects they have on people’s lives, fears that dying patients will become addicted or abuse narcotics are unrealistic and should not compromise pain relief decisions. Dying patients receive narcotics to relieve pain and other symptoms, not to achieve a drug-induced “high”.²⁶

The United States Supreme Court addressed these issues in the 1990s. While the Court did not support either using drugs to terminate life or the legalization of drugs and controlled

substances, it fully encouraged and supported adequate pain and symptom management, as reported in the New England Journal of Medicine in 1997:

*A [United States Supreme] Court majority effectively required all states to ensure that their laws do not obstruct the provision of adequate palliative care, especially for the alleviation of pain and other physical symptoms of people facing death.*²⁷

Compassionate Use of Marijuana: Marijuana relieves nausea and improves appetite for some seriously ill patients. Some state laws make it legal for terminally ill patients to use marijuana, which is otherwise illegal to possess and cultivate, for symptom relief. The Compassionate Use Act was first passed in California in 1996.²⁸ In 2004, Montana voters passed Initiative 148, which allows the cultivation, possession and use of marijuana, in limited amounts, for medical purposes. The initiative shields patients, their doctors and caregivers from arrest and prosecution.²⁹

Non-Drug Treatments for Pain and other Symptom Relief

Dying patients or their families may choose non-drug treatments—including hypnosis, massage therapy or aromatherapy—to relieve pain and other symptoms. Non-western forms of treatments are called complimentary and alternative medicine (CAM) by medical professionals. Frequently used by hospices and palliative care providers to relieve suffering for terminally ill patients, CAMs may also restore a feeling of control over the dying process.

Further Resources: Hospice and Palliative Care Organizations

Hospice Minnesota represents nearly all hospice programs throughout Minnesota, provides education, and promotes public policy to improve hospice care throughout the state. On the internet at www.hospicemn.org.

The National Hospice and Palliative Care Organization (NHPCO) is an association of programs that 1) provide hospice care, 2) advocate for the rights of terminally ill patients and 3) connect patients and families with hospice programs. On the internet at www.nhpco.org.

Hospice Association of America (HAA) represents about 2,800 home care and hospice programs and has a strong lobbying component. On the internet <http://www.hospice-america.org/>.

Hospice Education Institute focuses on educating, referring, and supporting people seeking hospice services for themselves or a loved one. On the internet at www.hospiceworld.org.

Beth Israel Medical Center website on Palliative Care contains information about palliative care for patients and families and information for professionals about integrating palliative care into a treatment plan. On the internet at www.stoppain.org.

The Center to Advance Palliative Care works to increase palliative care options for dying patients, particularly within hospitals. On the internet at www.capc.org.

Center for Spirituality and Healing at the University of Minnesota offers courses, programs and clinical services on complimentary and alternative medicine. On the internet at <http://www.csh.umn.edu/csh/about/home.html>.

Numbers to consider

3,000

Number of hospice programs operating in the United States.

105,000

The approximate number of people currently receiving hospice care in the United States.

80%

The percentage of hospice patients over the age of 65.

Hospice Facts. From the NHPCO website. www.nhpco.org. Accessed 2/24/04.

Part III

Ethical Challenges in End of Life Care

Access to Hospice Care

According to experts studying access to care, many Americans approaching the end of their lives are not able to receive hospice care. Fair and equitable access to hospice services does not exist in the United States, according to the Hasting Center Report.³⁰ Unfair access to hospice services violates the desire for **justice** in the medical system.³¹

Where you live may affect your access to hospice care.

For example, the Minnesota Commission on End of Life Care has found that rural Minnesotans have less access to hospice than do urban residents.³²

In addition, public awareness and the training of healthcare professionals also play a role in the availability of hospice care. The Commission discovered that very few nurses and physicians in Minnesota were certified in hospice and

palliative care and found that both rural and urban healthcare professionals “were not sufficiently knowledgeable about pain management, disease management and end of life issues.”³³

Unfair access is generated in part by governmental limitations on reimbursement to hospice organizations for Medicare patients. In addition, the difficulty of accurate prognosis may limit hospice effectiveness.³⁴ Moreover, hospice programs may put additional limits on the patients they accept, such as requiring patients to forgo specific treatments or sign a do-not-resuscitate order before receiving services.³⁵

Medicare

The vast majority of hospice patient care is paid for by Medicare, according to the National Hospice and Palliative Care Organization (on the internet at <http://www.nhpco.org>).

Medicare requires that a patient have a prognosis of six months or less to live before entering hospice care. The patient must also sign a consent form selecting the Medicare Hospice Benefit in lieu of regular Medicare benefits. Medicare then pays the hospice

Minnesota Palliative Care Partnership on the internet at <http://www.minnesotapartnership.org>. Their website includes “**The Commission on End Of Life Care Final Report,**” produced in collaboration with the Minnesota Department of Health.

program a specific amount per day for the patient, regardless of how much or how little it costs to care for the patient. (Four levels of care are available: Routine Home Care, Continuous Home Care, Inpatient Respite Care and General Inpatient Care. In 2004, Medicare paid hospice programs \$115 per day per patient.) The hospice then provides all care for the patient—including prescription drugs and bereavement services for loved ones after the patient dies.³⁶

These limitations required by Medicare—the requirement that a patient have a prognosis of six months or less to live and the amount of the daily payment—may prevent some patients from entering hospice and put financial constraints on some hospice programs.³⁷

On the other hand, hospice may have great potential to be just and equitable. With changes in government policy and by increasing the length of time people receive hospice care, hospice could become more widely available to those who could benefit from it.^{38,39} In fact, hospice may have more of a chance to reach sick people than many other existing medical treatments. **As many as 70 percent of Americans will have needs that could be addressed by hospice.**⁴⁰

Prognosis

Before a patient can receive Medicare Hospice Benefit (which pays for most of the hospice care given in the U.S.), a physician must offer a prognosis that the patient has six months or less to live.⁴¹ The ethical questions concerning prognosis include:^{42,43,44}

- 1. Accuracy** Developing an accurate prognosis is difficult to do considering the unpredictability of disease, the large number of life-extending technologies available, and the great number of unknown and unmeasurable variables that influence how and when a person will die.
- 2. Six-month limitation** Requiring a six-month prognosis cuts off people from hospice who are near the end of life, but may have longer than six months to live. These people may be able to benefit from the services offered by hospice care, but are unable to access these services without a six-month prognosis. This limits the effectiveness of hospice in reaching people who need it most.
- 3. Prognosis communications with patient** Asking a physician to make a prognosis and inform the patient of this prognosis may be unethical if the patient's culture (or the patient as an individual) does not embrace full and open discussion between doctors and patients about either health status or death.

Pain Management

As a patient with a serious illness nears the end of life, symptoms, including pain, may intensify. A major part of symptom relief is the use of drugs to relieve pain, soothe anxiety, and encourage rest. Many of the ethical dilemmas surrounding hospice and palliative care stem from the use of pain-relieving drugs in terminally ill patients.

Questions about the importance of treating symptoms, the value of individual autonomy, and fears of addiction to narcotics all play a role in how people view pain management.⁴⁵

(Narcotics are controlled addictive substances derived from opium. They act on the brain and spinal cord to relieve pain, reduce cough, and alleviate diarrhea. Side effects include drowsiness, an inability to focus, constipation, and – most seriously – respiratory depression.⁴⁶) Physicians are sometimes wary of legal and criminal scrutiny and punishment from prescribing narcotics excessively or to the wrong person.⁴⁷

Morphine is the most commonly used narcotic for treating pain and other symptoms experienced by seriously ill patients. Morphine is particularly good at relieving the two most common symptoms experienced by dying patients – pain and shortness of breath.⁴⁸

The fear that respiratory depression, a side-effect of morphine, will be severe and result in death may cause a physician to under-prescribe the drug, even to terminally ill patients suffering intense pain.

Fears of overdosing and hastening death in terminally ill patients may be unfounded, as recent **research has not found narcotics to shorten life or depress respiration in dying patients – even when higher doses of narcotics are given.**⁴⁹ However, fear of overdose and criminal punishment remain and may lead many physicians to under-prescribe drugs.^{50,51} (For more information, please see “Drug Treatment for Pain and Other Symptoms” included in the previous section on Palliative Care, page 16.)

Withholding and Withdrawing Medical Treatment

When seriously injured or ill and approaching death, medical interventions may save or prolong the life of a patient. But patients and loved ones often face decisions about when and if these treatments should be used or if they should be withdrawn.

Most people die in hospitals and long term care facilities, and a majority of deaths in these settings involve withholding or withdrawing at least one of the medical treatments listed above.⁵² Therefore, this issue will likely affect many people as they make decisions for either themselves, a family member, or a loved one. Nearly 60-70% of seriously ill patients are unable to speak for themselves when the time comes to decide whether or not to limit treatment.⁵³

Let's consider the ethical decisions surrounding the major types of medical care.

Resuscitation

Resuscitation treatments and technologies restore and maintain breathing and heart function.⁵⁴ **Cardiopulmonary resuscitation (CPR)** doubles a person's chance of survival from sudden cardiac arrest, which is the leading cause of death in adults.⁵⁵

However, while CPR is valuable for treating heart attacks and trauma, using CPR with some dying patients may be inappropriate and cause complications. For some terminally ill patients, CPR is an unwanted procedure. However, the universal use of CPR makes it difficult for health professionals to not use CPR with dying patients. Patients who do not wish to receive CPR may seek a **do-not-resuscitate (DNR) order** from their doctor. Family members of patients who cannot speak for themselves may also seek a DNR order on their relative's behalf.

DNR orders might be issued for the following patients:⁵⁶

- Patients for whom CPR may not provide benefit.
- Patients for whom surviving CPR would result in permanent damage, unconsciousness, and poor quality of life.
- Patients who have poor quality of life before CPR is ever needed, and wish to forgo CPR should breathing or heartbeat cease.

It may be easier for patients and families if physicians initiate the discussion about a DNR order. Physicians should talk with patients who are at risk of cardiopulmonary arrest (or that patient's healthcare decision-maker) and learn about their wishes regarding resuscitation, which the physician then has an ethical obligation to honor.⁵⁷

Whether or not it is ethical to apply CPR to all patients who stop breathing has become a subject of debate. One argument suggests that DNR orders would not be necessary if CPR was limited to those cases where it is a potentially beneficial treatment.⁵⁸

Mechanical ventilation uses a machine to inflate and empty a patient's lungs allowing oxygenation of the blood. Mechanical ventilation is delivered through tubes inserted through the nose or mouth into the trachea, or through non-invasive ventilation (NIV) where air is delivered with a mask.

Approximately 75% of dying patients experience breathlessness, or dyspnea, as they die.⁵⁹ The feeling can be uncomfortable to patients and frightening for loved ones to witness. Ventilation may be given to these patients, not to extend life but to help with breathlessness. Ventilation may help them sleep better, experience less anxiety, and eat and drink more comfortably.⁶⁰

Mechanical ventilation is the most common life support treatment withdrawn in anticipation of death.⁶¹ Mechanical ventilation is such a common treatment at the end of life, that some care providers may regard mechanical ventilation as "death-delaying" rather than "life-prolonging." Some patients become dependent on the ventilator or die while

being treated. Therefore, for some patients ventilation is considered a non-beneficial treatment that negatively affects patients by delaying natural death or requiring families and physicians to decide to withdraw treatment.⁶²

Nutrition and Hydration

These treatments provide nutrients and water to patients who are unconscious or cannot swallow.

Enteral nutrition with feeding tubes: Delivers nutrients directly into a patient's stomach or intestines with a feeding tube. Feeding tubes are either *gastrostomy tubes* inserted into the stomach through an incision in the abdomen or *nasogastric (NG) tubes* inserted through the nose and esophagus into the stomach.

Parenteral nutrition: Delivers nutrients directly into the bloodstream. One such treatment, *total parenteral nutrition (TPN)*, can supply a patient with nutrients to maintain his or her body weight over a long period of time.

Decisions about nutrition and hydration are among the most emotionally and ethically challenging issues in end of life care. The main dilemma concerns the nature and social meaning attached to providing people with food and water. Clinically, the American Medical Association does not distinguish between nutrition and hydration and other life-sustaining treatments.⁶³ Others argue that nutrition and hydration treatments are palliative care that fulfill a basic human need and should not be denied to patients at the end of life.⁶⁴

Legally, the United States Supreme Court ruled in 1990 that artificial nutrition and hydration are not different than other life-sustaining treatments.⁶⁵ In fact, courts in the United States have made the following rulings consistently in the recent past:

- Competent adults may refuse artificial nutrition and hydration treatments even though this action may hasten death;⁶⁶
- Surrogate decision makers may withdraw artificial nutrition and hydration;⁶⁷
- Surrogate decision makers may refuse artificial nutrition and hydration on behalf of an incompetent adult.⁶⁸

The second debate concerning nutrition and hydration centers on whether or not withholding food and water is similar to the act of killing a patient or allowing a person to die. A person cannot live without food and water. If nutrition and hydration are withheld or withdrawn the patient will die within a few days. However in practice, health professionals and loved ones usually come together to consider whether providing nutrition and hydration to extend life will be beneficial or burdensome to the patient.⁶⁹

Nutrition and hydration treatments may burden (or provide only minimal benefit to) some dying patients. As a person's physical body shuts down before death, food and water are no longer processed in the same way as a healthy body. Instead of hydrating the patient, water can cause bloating and swelling and nutrition may cause intestinal problems that can add to a patient's discomfort.⁷⁰

The idea that a treatment should provide the patient with some benefit that is sufficient to outweigh the burdens has been called the **principle of proportionality**. This principle, according to some, may be applied to artificial nutrition and hydration in the same manner in which it is applied to other life-sustaining treatments. **Thus, if a dying patient receiving nutrition and hydration suffers burdens that outweigh the benefit of extended life, artificial nutrition and hydration may be ethically withheld or withdrawn – whether or not the patient will die as a result of this action.**

Kidney Dialysis

Kidney dialysis filters waste from the blood in patients whose kidneys no longer function. Without dialysis, waste products would reach a toxic level in the body and result in death.

Dialysis is a time consuming and physical burden for patients with end stage renal disease. Some patients may eventually decide that this burden outweighs the benefits and then wish to discontinue this treatment. Today, discontinuing dialysis is considered an appropriate treatment option that respects a patient's autonomy and ability for self-direction.⁷¹

The ethical challenges for dialysis withdrawal arise when stopping dialysis becomes an option patients want to consider. The Renal Physicians Association and American Society of Nephrology have patient-physician guidelines for appropriately and ethically discussing and initiating withdrawal of dialysis.⁷²

- Withdrawal should occur when patients are either:
 - capable of making decisions and decide to forgo dialysis
 - a written health care directive expresses a desire to discontinue dialysis
 - a health care agent considers discontinuation of dialysis the best course of action
 - or when the physician decides dialysis no longer beneficial.
- Shared decision making between the patient and physician must occur, and if the patient lacks decision-making capacity, the health care agent should be involved.
- Physicians should provide patients with all available information – including available treatment options, consequences of dialysis withdrawal, and other end of life care options – like hospice and palliative care.

Antibiotic Treatments

Dying patients are susceptible to infection.⁷³ For many patients with life-threatening diseases, infection will affect their final days, and antibiotics may be given as a result. Anywhere between 32% and 88% of terminally ill patients receive antibiotics.⁷⁴ Antibiotic treatments may not cure an underlying cause of illness, but rather alleviate symptoms.⁷⁵ Treating an infection may extend life in circumstances under which a patient may not wish to continue.

Physicians often find it difficult to withhold antibiotic treatment from patients. Some believe that antibiotics are part of routine care and should not be denied to patients simply because they have a life-threatening condition. Others may consider an infection a “treatable” condition and not related to the “untreatable” and underlying, terminal illness.⁷⁶

One ethical concern raised by public health professionals is that excessive use of antibiotics can contribute to bacteria that mutate and become resistant to treatments.⁷⁷ Public health professionals express concern that over-prescribing antibiotics may result in resistant bacteria that could be more harmful to future patients – particularly in light of evidence that antibiotics may not be effective for treating infection in terminally ill patients.

Medical Futility

Medically futile treatments are those that are highly unlikely to benefit a patient.

Decisions to forgo or withdraw life-sustaining treatments are accompanied by an assessment that such treatments would be medically futile.

Ethical questions surround the concept of medical futility. First, some people question whether medical futility can be defined and how to prevent futility from becoming a judgment call made by health care staff. Second, there is the fear that treatments that provide a smaller benefit – or may not seem beneficial to health care professionals but are considered beneficial by patients – may be eliminated.⁷⁸

Finally, the biggest concern is that necessary treatments will be labeled futile in order to save money. This issue is of particular importance to some elderly, disabled, managed care, and socio-economically disadvantaged populations.⁷⁹

However, advocates wishing to limit medically futile care argue that :⁸⁰

- Futility can be defined using measures that include prognosis, estimates of the likelihood of recovery, and functional status.
- Not all medical treatments are beneficial.
- Health professionals would never label a beneficial treatment as futile.
- Futile treatments are expensive and an inefficient use of resources.
- By addressing medical futility, patients may be more appropriately cared for with other programs, such as hospice care.

Because of the complex ethical issues that arise, a few states have guidelines that address medically futile treatments.^{81,82} In 1999, Texas was the first state to adopt a law regulating end-of-life decisions, providing a mechanism to resolve medical futility disputes.⁸³

In an effort to address this delicate issue, the Minnesota Network of Ethics Committees drafted model futility guidelines in 2003-2004. Ideally, nursing homes and hospitals can adopt these guidelines on their own to reduce instances of futile treatment without requiring a legal process.

Published in the June 2004 issue of *Minnesota Medicine*, “Model Guidelines for Addressing Medical Futility in End-of-Life Care” is available online from either the Center for Bioethics at www.bioethics.umn.edu/resources/futility_policy_3.31.doc or *Minnesota Medicine*, at <http://www.mmaonline.net/publications/MNMed2004/June/Moldow.html>.

Terminal Sedation

For some dying patients, **agonal** suffering—the profound pain that may occur when dying—may not be relievable by any means other than **terminal sedation**. Terminal sedation uses sedatives to make a patient unconscious until death occurs from the underlying illness.⁸⁴ **Sedatives** are drugs that act on the brain and spinal cord and have a calming or tranquilizing affect on the body. In small doses, they relieve anxiety and may soothe coughs and nausea. In larger doses, sedatives can have a hypnotic effect, causing people to fall asleep.

Since terminal sedation is a delicate and risky treatment that leaves a patient unconscious, people frequently raise ethical concerns about its use, including:^{85,86}

- The unknown effect terminal sedation may have on hastening death.
- The potential for abuse of patients who are unconscious and cannot speak for themselves.
- Use of terminal sedation with patients who either do not require such strong relief or whose suffering is compounded by emotional, psychological, or spiritual suffering.
- How to value consciousness versus suffering.
- How far people should go in an attempt to relieve pain and other uncomfortable symptoms.

Advance Directives

In an effort to avoid the ethical conflicts associated with withholding and withdrawing medical treatment and to encourage appropriate treatment of dying patients, many advocates both for patient rights and “good deaths” suggest the use of advance directives or living wills.

Advance directives or living wills are documents used to:

- Outline the patient’s own goals and wishes regarding medical care.
- Provide specific instructions about treatments, including do-not-resuscitate orders, organ donation, palliative care, feeding tubes, etc.
- Designate power-of-attorney to a healthcare decision-maker who will speak for the patient should he or she become unable to communicate.

Advance Care Planning

The patient, the patient’s family, and the designated decision-maker participate in advance care planning. Sometimes, a nurse or social worker will facilitate the discussion.

During the planning process, patients are encouraged to express their desires concerning medical treatment goals with the healthcare decision-maker. This process ensures that the decision-maker understands the spirit of the patient’s advance directive, and not just specific instructions for particular medical situations. The process is thought to increase both the understanding and effectiveness of the decision-maker when the time comes to make difficult decisions.

Without this kind of discussion, decisions that must be made on behalf of an unconscious patient can be very difficult for both loved ones and health care providers. Advance directives are a tool used to ease that process and improve communication about wishes and goals of medical treatment.⁸⁷

Effectiveness of Advance Directives and Living Wills

Advance directives and living wills are tools that are underused. Many people who might benefit from them do not have them. Furthermore, even when present, they are frequently not followed or provide only limited value and instruction.⁸⁸ In certain situations, a physician may believe that honoring an advance directive would not be in the best interest of the patient.⁸⁹ For example, a living will that requests no ventilation may not be honored if the physician feels that the ventilator is only a temporary treatment that could extend life and diminish suffering.

Some studies have found that the effectiveness of advance directives and living wills has yet to be definitively shown.⁹⁰ People who question the effectiveness of *written* advance directives might agree that appointing a healthcare decision-maker by signing a Durable Power of Attorney for Health Care document is a better strategy. It is more helpful to physicians when they need to know what a patient would want in a particular medical situation and who can legally make decisions.

Legality of Advance Directives

All states legally recognize some form of advance directives.⁹¹ In addition, most laws require hospitals to follow written health care wishes when available. However, advance directives are often not legally enforced, and a medical provider may legally perform medical treatments that go against the patient's written wishes if the case can be made that it was in the best interest of the patient.

The Patient Self Determination Act (PSDA) passed by the United States Congress in 1990 requires health care facilities receiving federal funding to educate the community about advance directives. The PSDA specifically requires health providers and health care organizations to:⁹²

- Provide written information to all adult patients on their rights under state law to make decisions—including information about the right to execute an advance directive and how the institution implements them.

- Document presence of an advance directive in a patient’s medical record.
- Provide education for staff and the community about advance directives.
- Not condition care or discriminate against patients based on advance directives.

Ethical Issues Around Advance Directives

Advance directives aim to honor individual autonomy, respect individual choice, and prevent situations in which a patient is given treatments he or she would not have wanted. Because they involve critical decisions about end of life care, ethical concerns have been expressed about their use. These concerns include the following:⁹³

- Advance directives may improperly influence health care providers to limit care—leading to undertreatment.
- A person frightened of becoming disabled or incapacitated may use advance directives to limit treatment—when in reality a person cannot know in advance his or her ability to cope and adapt to living with a disability.
- Advance directives are time consuming for health professionals, and may not be useful if a medical treatment decision requires an immediate answer—even if a healthcare decision-maker has been named.

Possible Effect of Advance Directives on Patients and Families

Advance directives may provide patients with peace of mind.⁹⁴ Patients may be comforted knowing that difficult decisions—about procedures and treatments that they do or do not want—have already been made should they become unable to communicate. Further, they may gain peace from knowing that the advance directive may prevent or minimize disagreement among loved ones.

Further Resources

To obtain a form to execute advance directives, or more information, contact:

The Metropolitan Area Agency on Aging, online at www.tcaging.org, mails copies of the Minnesota Health Care Directive on request.

Partnership for Caring is a resource for living wills and medical powers of attorney.
Telephone: 1-800-989-9455 www.partnershipforcaring.org.

Resource Center at the Center for Bioethics—University of Minnesota online at <http://www.bioethics.umn.edu/>.

Part IV

End of Life Issues: Special Topics

Euthanasia and Physician Assisted Suicide

For some people at the end of life, continuing to suffer may appear worse than death. Watching a dying patient suffer can be nearly unbearable for loved ones. The suffering can be so great that the option of ending one's life through either euthanasia or physician assisted suicide may appear to be a reasonable and merciful choice.

Euthanasia

Euthanasia is an act where a third party, usually implied to be a physician, terminates the life of a person—either passively or actively. The modern concept of euthanasia came into being in the 20th century after the invention of life-extending technologies. These technologies help to save the lives of many people who suffer serious illness or injury.

However, the use of modern medical technologies can also keep patients alive who are a) living in a situation that they consider to be worse than death, b) are in a coma or c) are in a persistent vegetative state (PVS).

Persistent vegetative state, as defined by the Multi-Society Task Force on PVS, is one in which there is “complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.”⁹⁵

People who are kept alive without hope of recovery for lengthy periods of time can cause their loved ones much grief, survive in a state that the patient would not have chosen or wanted, and their care can cost a great deal of money. Families and patient advocates began to question the use of life-extending technologies in the 1970s and 1980s, leading to the debate over the moral role euthanasia can play in society.

Passive euthanasia allows a patient to die by stopping or refraining from beginning some type of medical intervention. For example, withholding ventilator support for breathing may be considered an act of passive euthanasia because the person would die on his or her

own without the ventilator. Discontinuing dialysis is another example. Passive euthanasia is often thought of as a “allowing a person to die” because while the action of the physician removes the supportive treatment, the life-threatening illness or medical situation actually ends the patient’s life.

Two of the earliest and most widely discussed cases involving the termination of life-extending treatment—or passive euthanasia—were the cases of Karen Ann Quinlan and Nancy Cruzan:^{96,97, 98,99}

Karen Ann Quinlan: In 1976, Karen Ann Quinlan, a 22-year-old woman in a persistent vegetative state with no hope of recovery, was kept alive using a ventilator to sustain her breathing. Quinlan’s parents wanted to discontinue treatment but the hospital would not do so. The Supreme Court of New Jersey ultimately decided that the hospital could legally discontinue treatment for a patient like Quinlan in a persistent vegetative state – after first consulting with an ethics committee – without fear of criminal or civil retribution.

Nancy Cruzan: In 1983, 25-year-old Nancy Cruzan was in a car crash that left her comatose. When Cruzan’s parents wanted to discontinue artificial nutrition and hydration several weeks after the crash, the hospital would not do so. The case went through the Missouri court system and ended up in front of the United States Supreme Court. The Supreme Court decided that food and water can be withheld in cases where there is *clear and convincing evidence* that the patient would not have wanted to live. However, the Court also determined that Nancy Cruzan did not meet this criteria. The Supreme Court’s decision in Cruzan was widely criticized. But it was not until Nancy’s parents were able to present additional evidence of her wishes to the Missouri State Court (where the case had been returned) that they received a ruling in their favor. They then requested removal of the artificial nutrition and hydration tubes, and, subsequently, Nancy Cruzan died.

Most situations in which euthanasia would be considered a potential option involve patients who are not conscious *and* not expected to recover. However, cases of voluntary, active euthanasia exist.

Active euthanasia requires performing some action that terminates the life of a person. An example of an active euthanasia intervention would be a situation where a physician would inject a patient with a lethal dose of a drug.¹⁰⁰

In cases of voluntary, active euthanasia, a competent patient who wishes to avoid suffering and a slow dying process asks a physician to terminate his or her life. The 1990s cases involving Dr. Jack Kevorkian injecting lethal doses of drugs into conscious adults and the euthanasia policies of the Netherlands and Belgium are examples of voluntary, active euthanasia practices.^{101, 102}

Ethical Issues Surrounding Euthanasia

A range of different ethical and moral positions and arguments exist regarding active euthanasia:

- Terminating life at the request of an individual **is not immoral** because it is the individual's decision to make.¹⁰³
- Terminating life **may be justified in some circumstances** if, and only if, there is compelling evidence that to continue living would be more harmful to the person than dying.¹⁰⁴
- Terminating life is **unethical in today's society** because there are not enough protections that would allow for a just and fair practice of euthanasia¹⁰⁵.
- Terminating life is **always unethical** because it violates a) the moral belief that life should never be taken intentionally or b) the basic human right not to be killed¹⁰⁶.

Some individuals believe that terminating a life – however it is achieved – goes against the principle that life is sacred. Euthanasia would be akin to murder. Some might even go as far as to suggest that anything less than aggressive treatment and all available means to save and prolong life are also murderous acts.

Justice and fairness come into question. Some fear that a climate of cost containment in the healthcare system could make euthanasia seem like a more viable option for patients who are expensive or problematic. Others believe that a very sick individual or stressed loved one does not have the objectivity required to make a rational decision about terminating life.¹⁰⁷

But there are groups and individuals who make moral distinctions between actively killing a person versus passively allowing a person to die. Supporters of the act of passive versus active euthanasia argue:¹⁰⁸

- Physicians do not kill a patient by omitting treatment, but rather the disease takes the patient's life.
- Patients have a right to a "death with dignity." Allowing a dignified death to occur naturally is a moral act, different from active euthanasia.

Physician participation in the active termination of a patient's life is controversial for several reasons. The primary moral objection to physician involvement in euthanasia argues that it violates the physician's oath to "do no harm." However, some advocates for euthanasia have argued that a physician violates the oath to "do no harm" if he or she extends the life of a suffering individual. The oath to "do no harm" is complicated by the fact that terminally ill patients represent an extremely frail and vulnerable population who also are heavily reliant on the medical system.

The concept of "death with dignity" or allowing a person to retain dignity as they die is a popular argument among those who support active euthanasia.¹⁰⁹ The idea stems from the idea that prolonged death in a medical setting is unnatural and undignified. Therefore, encouraging death with dignity supports people who wish to cease non-beneficial or unwanted treatment for themselves or a loved one.

Physician Assisted Suicide

With physician assisted suicide, a doctor provides a patient with a prescription for drugs that a patient could use to end his or her life. The main distinction between physician assisted suicide and active euthanasia is that the doctor is not the person physically administering the drugs. Physician assisted suicide is only contemplated by—and would only be considered as an option for—patients who are conscious and capable of making their own decisions.

In contrast to active euthanasia, where a physician would end a person's life, assisted suicide is an active choice by a person to end his or her own life. For some people, physician assisted suicide seems a viable option that would allow the opportunity to forgo suffering and loss of control.¹¹⁰ The primary ethical arguments offered to justify physician assisted suicide are that it:¹¹¹

- Allows autonomy and self-empowerment of the patient.
- Shows compassion and mercy.
- Gives freedom from suffering.

Historically, suicide has been considered by many to be an immoral act in any form.¹¹² People who think that suicide is a moral option may still object to physician assisted suicide because it requires physician involvement. They would argue that physicians are taught to treat illness and extend life, so physician-assisted suicide goes against their training.

Death With Dignity Act of Oregon

The Oregon Death With Dignity Act legalized physician assisted suicide in Oregon. (It was passed in 1994 but did not go into effect until 1997.) The Act allows patients to hasten their own death with a prescribed lethal dose of medication from a physician. The Task Force to Improve the Care of Terminally Ill Oregonians published a guidebook on the Act. The guidebook does not endorse physician assisted suicide, but rather offers guidelines for physicians on how best to implement the practice of physician assisted suicide.

Suggestions include:¹¹³

- Family members should be involved in the decision making process.
- Physicians should not suggest physician assisted suicide.
- Care should be exercised in prescribing appropriate doses of lethal medication.

Many groups feel that the legality of physician assisted suicide in Oregon reflects the poor state of end of life care in the United States. Advocates in favor of improving end of life care rather than utilizing physician assisted suicide suggest that if people choose to hasten death in an effort to avoid excessive pain and loss of control, then the health care system should do a better job of treating those symptoms.

Along similar lines, the Supreme Court heard two cases in 1997 that addressed the concept of pain control, symptom management, and physician assisted suicide. The decision from the cases of *Washington v. Glucksberg* and *Vacco v. Quill* both support the idea that better pain control and palliative care—and not the legalization of physician assisted suicide—should be the focus of improvements for dying patients.¹¹⁴

Oregon is the only state in the U.S. that has a law that *allows* physician assisted suicide. Many suggest that the discussion about legalizing physician assisted suicide in other states should be put on hold until the following issues are addressed.^{115,116}

- Terminal illness is not yet clearly defined.
- Assessing mental competency is a difficult, if not impossible, task for suffering patients and stressed families. Potential abuses of incompetent patients need to be adequately safeguarded against.
- Poor treatment of depression and inadequate addressing of fears at the end of life lead to feelings of despair and hopelessness.
- People who are socioeconomically disadvantaged may be unfairly pressured to accept the option of physician assisted suicide if suggested.

Communication: Patients and Healthcare Professionals

Good communication at the end of life is vital to good healthcare. If communication breaks down, mistrust and conflict can arise, resulting in inappropriate or unwanted treatment.

Patients may have trouble communicating about their symptoms. Pain and discomfort are complicated, unique experiences that may be difficult to describe. Healthcare staff may not know how best to ask about pain in a way that maximizes understanding.¹¹⁷ Some physicians may have difficulty telling the complete truth about a terminal prognosis. It may seem as if they are taking away all hope and optimism or they may feel bad that the patient was not cured.¹¹⁸

Cultural differences can affect communication with the dying. Many cultures do not support the idea of full disclosure when it comes to illness, while others want disclosure to family members or community leaders. In Russia, physicians are likely to make full disclosure about a terminal illness to the patient's family, who will then decide what to tell the patient about his or her condition.¹¹⁹

In the United States, the need to improve physicians' communications with the dying has been recognized.¹²⁰ Proper communication with dying patients may require a great deal of staff time that is not usually compensated. Some medical providers are experimenting with reimbursement or training other skilled providers—such as social workers—to facilitate communications.¹²¹

Despite the challenges of proper communication with dying patients, many healthcare providers wish to avoid the problems associated with communication breakdowns. These providers consider sensitive communication a priority and make time to integrate communication into patient care.

Children Who are Dying

When children suffer a terminal illness, the child’s family, community, and the healthcare system often rally to provide support and care. Dying children and their parents may face the same ethical issues at the end of life as adults do, such as treatment options and resuscitation decisions. However, there are also unique ethical issues specific to children.

Who Decides?

While parents have legal rights to make decisions for their children, the extent to which children become involved in their care and the limits placed on a parent’s decision making can be controversial.¹²² Many people believe that “parents know best” when it comes to their children and that parental decisions should prevail. However, others argue that parents may sometimes not be objective when it comes to making treatment decisions for their child. The suggestion has been made that while parents should be consulted, they perhaps should not always have the final word about treatment decisions.¹²³ Most important, children should be able to participate in decisions about their own care.^{124,125}

Family Members in Conflict

Conflicting opinions may arise among family members when making health care decisions for children:

- Parents can disagree with each other—Divorced parents may have different values or married parents may find that they are in conflict over the best course of action.
- Parents and other family members can disagree—Grandparents actively involved in childraising may differ with parents.
- Parents and child may not agree—These conflicts can arise at any age and may be particularly disheartening.

When Parents Refuse Treatment from the Physician

Parents who refuse a particular treatment for their child, whether due to religious beliefs or a preference for non-Western medicine, can find themselves in court. If a physician believes the parental refusal is not in the best interest of the child, he or she can seek court-ordered treatment under a state's child neglect laws.

Courts will not allow parents' religious beliefs to prevent necessary medical treatment. For example, if blood transfusions were required for a child's survival—and the parents objected to transfusions on religious grounds—the court would issue an order allowing the hospital to give the transfusions.

However, courts may not automatically order treatment in cases where the child is chronically ill and not expected to live. More often, courts are willing to consider a parent's right to refuse treatment in instances where children are dying.¹²⁶

When Parents Insist on Non-Recommended Treatment

In some cases, parents demand treatments that the physician believes are no longer helpful. These parents may be unwilling to acknowledge that their child is dying. Because of their fear and distress at losing their child, these parents continue to insist that 'everything possible be done'. They may seek treatments that are even potentially harmful.¹²⁷

What's Best for the Child

Disagreements over end of life care for a child are challenging and troubling for medical providers, parents and other family members, and the child.

In instances where consensus cannot be reached, it may be necessary for the healthcare institution to mediate. Many institutions have ethics committees that are intended to be objective bodies. The ethics committee may be in a unique position to resolve conflicts between parties by listening to the patient, the family and the healthcare providers.

Attempts are usually made to resolve the issues with conversation, however they may end up in the court system as a last resort.¹²⁸ If conflicts have to be moved to the legal system for resolution, the parent or party who advocates for treatment that will extend the life of the child will usually win.¹²⁹

When conflicts arise in cases of teenage patients, the legal age of consent (in that state) and the teen's understanding of the likely results of significant treatment decisions will be likely considerations for parents, healthcare professionals, hospital ethics committees and the court system.

Including the Child in Decisions

Many professionals who work with dying children believe that they—particularly adolescents—should be included in healthcare decisions. **Involving children in care decisions by allowing them to ask questions, raise fears and concerns, and express their opinions – to the extent that they are able – can prove invaluable in easing of tension between children, parents, and medical professionals.**^{130,131}

Research with Dying Patients

The ethical issues around medical research conducted with terminal and palliative care patients are complex. Some research review committees will not allow researchers access to dying patients because the patient is already overburdened with a terminal disease and the approach of death.¹³² Others consider research with dying patients a necessary evil, and may consider it unfair to specially classify and distinguish dying patients from other patients.^{133,134} The issues of most concern are these:

Demonstrating informed consent—where a patient feels that participation is voluntary and fully understands what he or she is being asked to do—can present challenges to researchers when suggesting research to a review committee.¹³⁵ These patients may be seen as particularly vulnerable because often they are reliant on the healthcare system and experience great amounts of emotional and physical stress.¹³⁶

Methodological issues are difficult because terminal patients may die during testing.¹³⁷ Researchers may have to include more patients than other projects would to account for this fact, thereby increasing the number of patients burdened by the research.

Requests for participation by dying patients in research projects must be conducted with compassion and the utmost respect for patients health and condition.¹³⁸ Those who advocate for research with the palliative care population acknowledge this necessity and encourage research that is both sensitive and responsible.¹³⁹

As a culture that embraces the concept of evidenced-based medicine, the medical community in the United States regards medical research as a necessity. A 2002 article which reviewed the ethics of palliative care research with dying patients concluded that “...provided investigators compassionately apply ethical principles to their work, there is no justification for not endeavoring to improve the quality of palliative care through research.”¹⁴⁰

Ethical Issues after Death

After someone dies, loved ones may have to consider one or more of the following issues:

Organ donation: When a person dies, the medical provider may consult the person's health care directive or their driver's license for their organ donation wishes. In the absence of these documents, the health care professional may ask a family member for permission to use the organs for organ donation. Solid organs and tissues may then be removed from the body and given to an ailing person. Family members may also be asked if the body of the newly deceased person may be donated to science as well.

Autopsy: Autopsies may be used to determine the cause of death, for research and education, or for forensic evidence if death was a result of a crime or questionable circumstance.¹⁴¹ Autopsies may be performed on an entire body or on a single organ or tissue. The practice of autopsy has declined in recent years, but many professionals find the autopsy an integral part of medicine. These professionals believe autopsies contribute much to the understanding of illness, the human body, disease, and death.¹⁴² Ethical issues concerning autopsy focus on respect for the dead body, retaining tissues from the body for study, and the applicability autopsy information has when examining the quality of care provided by a medical institution.¹⁴³

Practicing medical procedures on dead bodies: Medical students may practice procedures on newly dead bodies, usually without permission from the family. Two interests are in conflict when it comes to newly deceased patients: respecting the dignity of the deceased versus the educational value of practicing procedures for medical students. The prevailing recommendation from the American Medical Association is that because practice with deceased bodies is valuable to students, training should be performed with dignity; with permission from the family, if possible; and in a structured and closely supervised environment.¹⁴⁴

Grief: After a person dies, the family, loved ones, and friends will experience grief and bereavement. For some people, viewing the body helps grieving and acceptance.¹⁴⁵ Medical professionals can facilitate this by arranging a private and pleasant environment. Some believe that the medical profession has a duty to acknowledge the surviving family members after a patient's death and that this obligation has a potential to be rewarding. Professionals may choose to send condolence cards, attend a funeral or refer families to grief groups.¹⁴⁶

Posthumous parenthood: During the mid-1990s, requests to retrieve sperm—in the hopes of using it to conceive children of the deceased male—started to increase. The issue of gathering sperm from a deceased individual raises ethical questions about choice in parenthood.¹⁴⁷ Those who deal with this issue want to know: How should healthcare staff handle such a request? Who should be able to request sperm retrieval? What should be done if other family members raise objections? How can the wishes of the deceased be respected?

Homelessness at the End of Life

While day to day life is difficult for homeless people, dying homeless may be even harder. What happens to those who are dying without a home or an involved family concerns those who work to provide the homeless with food, temporary shelter and other services, including healthcare. Bioethicists have begun to focus on end of life issues of autonomy and justice for those without homes.

Homeless at Greater Risk of Death

It's been estimated that over 20,000 people are homeless in Minnesota.^{148,149} And those who live without the basic comforts of home get sick more often and die at a greater rate than others. Homeless people die at a rate at least 3 to 4 times that of people their own ages who live in homes.¹⁵⁰ A new study in Toronto, Canada, found that homeless women were dying at 10 times the rate of other women between 18 and 44.¹⁵¹

Ethical Issues Surrounding End of Life Care

Bioethicists at the University of Minnesota identified, through focus group interviews with homeless people, concerns surrounding end of life care for this group:¹⁵²

- **Autonomy:** Individual preference varies greatly among the homeless about whom they would want to make end of life decisions for them and whom they would want to be at their bedside as they die.
- **Fairness and Justice:** Some homeless people report they have experienced disrespect from healthcare providers in the past and lack access to primary care.

"The homeless don't have a place to live, let alone a place to die. We want to surround them with comfort."

—Margo Martin, who will manage the new Abbie Hunt Bryce Home in Indianapolis, that will provide hospice care for the homeless.

Source: "Facility established to provide homeless dying care, residence: Indianapolis home to give terminally ill a very rare option," By John J. Shaughnessy in The Indianapolis Star, Monday, July 12, 2004.

<http://www.courier-journal.com/localnews/2004/07/12in/B3-haven0712->

Further Resources

Dying in the shadows: the challenge of providing healthcare for homeless people

James J. O'Connell

eCMAJ 2004 170: 1251-1252. On the internet at

<http://www.cmaj.ca/cgi/content/full/170/8/1251>

A Perspective on Homelessness, Ethics, and Medical Care

Edward Ratner, M.D., Dianne Bartels, R.N., Ph.D. John Song, M.D., M.P.H., M.A.T.

Minnesota Medicine, June 2004/Volume 87. On the internet at

<http://www.mmaonline.net/publications/MNMed2004/June/Ratner.html>

GLOSSARY

Active euthanasia: An action that will physically end the life of the patient, such as injecting the patient with a lethal dose of a drug.

Advance care planning: The process of planning and discussing future healthcare options.

Advance directives: Oral and written instructions about the patient's goals and wishes concerning future medical care that becomes effective only when a person cannot speak for him or herself.

Agonal pain: The profound, agonizing pain, especially that associated with death.

Assisted suicide: The act of killing oneself with another person's assistance.

Autonomy: Respect for autonomy is one of the basic principles of health care. The concept of autonomy respects and advocates for an individual to retain control, direct situations, and dictate circumstances.

Autopsy: A physical examination of the body after death to determine the cause of death or the characteristics and extent of changes produced by disease.

Brain death: Cessation of brain and brain stem function.

Cardiopulmonary resuscitation (CPR): A group of treatments and technologies used to restore and maintain blood circulation and breathing in a person whose heart and/or lungs have stopped working. Includes the clearance of air passages to the lungs, mouth-to-mouth method of artificial respiration, and heart massage by the exertion of pressure on the chest.

Complimentary and alternative medicine (CAM): Treatments and techniques used to soothe or cure illness that are not associated with Western medical practices.

Deceased: No longer living.

Decedent: A person who is dead.

Do-not-resuscitate order (DNR): A physician order to not initiate CPR or life support treatments for a patient.

Dyspnea: A feeling of shortness of breath or breathlessness.

EEG: An electroencephalogram, or EEG, traces and records brain waves.

Enternal nutrition: Treatment that delivers nutrients directly into a patient's stomach or intestines with a feeding tube.

Euthanasia: Euthanasia is an act where a third party, usually implied to be a physician, terminates the life of a person, passively or actively.

Hospice: Hospice is a holistic and philosophical approach to caring for the dying patient in which doctors, nurses, social workers and other professionals work together to care for that patient. Hospice emphasizes pain control, symptom management, natural death, and quality of life to comfort the patient's physical body.

Kidney Dialysis: Process of filtering metabolic waste products from the blood.

Life support: General description of both simple (mouth-to-mouth resuscitation, chest compressions, etc.) and advanced resuscitation procedures (drugs, electric shock, etc.) used to restore and maintain breathing and heart function.

Living will: A will in which the person expresses their preferences regarding the use of life-support systems for themselves should they become terminally ill or injured beyond recovery.

Mechanical ventilation: Uses a machine to inflate and empty a patient's lungs allowing oxygenation of the blood.

Narcotics: Narcotics are a class of powerful, regulated drugs derived from opium.

Overdose: Administration of an overly large dose of a drug leading to harmful or potentially harmful drug levels in the body.

Palliative care: Care for dying patients emphasizing total and comprehensive care for all a patient's needs—particularly pain and symptom management, spiritual, social, psychological, and emotional well being.

Passive euthanasia: Passive euthanasia ends a patient's life by withholding or not beginning some type of medical intervention, such as kidney dialysis.

Patient Self-Determination Act (PSDA): A law passed by the United States Congress in 1990 that requires healthcare facilities receiving federal funding to educate the community about advance directives.

Persistent Vegetative State (PVS): A state of complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.

Physician assisted suicide: The act of ending one's life with the assistance of a physician. With physician assisted suicide, a doctor provides a patient with a prescription for drugs that a patient could use to end his or her life.

Power of attorney: A legal instrument that allows a person to choose someone else to act on their behalf if they should ever become incompetent.

Prognosis: A prediction or estimate about the course of an individual's disease.

Quality of life: Measure by which an individual's overall well being is assessed.

Sedatives: Drugs that have a calming or tranquilizing affect on the body by depressing activity in the brain and spinal cord.

Stereotyping: An oversimplified and broad opinion.

Terminal sedation: Terminal sedation uses sedatives to make a patient unconscious until death occurs from the underlying illness.

Thanatology: The study of death.

Uniform Determination of Death Act (UDDA): Passed by the U.S. Congress in 1981 to define when a person is definitively dead.

Will: A written instrument legally executed by which a person determines how their property and possessions will be distributed after his or her death.

Further Reading

Advance Directives

- Basta LL. Proper planning for end-of-life medical care; confronting the near irrelevance of currently used living wills. *American Journal of Geriatric Cardiology*, 2003; 12(2): 110-112.
- Rich BA. Personhood, patienthood, and clinical practice: reassessing advance directives. *Psychology, Public Policy, & Law*, 1998; 4(3): 610-628.
- Stein J. The ethics of advance directives: a rehabilitation perspective. *American Journal of Physical Medicine & Rehabilitation*, 2003; 82(2): 152-157.

Brain Death

- Bates P. Defining death, natural death legislation, and withdrawal of treatment. *Australian Health Review*, 1992; 15(4): 392-421.
- Bayertz K. Techno-thanatology: moral consequences of introducing brain criteria for death. *Journal of Medicine & Philosophy*, 1992; 17(4):407-417.
- Delmonico FL. Murray JE. A medical defense of brain death. *Ethics & Medics*, 1999; 24(10):1-2.
- DuBois JM. Ethical assessments of brain death and organ procurement policies: a survey of transplant personnel in the United States. *Journal of Transplant Coordination*, 1999; 9(4):210-218.
- Fisher CM. Brain death—a review of the concept. *Journal of Neuroscience Nursing*, 1991; 23(5):330-333.
- Garcia OD. A new formulation of death and its relevance to medical law. *Medicine & Law*, 1998; 17(4):493-501.
- Halevy A. Brody B. Brain death: reconciling definitions, criteria, and tests. *Annals of Internal Medicine*, 1993; 119(6):519-525.
- Lizza JP. Persons and death: what's metaphysically wrong with our current statutory definition of death? *Journal of Medicine & Philosophy*, 1993; 18(4):351-374.
- Lovasik D. Brain death and organ donation. *Critical Care Nursing Clinics of North America*, 2000; 12(4):531-538.
- Penticuff JH. Ethical issues in redefining death. *Journal of Neuroscience Nursing*, 1990; 22(1):48-49.

- Powner DJ. Darby JM. Current considerations in the issue of brain death. *Neurosurgery*, 1999; 45(5):1222-1226. (Discussion: 1226-1227.)
- Rothenberg LS. The anencephalic neonate and brain death: an international review of medical, ethical, and legal issues. *Transplantation Proceedings*, 1990; 22(3):1037-1039.
- Sass HM. Criteria for death: self-determination and public policy. *Journal of Medicine & Philosophy*, 1992; 17(4):445-454.
- Shewmon DA. "Brainstem death," "brain death" and death: a critical re-evaluation of the purported equivalence. *Issues in Law & Medicine*, 1998; 14(2):125-145.
- Sussman D. Biomedical ethics: confronting dilemmas of modern medicine. *Minnesota Medicine*, 1991; 74(6):19-23.
- Taylor RM. Reexamining the definition and criteria of death. *Seminars in Neurology*, 1997; 17(3):265-270.
- Truog RD. Is it time to abandon brain death? *Hastings Center Report*, 1997; 27(1):29-37.
- Veatch RM. Brain death and slippery slopes. *Journal of Clinical Ethics*, 1993; 4(4):376.
- Wikler D. Brain-related criteria for the beginning and end of life. *Transplantation Proceedings*, 1990; 22(3):989-990.

Burial, Cremation, and Body Disposal

- Williams ED. Crews JD. From dust to dust: ethical and practical issues involved in the location, exhumation, and identification of bodies from mass graves. *Croatian Medical Journal*, 2003; 44(3):251-258.

Grief

- Burton LA. Tarlos-Benka J. Grief-driven ethical decision-making. *Journal of Religion & Health*, 1997; 36(4):333-343.
- Coburn MU. Borges MC. Knake E. et al. The multidisciplinary approach to dealing with families: a model for medical examiners. *Journal of Forensic Sciences*, 2000; 45(6):1278-1279.
- Fisher J. Harming and benefiting the dead. *Death Studies*, 2001; 25(7):557-568.
- Haas F. Bereavement care: seeing the body. *Nursing Standard*, 2003; 17(28):33-37.
- Holland JC. Management of grief and loss: medicine's obligation and challenge. *Journal of the American Medical Womens Association*, 2002; 57(2):95-96.

Hospice and Palliative Care

- Addington-Hall J. Research sensitivities to palliative care patients. *European Journal of Cancer Care*, 2002; 11(3):220-224.
- Aroskar MA. Access to hospice: ethical dimensions. *Nursing Clinician of North America*, 1985; 20(2):299-309.
- Baumrucker SJ. Sedation, dehydration, and ethical uncertainty. *American Journal of Hospice & Palliative Care*, 2002; 19(5):299-300.
- Bernat JL. Ethical and legal issues in palliative care. *Neurologic Clinics*, 2001; 19(4):969-987.
- Casarett D. Ferrell B. Kirschling J. et al. NHPCO Task Force Statement on the Ethics of Hospice Participation in Research. *Journal of Palliative Medicine*, 2001; 4(4):441-449.
- Casarett DJ. Karlawish JH. Henry MI. et al. Must patients with advanced cancer choose between a Phase I trial and hospice? *Cancer*, 2002; 95(7):1601-1604.
- Casarett DJ. Knebel A. Helmers K. Ethical challenges of palliative care research. *Journal of Pain & Symptom Management*, 2003; 25(4):S3-5.
- Chilver K. Should we give palliative care to all those that need it? *International Journal of Palliative Nursing*, 2002; 8(2):75-77.
- Chrystal-Frances E. Palliative care: a discussion of management and ethical issues. *Nursing Forum*, 2003; 38(2):25-28.
- Dean RA. McClement SE. Palliative care research: methodological and ethical challenges. *International Journal of Palliative Nursing*, 2002; 8(8):376-380.
- de Haes H. Koedoot N. Patient centered decision making in palliative cancer treatment: a world of paradoxes. *Patient Education & Counseling*, 2003; 50(1):43-49.
- Donaldson MS. Field MJ. Measuring quality of care at the end of life. *Archives of Internal Medicine*, 1998; 158(2):121-128.
- Dugan DC. Pain and the ethics of pain management. *HEC Forum*, 1996; 8(6):330-339.
- Easson AM. Lee KF. Brasel K. et al. Clinical research for surgeons in palliative care: challenges and opportunities. *Journal of the American College of Surgeons*, 2003 196(1):141-151.
- Emanuel EJ. Cost savings at the end of life. What do the data show? *JAMA*, 1996; 275(24):1907-1914.
- Ersek M. Wilson SA. The challenges and opportunities in providing end-of-life care in nursing homes. *Journal of Palliative Medicine*, 2003; 6(1):45-57.
- Fine PG. Jennings B. CPR in hospice. *Hastings Center Report*, 2003 33(3):9. (Discussion 9-10.)
- Fine PG. Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life. *Journal of Pain & Symptom Management*, 2003; 25(4):S53-62.
- Fleming DA. Relieving pain: what are today's ethical and legal risks? *Missouri Medicine*, 2002; 99(10):560-565.

- Giblin MJ. Beyond principles: virtue and ethics in hospice and palliative care. *American Journal of Hospice & Palliative Care*, 2002; 19(4):235-239.
- Harper BC. Growth in caring and professional ethics in hospice. *Hospice Journal*, 1997; 12(2):65-70.
- Hermesen MA. ten Have HA. Practical ethics of palliative care. *American Journal of Hospice & Palliative Care*, 2003; 20(2):97-98.
- Illingworth P. Bursztajn H. Death with dignity or life with health care rationing. *Psychology, Public Policy, & Law*, 2000; 6(2):314-321.
- Joy M. Death in the home: the doctor's responsibility. *Journal of Long Term Home Health Care*, 1998; 17(4):2-8.
- Krouse RS. Easson AM. Angelos P. Ethical considerations and barriers to research in surgical palliative care. *Journal of the American College of Surgeons*, 2003; 196(3):469-474.
- Lee S. Kristjanson L. Human research ethics committees: issues in palliative care research. *International Journal of Palliative Nursing*, 2003; 9(1):13-18.
- Malloy M. Hospice: an alternative to needless suffering or suicide. *Minnesota Medicine*, 1997; 80(11):14, 59.
- Miller JL. Hospice care or assisted suicide: a false dichotomy. *American Journal of Hospice & Palliative Care*, 1997; 14(3):132-134.
- Miteff L. Palliative care ethics: autonomy in aged care. *Australian Nursing Journal*, 2001; 9(6):23-26.
- Morita T. Tei Y. Inoue S. Ethical validity of palliative sedation therapy. *Journal of Pain & Symptom Management*, 2003; 25(2):103-105.
- Musgrave CF. The ethical and legal implications of hospice care: an international overview. *Cancer Nursing*, 1987; 10(4):183-189.
- Pierce SF. Dalton JA. Duffey M. The nurse's ethical obligation to relieve pain: actualizing the moral mandate. *Journal of Nursing Law*, 2001; 7(4):19-29.
- Rees E. The ethics and practicalities of consent in palliative care research: An overview. *International Journal of Palliative Nursing*, 2001; 7(10):489-492.
- Rich BA. A legacy of silence: bioethics and the culture of pain. *Journal of Medical Humanities*, 1997; 18(4):233-259.
- Ryndes T. Emanuel L. Is discontinuity in palliative care a culpable act of omission? *Hastings Center Report*, 2003; Suppl:S45-47.
- Sykes N. Thorns A. The use of opioids and sedatives at the end of life. *Lancet Oncology*, 2003; 4(5):312-318.
- ten Have HA. Palliative care and genetics. *Medicine, Health Care & Philosophy*, 2001; 4(3):259-260.

Multicultural Issues

- Anonymous. The Muslim Law (Shariah) Council and organ transplants. *Accident & Emergency Nursing*, 1996; 4(2):73-75.
- Becker R. Teaching communication with the dying across cultural boundaries. *British Journal of Nursing*, 1999, 8 (14): 938-942.
- Beresford L. Cultural differences last a lifetime: tailoring end-of-life care to a diverse population. *ABCD Exchange*: March 1999 : Upfront - Cultural Diversity in EOL. Available online at <http://www.mywhatevery.com/cifwriter/content/19/abcd630.html>. Accessed 11/8/04.
- Caralis PV. Davis B. Wright K. Marcia E. The influence of ethnicity and race on attitudes toward advance directives, life-prolonging treatments, and euthanasia. *Journal of Clinical Ethics*, 1993;4(2):155-65.
- Ebrahim AF. Islamic jurisprudence and the end of human life. *Medicine & Law*, 1998; 17(2):189-196.
- Guild of Catholic Doctors, Catholic Union of Great Britain and Joint Ethico Medical Committee. A response to the British Medical Association consultation paper— Withdrawing and withholding treatment: a consultation paper from the BMA's Medical Ethics Committee. Published September 23, 1998 and available online at http://www.catholicdoctors.org.uk/Submissions/BMA_Withdrawing_Rx.htm. Accessed 10/7/04.
- Johnson CJ. McGee MG. eds. *How Different Religions View Death & Afterlife*. Charles Press Pubs; 2nd edition (May 1, 1998).
- Ott BB. Al-Khadhuri J. Al-Junaibi S. Preventing ethical dilemmas: understanding Islamic health care practices. *Pediatric Nursing*, 2003; 29(3):227-230.
- Parkes CM. Laungani P. Young B. eds. *Death and Bereavement Across Cultures*. Routledge; (November 1, 1996).
- Phipps EJ. True G. Murray GF. Community perspectives on advance care planning: report from the community ethics program. *Journal of Cultural Diversity*, Winter, 2003. Available online at http://www.findarticles.com/p/articles/mi_m0MJU/is_4_10/ai_113304785. Accessed 11/8/04.
- Sarhill N. LeGrand S. Islambouli R. Davis MP. Walsh D. The terminally ill Muslim: death and dying from the Muslim perspective. *American Journal of Hospice & Palliative Care*, 2001; 18(4):251-255.
- Stell LK. Diagnosing death: What's trust got to do with it? *Mount Sinai Journal of Medicine*, 1999; 66(4):229-235.

Physician Assisted Suicide and Euthanasia

- Awan F. Intention, manner, and culpability in death. *Princeton Journal of Bioethics*, 2002; 5:81-91.
- Bachelard S. On euthanasia: blindspots in the argument from mercy. *Journal of Applied Philosophy*, 2002; 19(2):131-140.
- Bagaric M. Amarasekara K. Euthanasia: why it doesn't matter (much) what the doctor thinks and why there is no suggestion that doctors should have a duty to kill. *Journal of Law & Medicine*, 2002; 10(2):221-231.
- Barilan YM. Revisiting the problem of Jewish bioethics: the case of terminal care. *Kennedy Institute of Ethics Journal*, 2003; 13(2):141-168.
- Braddock CH, Tonelli MR. Physician-assisted suicide. *Ethics in Medicine*, published by the University of Washington School of Medicine online at <http://eduserv.hscer.washington.edu/bioethics/topics/pas.html>. Accessed April 25, 2002.
- Campbell CS. Kimsma G. "Help me die". *Cambridge Quarterly of Healthcare Ethics*, 2001; 10(4):451-452. (Discussion 452-455).
- Coughenower M. Physician-assisted suicide. *Gastroenterology Nursing*, 2003; 26(2):55-59.
- Cranford RE. Gensinger R. Hospital policy on terminal sedation and euthanasia. *HEC Forum*, 2002; 14(3):259-264.
- Daruwala A. Euthanasia: how proponents justify it and provide models for regulation. *Princeton Journal of Bioethics*, 2002; 5:37-47.
- Deigh J. Physician assisted suicide and voluntary euthanasia: some relevant differences. *Journal of Criminal Law & Criminology*, 1998; 88(3):1155-1165.
- Gentzler J. What is a death with dignity? *Journal of Medicine & Philosophy*, 2003; 28(4):461-487.
- Gillon R. Physician assisted suicide—sympathy and skepticism. *University of Detroit Mercy Law Review*, 1998; 75(3):499-513.
- Guglielmo WJ. Assisted suicide? Pain control? Where's the line? *Medical Economics*, 2002; 79(19):48-49, 53-54, 59.
- Harvey MT. What does a 'right' to physician-assisted suicide (PAS) legally entail? *Theoretical Medicine & Bioethics*, 2002; 23(4-5):271-286.
- Lee P. Personhood, dignity, suicide, and euthanasia. *The National Catholic Bioethics Quarterly*, 2001; 1(3):329-343.
- Lorenz K. Lynn J. MSJAMA. Moral and practical challenges of physician-assisted suicide. *JAMA*, 2003; 289(17):2282.
- Marker RL.. Assisted suicide: the continuing debate. Published by The International Task Force on Euthanasia and Assisted Suicide online at <http://www.internationaltaskforce.org/iaa24.htm>. Accessed April 25, 2002

- McInerney F. "Requested death:" a new social movement. *Social Sciences and Medicine*, 1999; 50(2000):137–154.
- Moody J. Euthanasia: a need for reform. *Nursing Standard*, 2003; 17(25):40-44.
- Palmer LI. MSJAMA. The legal and political future of physician-assisted suicide. *JAMA*, 2003; 289(17):2283.
- Paterson I. The ethics of assisted suicide. *Nursing Times*, 2003; 99(7):30-31.
- Pierce SF. Allowing and assisting patients to die: the perspectives of oncology practitioners. *Journal of Advanced Nursing*, 1999; 30(3):616–622.
- Quill TE. Cassel CK. Professional organizations' position statements on physician-assisted suicide: A case for studied neutrality. *Annals of Internal Medicine*, 2003; 138(3):208-211.
- Rajkumar R. MSJAMA. Physician-assisted suicide. *JAMA*, 2003; 289(17):2278.
- Rodriguez E. The arguments for euthanasia and physician-assisted suicide: Ethical reflection. *Linacre Quarterly*. 68(3):251-261.
- ten Have HA. Euthanasia: moral paradoxes. *Palliative Medicine*, 2001; 15(6):505-511.
- Traina CL. Religious perspectives on assisted suicide. *Journal of Criminal Law & Criminology*, 1998; 88(3):1147-1154.

Resuscitation

- Berger JT. Ethical challenges of partial do-not-resuscitate (DNR) orders: placing DNR orders in the context of a life-threatening conditions care plan. *Archives of Internal Medicine*, 2003; 163(19):2270-2275.
- Berry P. Action vs. inaction: a case history in ethics. *Journal of Medical Ethics*, 2003; 29(4):225-226.
- Burns J, Edwards J, Johnson J, et al. Do-not-resuscitate order after 25 years. *Critical Care Medicine*, 2003; 31:1543–1550.
- Costello J. Horne M. Nurses and health support workers' views on cardiopulmonary resuscitation in a hospice setting. *International Journal of Palliative Nursing*, 2003; 9(4):157-165.
- da Costa DE. Ghazal H. Al Khusaiby S. Do Not Resuscitate orders and ethical decisions in a neonatal intensive care unit in a Muslim community. *Archives of Disease in Childhood Fetal & Neonatal Edition*, 2002; 86(2):F115-119.
- Putnam A. Do I have to resuscitate this patient against her wishes? *American Family Physician*, 2003; 67(9):2025-2026, 2028.
- Rabkin MT, Gillerman G, Rice NR. Orders not to resuscitate. *New England Journal of Medicine*, 1976; 295:364–366.
- Thorns A. Gannon C. The potential role for automatic external defibrillators in palliative care units. *Palliative Medicine*, 2003; 17(5):465-467.

Withholding and Withdrawing Treatment

- Andrews K. Clinical approaches to the withdrawal of nutrition and hydration. *Clinical Medicine*, 2003; 3(4):342-345.
- Basta LL. Proper planning for end-of-life medical care: confronting the near irrelevance of currently used living wills. *American Journal of Geriatric Cardiology*, 2003; 12(2):110-112.
- Brett AS. Jersild P. "Inappropriate" treatment near the end of life: conflict between religious convictions and clinical judgment. *Archives of Internal Medicine*, 2003; 163(14):1645-1649.
- Cantor NL. Making advance directives meaningful. *Psychology, Public Policy, & Law*, 1998; 4(3):629-652.
- Cohen LM. Germain MJ. Poppel DM. Practical considerations in dialysis withdrawal: "To have that option is a blessing." *JAMA*, 2003; 289(16):2113-2119.
- Fried C. Terminating life support: out of the closet! *New England Journal of Medicine*, 1976; 295:390-391.
- Hinshaw DB. Pawlik T. Mosenthal AC. et al. When do we stop, and how do we do it? Medical futility and withdrawal of care. *Journal of the American College of Surgeons*, 2003; 196(4):621-651.
- Huxtable R. Campbell AV. Palliative care and the euthanasia debate: recent developments. *Palliative Medicine*, 2003; 17(2):94-96.
- Isaacs D. To kill or to let die? *Journal of Paediatrics & Child Health*, 2003; 39(2):135-136.
- Kelley T. Ruling supports parents' rights to decide on child's life support. *New York Times*:B1, B4, 2003 May 17.
- Kowalski S. Withdrawal of nutritional support: a family's choice. *Gastroenterology Nursing*, 1996; 19(1):25-28.
- Krupp AN. Health care surrogate statutes: Ethics pitfalls threaten the interests of incompetent patients. *West Virginia Law Review*, 1998; 101(1):99-128.
- Levi BH. Withdrawing nutrition and hydration from children: legal, ethical, and professional issues. *Clinical Pediatrics*, 2003; 42(2):139-145.
- Marcus EL. Clarfield AM. Moses AE. Ethical issues relating to the use of antimicrobial therapy in older adults. *Clinical Infectious Diseases*, 2001; 33(10):1697-1705.
- Markowitz AJ. Rabow MW. Practical considerations in dialysis withdrawal: "To have that option is a blessing." *JAMA*, 2003; 290(6):815.
- McIlmoyle J. Vernon MJ. Artificial nutrition and hydration: science, ethics and law. *Clinical Medicine*, 2003; 3(2):176-178.
- Meisel A. Quality of life and end-of-life decisionmaking. *Quality of Life Research*, 2003; 12 Suppl 1:91-94.
- Oneschuk D. Fainsinger R. Medical and ethical dilemmas when an advanced cancer patient discontinues dialysis. *Journal of Palliative Care*, 2002; 18(2):123-126.
- Paterson C. On "killing" versus "letting die" in clinical practice: mere sophistry with words? *Journal of Nursing Law*, 2000; 6(4):25-44.

- Planas M. Camilo ME. Artificial nutrition: dilemmas in decision-making. *Clinical Nutrition*, 2002; 21(4):355-361.
- Prendergast TJ. Luce JM. A national survey of withdrawal of life support from critically ill patients. *American Journal of Respiratory Critical Care Medicine*, 1996; 153:A360.
- Prendergast TJ. Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *American Journal of Respiratory Critical Care Medicine*, 1997; 155:15-20.
- Slomka J. Withholding nutrition at the end of life: clinical and ethical issues. *Cleveland Clinic Journal of Medicine*, 2003; 70(6):548-552.
- Smedira NG. Evans BH. Grais LS. et al. Withholding and withdrawal of life support from the critically ill. *New England Journal of Medicine*, 1990; 322:309-315.
- Stroud R. The withdrawal of life support in adult intensive care: an evaluative review of the literature. *Nursing in Critical Care*, 2002; 7(4):176-184.
- Torchia J. Postmodernism and the persistent vegetative state. *The National Catholic Bioethics Quarterly*, 2002; 2(2):257-275.
- White M. Callahan D. Oregon's first year: the medicalization of control. *Psychology, Public Policy, & Law*, 2000; 6(2):331-341.
- White PH. Kuhlenschmidt HL. Vancura BG. et al. Antimicrobial use in patients with advanced cancer receiving hospice care. *Journal of Pain & Symptom Management*, 2003; 25(5):438-443.
- Zamperetti N. Bellomo R. Ronco C. Setting limits in intensive care. *Intensive Care Medicine*, 2002; 28(7):997.

References

- ¹ Kochanek, et al. 2002 *National Vital Statistics Report*, 11 Feb 2004. 52(13). Available online at: www.cdc.gov/nchs/ . Accessed 2/26/04.
- ² Kochanek, et al. 2002 *National Vital Statistics Report*, 11 Feb 2004. 52(13). Available online at: www.cdc.gov/nchs/. Accessed 2/26/04.
- ³ World Health Organization. *Injury: A Leading Cause of the Global Burden of Disease*. Krug E., ed. Online at http://whqlibdoc.who.int/hq/1999/WHO_HSC_PVI_99.11.pdf. Accessed 3/1/04.
- ⁴ Capron AM. Definition and determination of death: II. Legal issues in pronouncing death. In: Reich WT, ed. *Encyclopedia of Bioethics*. New York: Simon & Schuster MacMillan. 1995:536.
- ⁵ Guidelines for the determination of death: report of the medical consultants on the diagnosis of death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Journal of the American Medical Association*, 1981; 246(19):2184-2186.
- ⁶ TransWeb website. Online at www.transweb.org. Accessed 10/31/03.
- ⁷ National Conference of Commissioners on Uniform State Laws website. Online at www.nccusl.org. Accessed 10/31/03.
- ⁸ Gervais KG. Definition and determination of death: III. Philosophical and theological perspectives. In: Reich WT, ed. *Encyclopedia of Bioethics*. New York: Simon & Schuster MacMillan. 1995:542.
- ⁹ Hershenov D. The problematic role of irreversibility in the definition of death. *Bioethics*, 2003; 17(1):89-100.
- ¹⁰ United Network for Organ Sharing (UNOS), available online at www.unos.org. Accessed 9/7/04.
- ¹¹ McKenney E. Legal and ethical issues related to non heart beating organ donation. *AORN Journal*, 2003; 77: 973.
- ¹² Institute of Medicine, Committee on Non-heartbeating Transplantation II: The Scientific and Ethical Basis for Practice and Protocols. *Non-Heart-Beating Organ Transplantation: Practice and Protocols*. National Academy Press, Washington DC, 2000, p.6-7.]
- ¹³ Jennings B. Rundes T. D'Onofrio C. et al. Access to hospice care:expanding boundaries, overcoming barriers. *The Hastings Center Report*, 2003; 33(2):S3-4. Available online at http://www.thehastingscenter.org/pdf/access_hospice_care.pdf. Accessed 10/7/04.
- ¹⁴ Steihauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine*, 2000; 132:825-832.
- ¹⁵ Singer PA, Martin DK, Kelner M. Quality end of life care: patient's perspectives. *Journal of the American Medical Association*, 1999; 281:163-168.
- ¹⁶ Steihauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and Other Care Providers. *Journal of the American Medical Association*, 2000; 284:2476-2482.

-
- ¹⁷ The National Hospice and Palliative Care Organization website online at www.nhpc.org. Accessed 5/20/04.
- ¹⁸ World Health Organization website. Online at <http://www.who.int/cancer/palliative/en/>. Accessed 2/15/04.
- ¹⁹ Ruddick W. Do doctors undertreat pain? *Bioethics*, 1997; 11(3-4):246-55.
- ²⁰ Chrystal-Frances E. Palliative care: A discussion of management and ethical issues. *Nursing Forum*, 2003; 38(2):25-29.
- ²¹ LaDuke, S. Terminal dyspnea & palliative care. *AJN*. 101(11):26-31.
- ²² Weiss SC, et al. Understanding the experience of pain in terminally ill patients. *Lancet*, 2001; 357(9265):1311-5.
- ²³ Barraclough J. *Cancer and emotion: a practical guide to psycho-oncology*. Abingdon: Radcliffe Medical, 1994.
- ²⁴ U.S. Drug Enforcement Administration. Narcotics. Available online at <http://www.usdoj.gov/dea/concern/narcotics.html>. Accessed 11/9/04.
- ²⁵ Lynn J. Schuster JL. Kabcenell A. *Improving Care for the End of Life*. Oxford University Press; 2000. Available online at <http://www.mywhatever.com/cifwriter/content/66/4181.html>. Accessed 12/19/04.
- ²⁶ Pellegrino, Edmund D. Emerging ethical issues in palliative care. *Journal of the American Medical Association*, 1998; 279(19):1521-1522.
- ²⁷ Burt RA. The Supreme Court speaks: not assisted suicide but a constitutional right to palliative care. *New England Journal of Medicine*, 1997; 337:1234-1236.
- ²⁸ Medical Board of California. "Medical board reaffirms its commitment to physicians who recommend medical marijuana," Press Release, May 13, 2004. Online at http://www.medbd.ca.gov/PR_2004_05-13_Marijuana.htm. Accessed 10/7/04.
- ²⁹ Gallagher S. Voters pass measures for medical marijuana, tobacco tax. *Billingsgazette.com*. Article available online at <http://www.billingsgazette.com/index.php?id=1&display=rednews/2004/11/03/buil d/state/45-tobacco-marijuana.inc>. Accessed 11/10/04.
- ³⁰ Jennings B. Rundes T. D'Onofrio C. et al. Access to hospice care: expanding boundaries, overcoming barriers. *The Hastings Center Report*, 2003; 33(2):S3-7. Online at http://www.thehastingscenter.org/pdf/access_hospice_care.pdf. Accessed 10/7/04.
- ³¹ Jennings B. Rundes T. D'Onofrio C. et al. Access to hospice care: expanding boundaries, overcoming barriers. *The Hastings Center Report*, 2003; 33(2):S13-24. Online at http://www.thehastingscenter.org/pdf/access_hospice_care.pdf. Accessed 10/7/04.
- ³² Commission on End of Life Care Final Report, January 2002. Minnesota Partnership to Improve End of Life Care and the MN Dept. of Health. p.34. Online at www.minnesotapartnership.org. Accessed 10/7/04.
- ³³ Commission on End of Life Care Final Report, January 2002. Minnesota Partnership to Improve End of Life Care and the MN Dept. of Health. p.44. Online at www.minnesotapartnership.org. Accessed 10/7/04.

-
- ³⁴ Brown GM. This porridge is too thin. *Cambridge Quarterly of Healthcare Ethics*, 1998; 7:206-208.
- ³⁵ Jennings B, Rundes T, D'Onofrio C. et al. Access to hospice care: expanding boundaries, overcoming barriers. *The Hastings Center Report*, 2003; 33(2):S3-7. Online at http://www.thehastingscenter.org/pdf/access_hospice_care.pdf. Accessed 10/7/04.
- ³⁶ National Hospice and Palliative Care Organization on the internet at <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3283&openpage=3283>. Accessed 9/9/04.
- ³⁷ Brown GM. This porridge is too thin. *Cambridge Quarterly of Healthcare Ethics*, 1998; 7:206-208.
- ³⁸ Jennings B, Rundes T, D'Onofrio C. et al. Access to hospice care: expanding boundaries, overcoming barriers. *The Hastings Center Report*, 2003; 33(2):S3-7. Available online at http://www.thehastingscenter.org/pdf/access_hospice_care.pdf. Accessed 10/7/04.
- ³⁹ Virnig BA, Kind S, McBean M, et al. Geographic variation in hospice use prior to death. *Journal of the American Geriatrics Society*, 2000; 48(9):1117-1120.
- ⁴⁰ Sulmasy DP. Health care justice and hospice care. *Hastings Center Report*, 2003; 33(2):S14-S15. Available online at http://www.thehastingscenter.org/pdf/access_hospice_care.pdf. Accessed 10/7/04.
- ⁴¹ National Hospice and Palliative Care Organization. On the internet at <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3283&openpage=3283>. Accessed 9/9/04.
- ⁴² Brown GM. This porridge is too thin. *Cambridge Quarterly of Healthcare Ethics*, 1998; 7:206-208.
- ⁴³ Haddad A. Ethics in action (Acute care decisions). *RN*, 2003; 66(5):27-30.
- ⁴⁴ Kinzbrunner BM. Ethical dilemmas in hospice and palliative care. *Supportive Care in Cancer*, 1995; 3(1):28-36.
- ⁴⁵ Chrystal-Frances E. Palliative care: a discussion of management and ethical issues. (Said Another Way). *Nursing Forum*, 2003; 38(2):25-29.
- ⁴⁶ U.S. Drug Enforcement Administration website. Online at <http://www.usdoj.gov/dea/concern/narcotics.html>. Accessed 3/2/04.
- ⁴⁷ Fleming DA. Relieving pain: What are today's ethical and legal risks? *Missouri Medicine*, 2002; 99(10):560-565.
- ⁴⁸ U.S. Drug Enforcement Administration website. Online at <http://www.usdoj.gov/dea/concern/narcotics.html>. Accessed 3/2/04.
- ⁴⁹ Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *Oncology*, 2003; 4(5):312-318.
- ⁵⁰ Fleming DA. Relieving pain: What are today's ethical and legal risks? *Missouri Medicine*, 2002; 99(10):560-565.
- ⁵¹ Pellegrino ED. Emerging ethical issues in palliative care. *Journal of the American Medical Association*, 1998; 279(19):1521-1523.

-
- ⁵² Pendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *American Journal of Respiratory and Critical Care Medicine*, 1997; 155:15-20.
- ⁵³ Faber-Langendoen K, Lanken PN. Dying patients in the intensive care unit: forgoing treatment, maintaining care. *Annals of Internal Medicine*; 2000; 133:886-893.
- ⁵⁴ Seniors-Site website. Online at <http://seniors-site.com/ultimate/glossary.html>. Accessed 2/11/04.
- ⁵⁵ Learn CPR website. Online at <http://depts.washington.edu/learncpr/facts.html>. Accessed 3/3/04.
- ⁵⁶ Tomlinson T, Brody H. Sounding board: ethics and communication in Do-Not-Resuscitate orders. *The New England Journal of Medicine*, 1988; 318(1):43-46.
- ⁵⁷ Council on Ethical and Judicial Affairs, American Medical Association. *Journal of the American Medical Association* 1991;265:1981.
- ⁵⁸ Jude JR, Elam JO. *Fundamentals of Cardiopulmonary Resuscitation*. Philadelphia: F.A. Davis Company; 1965:4.
- ⁵⁹ LaDuke S. Terminal dyspnea & palliative care. *AJN*, 101(11):26-31, 2001 Nov.
- ⁶⁰ Shee CD, Green M. Non-invasive ventilation and palliation: experience in a district general hospital and a review. *Palliative Medicine*, 2003; 17(1):21-26.
- ⁶¹ Cook D, Rocker G, Marshall J, et al. Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. *The New England Journal of Medicine*, 2003; 349(12):1123-1132.
- ⁶² Singer GR. Disconnecting the ventilator: life saving or death delaying? *Journal of the Florida Medical Association*, 1997; 84(8):498-501.
- ⁶³ American Medical Association website. AMA Policy E-2.20 Withholding or Withdrawing Life Sustaining Treatment. Online at www.ama-assn.org/. Accessed 2/11/04.
- ⁶⁴ Guild of Catholic Doctors, Catholic Union of Great Britain and Joint Ethico Medical Committee. A response to the British Medical Association consultation paper—Withdrawing and withholding treatment: a consultation paper from the BMA’s Medical Ethics Committee. Published September 23, 1998 and available online at http://www.catholicdoctors.org.uk/Submissions/BMA_Withdrawing_Rx.htm. Accessed 10/7/04.
- ⁶⁵ *Cruzan v. Director*, Missouri Department of Health, 110 S.Ct. 2841 (1990).
- ⁶⁶ *Bouvia v. Superior Court*. 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (Ct. App.), review denied (June 5, 1986).
- ⁶⁷ *In re Conroy*. 98 N.J. 321, 486 A.2d 1209 (1985).
- ⁶⁸ *Brophy v. New England Sinai Hospital, Inc.* 398 Mass. 417, 497 N.E. 2d626 (1986).
- ⁶⁹ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment*, Washington, D.C.: U.S. Government Printing Office, 1983.
- ⁷⁰ Ackermann RJ. Withholding and withdrawing life-sustaining treatment. *American Family Physician*, October 1, 2000. Published online by the American Academy of

-
- Family Physicians at <http://www.aafp.org/afp/20001001/1555.html>. Accessed 10/7/04.
- ⁷¹ Cohen LM. Germain MJ. Poppel DM. Practical considerations in dialysis withdrawal: “To have that option is a blessing.” *Journal of the American Medical Association*, 2003; 289(16):2113-2119.
- ⁷² Renal Physicians Association and American Society of Nephrology. Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. *Clinical Practice Guideline*, 2000:2. <http://www.renalmd.org> Accessed 3/3/04.
- ⁷³ Pereira J. Watanabe S. Wolch G. A retrospective review of the frequency of infections and patterns of antibiotic utilization on a palliative care unit. *Journal of Pain & Symptom Management*, 1998; 16(6):374-381.
- ⁷⁴ Marcus EL. Clarfield AM. Moses AE. Ethical Issues Relating to the Use of Antimicrobial Therapy in Adults. *Clinical Infectious Diseases*, 2001; 33:1697-1705.
- ⁷⁵ Pereira J. Watanabe S. Wolch G. A retrospective review of the frequency of infections and patterns of antibiotic utilization on a palliative care unit. *Journal of Pain & Symptom Management*, 1998; 16(6):374-381.
- ⁷⁶ Marcus EL. Clarfield AM. Moses AE. Ethical issues relating to the use of antimicrobial therapy in older adults. *Clinical Infectious Diseases*, 2001; 33(10):1697-1705.
- ⁷⁷ Marcus EL. Clarfield AM. Moses AE. Ethical issues relating to the use of antimicrobial therapy in older adults. *Clinical Infectious Diseases*, 2001; 33(10):1697-1705.
- ⁷⁸ Coppa S. Futile Care: Confronting the high costs of dying. *Journal of Nursing Administration*, 1996; 26(12):18-23.
- ⁷⁹ Kapp MB. Economic influences on end-of-life care: empirical evidence and ethical speculation. *Death Studies*, 2001; 25(3):251-263.
- ⁸⁰ Coppa S. Futile Care: Confronting the high costs of dying. *Journal of Nursing Administration*, 1996; 26(12):18-23.
- ⁸¹ Fine RL, Mayo TW. Resolution of futility by due process: early experience with the Texas Advance Directives Act. *Annals of Internal Medicine*, 2003;138:743-746.
- ⁸² American College of Obstetricians and Gynecologists (ACOG) Committee on Ethics (2003-2004). *Ethics in Obstetric and Gynecology* 2nd edition:67-69.
- ⁸³ Fine RL. Mayo TW. Resolution of futility by due process: early experience with the Texas Advance Directives Act. *Annals of Internal Medicine* 2003;138:743-746.
- ⁸⁴ Loewy EH. Terminal sedation, self-starvation, and orchestrating the end of life. *Archives of Internal Medicine*, 2001; 161(3):329-332.
- ⁸⁵ Loewy EH. Terminal sedation, self-starvation, and orchestrating the end of life. *Archives of Internal Medicine*, 2001; 161(3):329-332.
- ⁸⁶ Valko NG. Sedated to Death? When “comfort care” becomes dangerous. *Women for Faith & Family*, Volume XVII, No. 2. Available online at <http://www.wf-f.org/02-2-terminalsedation.html>. Accessed 11/9/04.

-
- ⁸⁷ Thompson TD. Barbour RS. Schwartz L. Health professionals' views on advance directives: A qualitative interdisciplinary study. *Palliative Medicine*, 2003; 17(5):403-409.
- ⁸⁸ Winick BJ. Foreword: Planning for the future through advance directive instruments. *Psychology, Public Policy, & Law*, 1998; 4(3):579-609.
- ⁸⁹ Hickey DP. The disutility of advance directives: We know the problems, but are there solutions? *Journal of Health Law*, 2003; 36(3):455-473.
- ⁹⁰ Hickey DP. The disutility of advance directives: We know the problems, but are there solutions? *Journal of Health Law*, 2003; 36(3):455-473.
- ⁹¹ Hickey DP. The disutility of advance directives: We know the problems, but are there solutions? *Journal of Health Law*, 2003; 36(3):455-473.
- ⁹² U.S. Government Printing Office website. Patient Self-Determination Act: Providers Offer Information on Advance Directives but Effectiveness Uncertain. Letter Report, 09/01/95, GAO/HEHS-95-135 <http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=gao&docid=f:he95135.txt>. Accessed 3/17/04.
- ⁹³ Stein J. The ethics of advance directives: a rehabilitation perspective. *American Journal of Physical Medicine & Rehabilitation*, 2003; 82(2):152-157.
- ⁹⁴ Thompson TD. Barbour RS. Schwartz L. Health professionals' views on advance directives: a qualitative interdisciplinary study. *Palliative Medicine*, 2003; 17(5):403-409.
- ⁹⁵ The Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state— first of two parts. *New England Journal of Medicine*, 1994; 330:1499-1508.
- ⁹⁶ 70 N.J. 10: *In the Matter of Karen Quinlan, an Alleged Incompetent. Killing and Letting Die* 2nd Edition. Ed. Steinbock B Norcross A. New York: Fordham University Press, 1994.
- ⁹⁷ *Cruzan V. Director Missouri Department of Health. Killing and Letting Die* 2nd Edition. Ed. Steinbock B Norcross A. New York: Fordham University Press, 1994.
- ⁹⁸ Uelmen GF. Mortal decisions: who decides? *Issues in Ethics* 4 (2) Fall 1991. Published by Markkula Center for Applied Ethics—Santa Clara University. On the Internet at <http://www.scu.edu/ethics/publications/iie/v4n2/homepage.html>. Accessed 10/7/04.
- ⁹⁹ Uelmen GF. Mortal decisions: who decides? *Issues in Ethics* 4 (2) Fall 1991. Published by Markkula Center for Applied Ethics—Santa Clara University. On the Internet at <http://www.scu.edu/ethics/publications/iie/v4n2/homepage.html>. Accessed 10/7/04.
- ¹⁰⁰ Steinbock B. Introduction. *Killing and Letting Die* 2nd Edition. Ed. Steinbock B Norcross A. New York: Fordham University Press, 1994.
- ¹⁰¹ Coughenower M. Physician-assisted suicide. *Gastroenterology Nursing* 26 (2) March/April 2004. 55-59.
- ¹⁰² Singer P. Voluntary euthanasia: a utilitarian perspective. *Bioethics* 17 (5-6) 2003. 526-541.
- ¹⁰³ Brock DW. Death and dying: euthanasia and sustaining life. *Encyclopedia of Bioethics*. New York: Simon & Shuster Macmillan, 1995.

-
- ¹⁰⁴ Brock DW. Death and dying: euthanasia and sustaining life. *Encyclopedia of Bioethics*. New York: Simon & Shuster Macmillan, 1995.
- ¹⁰⁵ Brock DW. Death and dying: euthanasia and sustaining life. *Encyclopedia of Bioethics*. New York: Simon & Shuster Macmillan, 1995.
- ¹⁰⁶ Brock DW. Death and dying: euthanasia and sustaining life. *Encyclopedia of Bioethics*. New York: Simon & Shuster Macmillan, 1995.
- ¹⁰⁷ Brock DW. Death and dying: euthanasia and sustaining life. *Encyclopedia of Bioethics*. New York: Simon & Shuster Macmillan, 1995.
- ¹⁰⁸ Fernandes AK. Euthanasia, assisted suicide, and the philosophical anthropology of Karol Wojtyla. *Christian Bioethics*, 2001; 7(3):379-402.
- ¹⁰⁹ Fernandes AK. Euthanasia, assisted suicide, and the philosophical anthropology of Karol Wojtyla. *Christian Bioethics*, 2001; 7(3):379-402.
- ¹¹⁰ Coughenower M. Physician-assisted suicide. *Gastroenterology Nursing*, 26(2):55-59.
- ¹¹¹ Fernandes AK. Euthanasia, assisted suicide, and the philosophical anthropology of Karol Wojtyla. *Christian Bioethics*, 2001; 7(3):379-402.
- ¹¹² Coughenower M. Physician-assisted suicide. *Gastroenterology Nursing*, 26(2):55-59.
- ¹¹³ O'Brien CN, Madek GA, Ferrera GR. Oregon's guidelines for physician-assisted suicide: A legal and ethical analysis. *University of Pittsburgh Law Review*, 2000; 61(2):329-365.
- ¹¹⁴ Burt RA. The Supreme Court speaks – not assisted suicide but a constitutional right to palliative care. *The New England Journal of Medicine*, 1997; 337:1234-1236.
- ¹¹⁵ Committee on Care at the End of Life. *Legal Issues—Approaching Death: Improving Care at the End of Life*. Ed. Field MJ Cassel CK. Washington, D.C.: National Academy Press, 1997.
- ¹¹⁶ Snyder L Sulmasy DP. Physician-assisted suicide: position paper. *Annals of Internal Medicine*, 2001; 135(3):209-216.
- ¹¹⁷ Van Hooft S. Pain and communication. *Medicine, Health Care & Philosophy*, 2003; 6 (3):255-262.
- ¹¹⁸ Videen, SD. Let me die laughing. *Supportive Voice*, Summer 1999, 5 (3) 9-11, 18. Published on the internet by Supportive Care of the Dying at <http://www.careofdying.org/SV/PUBSART.ASP?ISSUE=SV99SU&ARTICLE=I>. Accessed 10/7/04.
- ¹¹⁹ Becker R. Teaching communication with the dying across cultural boundaries. *British Journal of Nursing*, 1999, 8 (14): 938-942.
- ¹²⁰ Wenrich MD, Curtis JR, Shannon SE, et al. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. *Archives of Internal Medicine*, March 26, 2001;161(6): 868-874. Available for a fee on the internet at <http://archinte.ama-assn.org/cgi/content/full/161/6/868>. Accessed 10/7/04.
- ¹²¹ Towers A, MacDonald N, Wallace E. Ethical issues in palliative care: views of patients, families, and nonphysician staff. *Canadian Family Physician*, 2003; 49:1626-1631.

-
- ¹²² Anonymous. Ethical and Legal Issues. In: Field MJ, Berman RE, eds. *Institute of Medicine. When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: The National Academies Press, 2003.
- ¹²³ Freyer DR. Care of the dying adolescent: special considerations. *Pediatrics* 113 (2) February 2004:381-388.
- ¹²⁴ Anonymous. Ethical and Legal Issues. In: Field MJ, Berman RE, eds. *Institute of Medicine. When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: The National Academies Press, 2003.
- ¹²⁵ Freyer, DR. Care of the dying adolescent: special considerations. *Pediatrics* 113 (2) February 2004:381-388.
- ¹²⁶ Anonymous. Ethical and Legal Issues. In: Field MJ, Berman RE, eds. *Institute of Medicine. When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: The National Academies Press, 2003.
- ¹²⁷ Stevens, MM. Family Adjustment and Support. In: Doyle D, Hanks GWC, Macdonald N, eds. *Oxford Textbook of Palliative Medicine*. Oxford University Press, 1993: 707-717.
- ¹²⁸ Anonymous. Ethical and Legal Issues. In: Field MJ, Berman RE, eds. *Institute of Medicine. When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: The National Academies Press, 2003.
- ¹²⁹ Anonymous. Ethical and Legal Issues. In: Field MJ, Berman RE, eds. *Institute of Medicine. When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: The National Academies Press, 2003.
- ¹³⁰ Anonymous. Ethical and Legal Issues. In: Field MJ, Berman RE, eds. *Institute of Medicine. When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: The National Academies Press, 2003.
- ¹³¹ Freyer, DR. Care of the dying adolescent: special considerations. *Pediatrics* 113 (2) February 2004:381-388.
- ¹³² Lee S, Kristjanson L. Human research ethics committees: issues in palliative care research. *International Journal of Palliative Care Nursing*, 2003; 9(1):13-18.
- ¹³³ Lee S, Kristjanson L. Human research ethics committees: issues in palliative care research. *International Journal of Palliative Care Nursing*, 2003; 9(1):13-18.
- ¹³⁴ Jubb, AM. Palliative care research: trading ethics for an evidence base. *Journal of Medical Ethics*, 2002; 28(6):342-346.
- ¹³⁵ Casarett DJ, Knebel A, Helmers K. Ethical challenges of palliative care research. *Journal of Pain and Symptom Management*, 2003; 25(4):S3-5.
- ¹³⁶ Agrawal M. Voluntariness in clinical research at the end of life. *Journal of Pain and Symptom Management*, 2003; 25(4):S25-32.

-
- ¹³⁷ Lee S, Kristjanson L. Human research ethics committees: issues in palliative care research. *International Journal of Palliative Nursing*, 2003; 9(1):13-18.
- ¹³⁸ Jubb, AM. Palliative care research: trading ethics for an evidence base. *Journal of Medical Ethics*, 2002; 28(6):342-346.
- ¹³⁹ Jubb, AM. Palliative care research: trading ethics for an evidence base. *Journal of Medical Ethics*, 2002; 28(6):342-346.
- ¹⁴⁰ Jubb, AM. Palliative care research: trading ethics for an evidence base. *Journal of Medical Ethics*, 2002; 28(6):342-346.
- ¹⁴¹ MedicineNet.com website. <http://www.medicinenet.com/Autopsy/article.htm>. Accessed 3/24/04.
- ¹⁴² Pellegrino, ED. The autopsy: some ethical reflections on the obligations of pathologists, hospitals, families, and society. *Archives of Pathology & Laboratory Medicine*, 1996; 120(8):739-742.
- ¹⁴³ American Medical Association. Autopsy: Life's Final Chapter. On the internet at http://www.medem.com/MedLB/article_detailb.cfm?article_ID=ZZZPIEJD81D&sub_cat=385. Accessed 10/7/04.
- ¹⁴⁴ Council on Ethical and Judicial Affairs of the American Medical Association. Performing procedures on the newly deceased. *Academic Medicine*, 2002; 77(12 Pt. 1):1212-1216.
- ¹⁴⁵ Haas F. Bereavement care: seeing the body. *Nursing Standard*, 2003; 17(28):33-37.
- ¹⁴⁶ Holland JC. Management of grief and loss: medicine's obligation and challenge. *Journal of the American Medical Women's Association*, 2002; 57(2):95-96.
- ¹⁴⁷ Kahn JP. Forced Fatherhood. CNN ethicsmatters. 1999. Available online at <http://www.cnn.com/HEALTH/bioethics/9904/postmortem.sperm/template.html>. Accessed 11/9/04.
- ¹⁴⁸ Moore, Rick. Sleeping (and dying) on Minnesota streets UMNnews, reprinted from *M, Spring, 2004*. On the internet at http://www1.umn.edu/umnnews/Feature_Stories/Sleeping_and_dying_on_Minnesota_streets.html. Accessed 10/7/04.
- ¹⁴⁹ Wilder Research Center. *Homeless in Minnesota 2003*. February 2004 . Available online at <http://www.wilder.org/research/reports/pdf/Homeless2003.pdf>. Accessed 11/9/04.
- ¹⁵⁰ Barrow SM, Herman DB, Cordova P, et al. Mortality among homeless shelter residents in New York City. *American Journal of Public Health*, 1999;89 (4):529-534.
- ¹⁵¹ Cheung AM, Hwang SW. Risk of death among homeless women: a cohort study and review of the literature. *CMAJ* 170 (8). On the internet at <http://www.cmaj.ca/cgi/content/full/170/8/1243>. Accessed 10/7/04.
- ¹⁵² Ratner E, Bartels D, Song J. A Perspective on Homelessness, Ethics, and Medical Care. *Minnesota Medicine*, June 2004/Volume 87. On the internet at <http://www.mmaonline.net/publications/MNMed2004/June/Ratner.html>. Accessed 10/7/04.

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