Aid in Dying: Personal, Professional and Agency Responsibilities

Carol Taylor, PhD, RN

For many years, professional caregivers knew exactly how to respond when a patient expressed suicidal ideation. We “knew that healthy minds didn’t choose to end life and our responsibility was to prevent suicide, so we placed these individuals on suicide precautions.” Today, many accept the concept of rational suicide as an autonomous choice, opening the question of what our roles should be if someone chooses to end life sooner rather than later. This question is vitally important for palliative caregivers given the hospice philosophy to do nothing to hasten or postpone dying.

Questions for Reflection and Discussion

1. If a patient appropriately expresses the wish to commit suicide, what are our personal, professional, and agency obligations? Select all that apply.
   a. Compassionately counsel them about choosing to live and initiate suicide precautions.
   b. Share this information with the team—even if the patient requests that this be kept confidential.
   c. Ask them to talk more about why they are feeling this way... Use nondirective counseling to help them clarify what they want to do.
   d. Counsel them about safe, effective, legal ways to achieve their goal. Become the patient’s advocate.
   e. Develop and implement a plan of care that honors the patient’s wishes.

2. Many consider suicide to be a private decision. Is suicide ever private? What is the impact of a patient’s successful suicide on family and staff?
3. How confident are we that we can distinguish a rational suicide from a mental health crisis?
4. How confident are we that we are meeting the physical, psychological, social and spiritual needs of patients? If unmet patient needs are prompting the request to die sooner rather than later what are our responsibilities?
5. How can professional caregivers better respond to attempted and successful suicide attempts? What strategies will best meet the needs of families and staff?
6. A New York Times article on April 22, 2016, reported that the U.S. suicide rate surged to a 30-year high, with increases in every age group except older adults. The rise was particularly steep for women. It was also substantial among middle-aged Americans, sending a signal of deep anguish from a group whose suicide rates had been stable or falling since the 1950s. Causative factors linked to the increase in suicides include: economic recession, more drug addiction, “gray divorce,” increased social isolation, and the rise of the Internet and social media. What are our obligations to prevent suicide?
7. How should one respond if one’s personal beliefs about suicide differ from that of a patient or from an agency’s philosophy/policies?
8. What about voluntarily stopping to eat and drink? Is this suicide? Am I obligated to mention this as an option to patients wanting to die? If I recommend this, or even tacitly allow it, am I participating in a suicide?
9. Is there an ethical difference between attempting suicide with a gun, an overdose of liquid morphine, or stopping eating and drinking?
10. Should agencies be more careful about limiting a patient’s access (or a family member’s access) to liquid morphine or other medications if we suspect they are stock-piling medications to cause the patient’s death?

11. What about palliative sedation to unconsciousness? If someone wants to go to sleep and never wake up, is this an option? Are policies which require that the patient be imminently dying and which exclude emotional angst or existential suffering as criteria, appropriate? Since individuals choosing this will die if we do not feed them, is this the back door to euthanasia?


BIOETHICAL CHALLENGES AT THE END OF LIFE
How Who We Are and What We Believe Influence Treatment Options and Counseling for the Seriously Ill and Dying
Carol Taylor, PhD, RN

New technologies and fundamental changes in the way we perceive basic human realities, fertility, conception and birth, aging, death and dying, are dramatically altering the way we are born, live and die. In this exercise, participants will explore some of the ethical issues surrounding these changes at the end of life. Participants will critique new scientific advances, the changing culture of health care, and public policy proposals in light of their potential to influence human wellbeing. The primary objective of this exercise is to clarify personal beliefs, what informs these beliefs, and how these beliefs will affect clinical conversations and actions.

And now, weak, short of breath, my once-firm muscles melted away by cancer, I find my thoughts, increasingly, not on the supernatural or spiritual, but on what is meant by living a good and worthwhile life — achieving a sense of peace within oneself. I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one's life as well, when one can feel that one's work is done, and one may, in good conscience, rest. [Sacks, O. (August 14, 2015). Oliver Sacks: Sabbath. Sunday Review, New York Times.]

TheClinician’s Role and Integrity when Counseling Persons Struggling with Life Limiting Diagnoses

The 1983 President’s Commission Report on Health Care Decision Making recommended the model of shared decision making over the Hippocratic/paternalistic model and the patient sovereignty model. In recent years major forces in the U.S., including the current HCAHPS patient satisfaction scores, have resulted in many clinicians abdicating their role in treatment decisions and capitulating to patient preferences/demands. Too often these choices result from deficient knowledge, unrealistic expectations, fears, etc.

Recently several very public figures have engaged media attention by sharing their preferences about how to confront aging, serious illness, and anticipated death. Given the moral heterogeneity in the U.S. and the lack of consensus about the role aging, suffering, illness, dying and death play for humans: evils to be avoided at all costs, necessary evils to be suffered stoically, or paths to our transformation and flourishing, what guidance can/should any clinician, ethicist or sage offer?

We share the following questions for your reflection and discourse.

1. In his new book, The Road to Character (2015), David Brooks focuses on the deeper values that should inform our lives. Responding to what he calls the culture of the Big Me, which emphasized external success, Brooks challenges us, and himself, to rebalance the scales between our “resume virtues”—achieving wealth, fame, and status—and our “eulogy virtues,” those that exist at the core of
our being: kindness, bravery, honesty, or faithfulness, focusing on what kind of relationships we have formed. What role can the challenges of aging, suffering, illness, dying and death play in our lives? Are they necessarily evils to be avoided at all costs? Might they be invitations/opportunities to focus on what really matters and to cultivate the virtues that give meaning and purpose to our lives? If Brittany Maynard was your patient and she confided to you that she planned to move to Oregon so that she could die on her terms, how would you respond?

2. Have we each clarified our beliefs about what is ethically permissible when aging, suffering, illness, dying and death make lives unbearable? Do religious beliefs inform our judgments and if yes, how? Is assisting with suicide or euthanasia compatible with the roles of medicine and nursing? Should our faith beliefs conflict with our understanding of our clinical responsibilities, what trumps? Our religious or professional obligations? How should we negotiate conflicts of commitment?

3. Do health care professionals working with individuals experiencing aging, suffering, illness, dying and death have an obligation to “journey” with them as experienced and wise guides? Is it ever appropriate to make a recommendation or to challenge an expressed preference? Is it obligatory to do so? Do any of us believe we are qualified to be “wise guides?” Should we be?

4. What role do/should clinical ethicists play in informing conversations and decisions about treatment and care for those experiencing aging, illness, suffering, dying and death? Is “value neutrality” possible? Do you believe nondirective counseling is always the right choice?

5. Given the coming silver tsunami (mass geriatric society) these questions assume a special urgency. Is there a better way to think about aging and death than enemies to be conquered? [Think war on aging and death...] When we think about human flourishing... what do we do with the assaults related to aging, illness and death? Recently someone suggested that we give cyanide capsules to everyone newly diagnosed with dementia to be used when life is no longer deemed worthy of living. "No one wants to live that way." We live in a society that hardly reveres its elders. Should we/must we be part of challenging what we message to older and seriously ill brothers and sisters?

Codes

It is understandable, though tragic, that some patients in extreme duress--such as those suffering from a terminal, painful, debilitating illness--may come to
decide that death is preferable to life. However, allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.


The nurse should provide interventions to relieve pain and other symptoms in the dying patient consistent with palliative care practice standards and may not act with the sole intent to end life. Provision 1.4, p. 3


**Recommended Readings/Viewings**


  That’s how long I want to live: 75 years.
  I am sure of my position. Doubtless, death is a loss. It deprives us of experiences and milestones, of time spent with our spouse and children. In short, it deprives us of all the things we value. But here is a simple truth that many of us seem to resist: living too long is also a loss. It renders many of us, if not disabled, then faltering and declining, a state that may not be worse than death but is nonetheless deprived. It robs us of our creativity and ability to contribute to work, society, the world. It transforms how people experience us, relate to us, and, most important, remember us. We are no longer remembered as vibrant and engaged but as feeble, ineffectual, even pathetic. [Emanuel, E.J. October 2014. *The Atlantic Monthly*. Why I hope to die at 75].


  Kalanithi’s diagnosis is both a death sentence and an opportunity—albeit an unwanted one—for the kind of introspection that many of us claim to want but that never seems possible unless forced by tragedy.
  His decision to go to medical school, he writes, was an effort “to forge relationships with the suffering, and to keep following the question of what makes human life meaningful, even in the face of death and decay.” Krug, N. January 9, 2016. An affirmation of life in the face of death. *Book World. The Washington Post*, C1, 4.

In April, I learned that not only had my tumor come back, but it was more aggressive. Doctors gave me a prognosis of six months to live. After months of research, my family and I reached a heartbreaking conclusion: There is no treatment that would save my life, and the recommended treatments would have destroyed the time I had left.

I considered passing away in hospice care at my San Francisco Bay-area home. But even with palliative medication, I could develop potentially morphine-resistant pain and suffer personality changes and verbal, cognitive and motor loss of virtually any kind. Because the rest of my body is young and healthy, I am likely to physically hang on for a long time even though cancer is eating my mind. I probably would have suffered in hospice care for weeks or even months. And my family would have had to watch that.

I did not want this nightmare scenario for my family, so I started researching death with dignity. It is an end-of-life option for mentally competent, terminally ill patients with a prognosis of six months or less to live. It would enable me to use the medical practice of aid in dying: I could request and receive a prescription from a physician for medication that I could self-ingest to end my dying process if it becomes unbearable.

I quickly decided that death with dignity was the best option for me and my family. [Maynard, B. November 2, 2014. My right to death with dignity. http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html]


“I am now face to face with dying but I am not finished with living.”

It is up to me now to choose how to live out the months that remain to me. I have to live in the richest, deepest, most productive way I can. I feel intensely alive, and I want and hope in the time that remains to deepen my friendships, to say farewell to those I love, to write more, to travel if I have the strength, to achieve new levels of understanding and insight. I cannot pretend I am without fear. But my predominant feeling is one of gratitude. I have loved and been loved; I have been given much and I have given something in return; I have read and traveled and thought and written. I have had an intercourse with the world, the special intercourse of writers and readers. Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure. [Sacks, O. February 19, 2015. My Own Life. *The New York Times*]

And now, weak, short of breath, my once-firm muscles melted away by cancer, I find my thoughts, increasingly, not on the supernatural or spiritual, but on what is meant by living a good and worthwhile life — achieving a sense of peace within oneself. I find my thoughts drifting to the Sabbath, the day of rest, the seventh day of the week, and perhaps the seventh day of one’s life as well, when one can feel that one’s work is done, and one may, in good conscience, rest. [Sacks, O. (August 14, 2015). Oliver Sacks: Sabbath. Sunday Review, *New York Times*]

• 24 & ready to die. Economist Films. YouTube: https://www.youtube.com/watch?v=SWWkUzkfJ4M
24 & Ready to Die: Using Emily’s Narrative to Reflect about the Ethics of Allowing Euthanasia for Patients Who Suffer from Severe and Incurable Distress, including Psychological Disorders

In November 2015, the Economist invited subscribers to visit their film site to watch “24 & Ready to Die,” a narrative about Emily, a young woman who found life unbearable and requested assisted dying under Belgium’s euthanasia law. See: https://www.youtube.com/watch?v=SWWkUzkfJ4M

The release of this narrative followed an influential article in The New Yorker entitled “The Death Treatment” by Rachel Aviv (June 22, 2015) critiquing euthanasia as a “treatment” for incurable psychological suffering. See: http://www.newyorker.com/magazine/2015/06/22/the-death-treatment

While many are adamantly against any physician involvement in suicide or euthanasia and others adamant proponents of the same, some of us are unsure of what we ought to think and believe about these as options in a moral society, about what role physicians and other clinicians should play in counseling and assisting, and about what the criteria should be, including whether or not incurable psychological suffering is sufficient ground for a request to end one’s life. This session explores how ethicists might best use a film like “24 & Ready to Die” to invite moral reflection and discourse about these topics.

Discussion Questions

• Should Assisted Suicide and Euthanasia be allowed for patients who suffer from severe and incurable distress, including psychological disorders?
• In what way, if any, should clinicians’ beliefs about assisted dying inform what they say or don’t say when counseling patients who want to control how and when they die?
• What value does a film like “24 & Ready to Die” have in educating the public about assisted suicide and euthanasia?

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A bill introduced in Canada, April 14, 2016, would allow doctors to prescribe life-ending medication to Canadians who have an illness that causes “enduring physical or psychological suffering that is intolerable to them” and whose “natural death has become reasonably foreseen.” Two doctors must approve each request and the patient must wait for 15 days before it can be
fulfilled. …Some European countries, like Switzerland and Belgium, allow aid in dying for people who are not terminally ill. Critics of the Canadian proposal argue that Canada should also allow people who are suffering with no prospect of relief to end their lives, even if they do not have a terminal condition. New York Times Editorial, April 24, 2016.

Should Aid-in-Dying be allowed for people who are not terminally ill?

What are the attending physician’s duties and responsibilities under the Washington Death with Dignity Act?
http://depts.washington.edu/bioethx/topics/pad.html

1. Confirm the following eligibility criteria:
   o Washington State resident
   o Age 18 and older
   o Competent (able to make and communicate an informed decision to health care providers)
   o Terminally ill (incurable, irreversible disease expected to cause death within six months, as determined by the attending physician and a consulting physician)
   o Able to voluntarily express his or her wish to die

2. Assure that it is an informed decision, which means the patient has an appreciation of the relevant facts, after being fully informed about the following:
   o Medical diagnosis
   o Prognosis
   o Potential risks associated with taking the prescribed medication
   o Probable result of taking the prescribed medication
   o Feasible alternatives including, but not limited to, comfort care, hospice care, and pain control

3. Evaluate the patient's request:
   o Assess reasons,
   o Explore and recommend alternatives (palliative care, hospice, pain/symptom management, psychosocial and/or spiritual counseling, palliative sedation).

4. Counsel patient about the following:
   o Opportunities to rescind request at any time.
   o Recommend notifying next of kin.
   o Importance of having another person present and not taking medications in a public place.
5. Refer to a consulting physician, who reviews the medical record and interviews the patient to confirm the diagnosis, and confirm that the patient is competent and is making a voluntary request.

6. Refer to a counselor if concerned about a psychiatric or psychological disorder or depression causing impaired judgment.

7. Work with pharmacists to prescribe/get medications.

8. Document all steps in the medical record.

   - List the underlying terminal disease as the cause of death.

10. Send a copy of the dispensing record to DOH within 30 days.


Provision 1.4 the right to self-determination

..Patients have the moral and legal right to be given accurate, complete, and understandable information in a manner that facilitates an informed decision; and to be assisted with weighing the benefits, burdens, and available options in their treatment, including the option of no treatment. They also have the right to accept, refuse, or terminate treatment without deceit, undue influence, duress, coercion, or prejudice, and to be given necessary support throughout the decision making and treatment process.

..The importance of carefully considered decisions regarding resuscitation status, withholding and withdrawing life-sustaining therapies, foregoing nutrition and hydration, palliative care and advance directives is widely recognized. Nurses assist patients as necessary with these decisions. Nurses should promote advance care
planning conversations and must be knowledgeable about the benefits and limitations of various advance directive documents. The nurse should provide interventions to relieve pain and other symptoms in the dying patient consistent with palliative care practice standards and may not act with the sole intent to end life. ...
Providing good care for dying patients requires that physicians be knowledgeable of ethical issues pertinent to end-of-life care. Effective advance care planning can assure patient autonomy at the end of life even when the patient has lost decision-making capacity. Medical futility is difficult to identify in the clinical setting but may be described as an intervention that will not allow the intended goal of therapy to be achieved. Medical interventions, including artificial nutrition and hydration, can be withheld or withdrawn if this measure is consistent with the dying patient’s wishes. Physicians caring for terminally ill patients receive requests for physician-assisted suicide. The physician should establish the basis for the request and work with the healthcare team to provide support and comfort for the patient. Physician-assisted suicide could negate the traditional patient-physician relationship and place vulnerable populations at risk. Physicians need to incorporate spiritual issues into the management of patients at the end of life. The integrity of the physician as a moral agent in the clinical setting needs to be recognized and honored. The physician has a moral imperative to assure good care for dying patients.

(Key words: end-of-life care, ethics, palliative medicine, advance care planning)

Physicians and other healthcare professionals providing care for dying patients will confront many ethical dilemmas and challenges. Providing good care to dying patients requires physicians to be knowledgeable of potential ethical dilemmas and be aware of strategies and interventions aimed at avoiding conflict. It is important for the physician to be proactive with regard to decision making and have good communication skills. Keeping the patient central in all decision making, that is, respecting patient autonomy, is essential to ethical care for dying patients. Thus, the role of advance care planning is important in caring for patients at the end of life. The physician needs to have a good understanding of ethical principles and issues such as medical futility and the withdrawing and withholding of medical interventions as well as the legal ramifications of these ethical issues. With the growing attention on physician-assisted suicide and euthanasia, physicians need not only to be knowledgeable of the ethical, legal, and professional ramifications of these issues, but also to have a clear understanding of their own beliefs on this and other ethical issues at the end of life.

Good care for dying patients also encompasses attention to spiritual issues at the end of life. Therefore, physicians need to be comfortable with their role regarding end-of-life care and spirituality. It is important that physicians have an understanding of the ethical principles that underlie biomedical ethics and how they relate to providing care for dying patients. Providing good care to dying patients is an ethical mandate inherent in the very nature of the physician’s role. As indicated in the 18th Century by John Gregory, “It is as much the business of a physician to alleviate pain as to smooth the avenues of death...as to cure disease.”

**Ethical Principles and End-of-Life Care**

An understanding of the principles that underlie biomedical ethics is important in addressing the issues that confront physicians and their patients at the end of life. The ethical principles include autonomy, beneficence, nonmaleficence, justice, and fidelity (Figure 1).

If one of the ethical principles could be viewed as central to ethical decision making, autonomy would meet that description. Autonomy calls for the patient to be the decision maker, that is, having the right to self-determination. This principle calls for physicians to preserve a patient’s right to self-determination even when the patient has lost decision-making capacity. This preservation can be achieved through the appropriate use of advance directives. Because of the difficulty physicians and patients have in discussing end-of-life issues, physicians frequently resort to caregivers to make decisions in lieu of the patient. This action may be a violation of the principle of autonomy if the patient still has decisional capacity and has not authorized a surrogate decisionmaker, or if the patient no longer has decisional capacity and the decision maker was not designated by the patient or is unaware of the patient’s wishes.

The ethical principle of beneficence calls for the physician to advocate for what is good or beneficial for the patient. Fre-
Cavalieri • Ethical Issues at the End of Life

Consequently, patients’ choices regarding end-of-life decisions have not been expressed through advance care planning and caregivers who are knowledgeable of the patient’s wishes may be absent. In this case, the physician’s role for the dying patient must always be to advocate for approaches that promote good care for the patient at the end of life. The physician needs to be careful that patient autonomy must not be violated in an attempt to do what the physician views is in the patient’s best interest. The patient’s desire to choose an option should be respected even if the physician views the option as not in the patient’s best interest. Thus, patient autonomy should prevail over paternalism.1

The principle of nonmaleficence calls for the physician not to inflict harm intentionally. This principle relates to a basic maxim in good medical care, Primum non nocere (“above all, do no harm”). Many physicians view participation in physician-assisted suicide as a violation of this principle.

Figure 1.
Physician-assisted suicide as a violation of this principle.\textsuperscript{4,5} This position is reflected in the Osteopathic Oath required of all graduates of colleges of osteopathic medicine, which states “I will give no drug for deadly purposes to any person though it may be asked of me.”

The ethical principle of justice demands fairness in the delivery of healthcare. It may apply on a societal level by assuring a just distribution of healthcare resources, or it may apply to an individual patient by assuring fair treatment to that patient at the end of life. In either case, physicians have an ethical obligation to advocate for fair and appropriate treatment of patients at the end of life.

The last ethical principle, fidelity, requires the physician to be faithful and truthful to the dying patient. The physician should provide ongoing information about the patient’s condition when appropriate. Also, the physician needs to be truthful in issues such as diagnosis and prognosis and be faithful in defending the choices and decisions of the patient even when the patient can no longer speak for himself or herself. This defense, of course assumes that the patient’s request not violate the physician’s own moral code or values.\textsuperscript{1}

**Advance Care Planning**

Effective advance care planning is important in providing good care at the end of life because it enhances a discussion of end-of-life issues between the patient, physician, and caregivers. Perhaps even more important, it provides the mechanism to honor the patient’s wishes even at a time when the patient may lack decision-making capacity. Therefore, effective advance care planning can promote patient autonomy.\textsuperscript{3}

The Patient Self-Determination Act passed by the US Congress in 1990 has had a significant impact in bringing attention to advance care planning through the use of advance directives. As part of the Omnibus Budget Reconciliation Act, this act requires institutions receiving Medicare and Medicaid reimbursement to inform patients about the use of advance directives. Whether the Patient Self-Determination Act has been successful in promoting advance care planning is a question that is still uncertain; however, it clearly has introduced this important subject regarding end-of-life care. Many believe that advance care planning can be most effective when not linked to an institutional setting but when it is part of the important dialogue between patients and their primary care physicians in the community setting.\textsuperscript{6}

Discussions regarding the patient’s wishes for care at the end of life are critical for advance care planning. Advance care planning can prevent confusion and conflict when end-of-life decisions need to be made. Without effective advance care planning, the physician is at risk of providing interventions that the patient may not have wanted. Alternatively, the physician may end up in the middle of conflict between the patient’s caregivers. Advance care planning can be achieved through appropriate use of advance directives. Advance directives may be in the form of oral statements by the patient, through a living will, or by the identification of a surrogate proxy decision maker. Oral statements regarding end-of-life care consist of an expression of the patient’s wishes for care at the end-of-life. It is important that oral statements be carefully documented in the patient’s medical record. The living will, or instruction directive, is a written document that identifies the patient’s wishes for end-of-life care. Both oral statements and the living will may include and address issues such as pain management, location for end-of-life care, acceptance or rejection of life-sustaining interventions, or even issues related to organ transplantation. One of the pitfalls to written communication of end-of-life care is the challenge of appropriate interpretation of the patient’s wishes. The identification of a surrogate or proxy decision maker calls for the patient to identify someone who can make decisions when the patient has lost decision-making capacity. This is referred to as the proxy directive. It is important for the proxy decision maker to be aware of the patient’s wishes regarding end-of-life care. Therefore, effective communication on end-of-life issues between patients and their proxy decision makers must be encouraged.\textsuperscript{5}

Variations exist among states regarding laws related to the requirements for advance directives. Physicians must therefore be aware of local legislation to assure the legal status of an advance directive. Physicians and their patients should review advance directives regularly, particularly as the end of life approaches. The discussion should also include proxy decision makers. It is generally recommended that advance care planning include all three forms of advance directives. Advance care planning will enable the patient’s values and goals to be identified and documented; it can build trust between the patient, physician, and caregiver; it will aid in preventing confusion and conflict in the future; and it can provide peace of mind for the patient. Many standardized advance care planning and advance directives are available to aid in effective planning. Standardized forms may emanate from state agencies, healthcare organizations, and advocacy or religious groups. Research is under way to identify the most effective format for advance care planning.\textsuperscript{8}

Effective advance care planning should include both patient and proxy education. The physician has a key role in carefully explaining the benefits and burdens of interventions near the end of life so that patients can make informed decisions regarding refusal or acceptance of these interventions. Common pitfalls related to advance care planning frequently result from the patient’s preferences being unclear; the proxy decision maker not being informed or educated regarding the patient’s preferences; and the failure of the advance care
planning discussions to include a broad array of issues frequently confronted at the end of life. Thus, conflicts may arise between the physician, other healthcare professionals, the proxy decision maker, and the family regarding the patient’s care at the end of life. This conflict often occurs after the patient has lost decision-making capacity and frequently involves the proxy decision maker. Ethics committees are often helpful in resolving disagreements. Effective advance care planning will often avoid such conflict.9

In addition to the role of advance care planning in clarifying healthcare issues at the end-of-life, advance care planning may also include issues such as financial and legal affairs, final gifts, and issues such as spirituality, autopsy, burial, memorial services, and guardianship. Effective advance care planning should involve input from other professionals such as social workers, attorneys, and the clergy. Advance care planning for patients at the end of life will not only uphold and support patient autonomy, but it also will promote the ethical principles of fidelity and beneficence by enabling the physician and proxy decision maker to honor and support the patient’s wishes and values at the end of life.1,9

Ethical Issues in End-of-Life Care
The management of patients at the end-of-life will involve several issues that can be challenging ethical dilemmas. These may include issues such as withdrawing and withholding of interventions, medical futility, and physician-assisted suicide.

Withdrawing and Withholding Interventions
The withdrawing and withholding of life-sustaining treatment in the management of patients at the end of life may be appropriate both medically and ethically. First, certain interventions may simply be medically futile, in which case there are no ethical, legal, or medical requirements to administer care that offers no benefit. Second, it is appropriate to withdraw and withhold treatment that is not wanted by the patient or the patient’s proxy decision maker. Physicians often have difficulty withdrawing interventions that have already been initiated. However, if an intervention can no longer achieve its intended goal or the patient no longer wants this specific intervention, the intervention should be withdrawn. Thus, from an ethical perspective, withholding and withdrawing treatment are moral equivalents.7,9

Although end-of-life care involves a team approach, the physician is the only member of the healthcare team who is authorized to write orders identifying interventions that are to be withheld or withdrawn. Therefore, it is important that physicians are knowledgeable about the principles of withdrawing and withholding interventions in caring for patients near the end-of-life. Unfortunately, a recent study demonstrated that the majority of patients in the intensive care unit setting die without attention to their wishes regarding life-sustaining treatment. Often, invasive medical interventions are administered against the previously stated wishes of these patients.6

The decision to withdraw or withhold cardiopulmonary resuscitation, elective intubation and mechanical ventilation, and artificial nutrition and hydration are issues frequently encountered in the management of patients near the end of life. However, other interventions that may be withdrawn or withheld could include surgery, dialysis, antibiotics, diagnostic tests, medications, or admissions to acute care facilities. A decision to withhold or withdraw a specific medical intervention is based on whether that intervention is able to achieve a goal established by the physician, the patient, and the proxy decision maker. From a medical perspective, the goal must be reasonably achievable and realistic. It is acceptable to agree to a specific intervention that is time limited and withdraw that intervention if the goal has not been achieved within the time specifications. For example, a time-limited use of mechanical ventilation may be appropriate if its benefits could not be achieved in a specified time.9

The decision to withdraw ventilator care may be challenging for the physician, the patient, and the proxy decision maker. Once the goal for artificial ventilation can no longer be achieved, it is ethically acceptable to withdraw ventilator care as long as this is consistent with the patient’s wishes. Methods for immediate extubation or terminal weaning have been described, and management of symptoms with narcotic analgesics and anxiolytics are important for patient comfort post-extubation. Establishing the do-not-resuscitate (DNR) status of the patient at the end of life is important to avoid unnecessary and unwarranted cardiopulmonary resuscitation. However, it is important to assure the patient and the caregivers that all other interventions aimed at providing care and comfort at the end of life will continue.9

Withdrawing and withholding of artificial nutrition and hydration require special consideration. For many years, physicians and other healthcare professionals have viewed the provision of nutrition and hydration, even for the dying patient, as standard, obligatory care. However, both from an ethical and a legal perspective, artificial nutrition and hydration are viewed as any other medical intervention. The decision to withdraw or withhold them can be burdensome, particularly for families, as the provision of nutrition and hydration has traditionally been a symbol of caring. When artificial nutrition and hydration no longer can achieve the overall goals of care, they can be withheld or withdrawn based on the decision of the patient or proxy decision maker. It is important for the physician to reassure, counsel, and educate the patient and the patient’s proxy decision maker when confronted with this dilemma. Families need to understand that
signs and symptoms such as dry mouth can be effectively managed and that often the administration of fluids may actually exacerbate other symptoms at the end of life, such as shortness of breath or pain caused by edema.¹⁷

**Medical Futility**

The issue of medical futility is a clinical situation in medical ethics that may pose challenges in providing care at the end of life. Reference to an intervention as being medically futile is a common description; however, clear definitions of medical futility are still lacking and few clinical scenarios exist in which there may be uniform agreement that a specific intervention is medically futile. For example, most would agree that providing cardiopulmonary resuscitation to a patient who is determined to have brain death would be futile. In contrast, there would not be uniform agreement that the provision of artificial nutrition and hydration to a patient in a persistent vegetative state would be medically futile. Yet, either of these interventions may be considered medically futile, depending on one’s definition of medical futility. Thus, unequivocal cases of medical futility are not commonplace.¹¹

Although a precise definition of medical futility has been described as an intervention that is ineffective more than 99% of the time or an intervention that does not conform to accepted community standards, a more workable definition describes medical futility as an intervention that will not enable the achievement of the intended goal of the intervention. Thus, in this latter description of medical futility, an intervention is considered useless if it does not conform to the patient’s expressed wishes or advance directive if the patient has lost decision-making capacity.¹²

Conflicts regarding futility frequently arise when the dying patient has lost decision-making capacity and decisions about healthcare lie in the hands of the proxy decision maker. Conflicts may result because of the proxy decision maker’s misunderstanding of the prognosis, difference in values, or loss of trust in the healthcare system. Often, conflicts can be resolved through education, clarifying the goals and intent of the patient and by encouraging a team approach to decision making after involving clergy. The institutional ethics committee may be a valuable resource for conflict resolution. When a conflict cannot be resolved, a transfer of service may be indicated. On most occasions, effective advance care planning can avoid conflicts related to medical futility.⁹¹¹²

**Physician-Assisted Suicide**

Most physicians involved in end-of-life care have received requests for physician-assisted suicide. Physician-assisted suicide involves the physician’s providing the means to end the patient’s life, usually by prescribing a lethal dose of a sedative-hypnotic medication that the patient self-administers. In contrast, euthanasia involves the physician’s performing the intervention that takes the patient’s life. Currently, physician-assisted suicide in the United States is legal only in the state of Oregon. Although a slight majority of physicians oppose physician-assisted suicide, most physician professional organizations such as the American Osteopathic Association, American College of Osteopathic Internists, American Medical Association, and American Geriatrics Society have identified physician-assisted suicide as morally unacceptable and a violation of the patient-physician relationship.¹³¹⁴ Until recently, this relationship has not embraced the provision of a means for ending life. Many believe that acceptance of physician-assisted suicide will negate a societal commitment to hospice care and palliative medicine. Also, many indicate that abuse of vulnerable populations such as the elderly and disabled will occur.⁴

Patients may request physician-assisted suicide because of intractable pain, depression, fear of being a burden on their family, or fear of loss of their dignity. It is important that the physician identify the underlying cause of the patient’s suffering. Depression should be assessed and managed, and other professionals such as psychiatrists, psychologists, and the clergy should be engaged when appropriate. Patients should be reassured that physical symptoms such as pain can be effectively managed. Spiritual symptoms of guilt, loss of purpose in life, and abandonment often can be addressed by including the chaplain as part of the healthcare team. The physician should address common fears that the patient may exhibit which lead to the desire for physician-assisted suicide. It is important that the physician work as part of a healthcare team in addressing the varied etiologies that lead to a patient’s request for physician-assisted suicide. Through a team approach, nearly all the reasons for which patients may request physician-assisted suicide can be addressed effectively. It is important for the physician to provide support and a commitment to dying patients that they will not be abandoned and their symptoms will be managed throughout the dying process. Physicians must be cautious not to affirm the patient’s request for physician-assisted suicide as the request frequently emanates from the patient’s feelings of self-worthlessness. Therefore, the patient could interpret the physician’s affirmation as supporting that perception of self-worthlessness.⁹¹⁵¹⁶

A survey of osteopathic physicians conducted by my colleagues and me revealed that most opposed physician-assisted suicide (unpublished data). In fact, many cite the holistic and the mind-body-spirit approach to care that characterizes osteopathic medicine as being integral in shaping their view of the issue. Also, many osteopathic physicians indicated that the Osteopathic Oath that they took at graduation had an impact on their view opposing physician-assisted suicide.
RECOMMENDATIONS FOR ETHICAL CARE AT THE END OF LIFE

- Adhering to the dying patient’s right to self-determination (autonomy) is central to ethical care at the end of life.

- Advance care planning, through a living will and identification of a proxy decision maker, could enable the patient’s wishes to be upheld even when patient’s decision-making capacity has been lost.

- Conflict regarding end-of-life decisions can be avoided with effective advance care planning, proper education, and good communication between the physician, patient, and caregivers.

- Medical futility may be best described as an intervention that will not enable the achievement of the intended goals; therefore, futile interventions should be avoided in the care of dying patients.

- Withdrawing an initiated intervention has the same ethical significance as withholding an intervention that has not been initiated.

- The provision of artificial nutrition and hydration should be viewed as analogous to other medical interventions.

- Requests for physician-assisted suicide typically reflect an outcry for help resulting from an unidentified problem; the physician is in a key role to identify the issue and address the underlying needs of the patient.

- Effective management of pain at the end of life is a critical role of the physician; the principle of double effect allows for aggressive pain management even at risk of hastening the dying process.

- The physician is a moral agent who serves a major role in the ethical decision-making process; therefore, the physician’s values and ethical standards also need to be respected.

- The physician should recognize the importance of spiritual issues at the end of life, be aware of how to do a spiritual assessment, and facilitate available resources for the patient’s spiritual care.

- Because the inherent patient-physician relationship calls for physicians to provide care and comfort to their patients, physicians have an ethical obligation to assure the provision of good care for their dying patients.

Pain Management and the Principle of Double Effect

Traditionally, there has been reluctance on the part of physicians to use higher doses of narcotic analgesics in terminally ill patients because of a fear of causing death due to central nervous system depression. Some have viewed this administration of such medication as euthanasia. Data have indicated that this effect has largely been overstated. Nevertheless, even if administration of a narcotic analgesic may hasten the dying process in patients who are near death, as long as the prime intention of administering the narcotic analgesic is for the purpose of pain management and not the purposeful hastening of death, it is ethically acceptable to administer the analgesic. In this case, the ethical principle of the double effect allows for the unintended, secondary consequences—that is, the hastening of death—because of the good primary intention of the principle intervention—that is, pain management. One assumes that the patient or proxy decision maker is aware of the unintended consequences of aggressive pain management.1

The Ethical Integrity of the Physician

The physician’s role as a moral agent in medical ethics is frequently overlooked. Although few argue about the centrality of patient autonomy as it relates to ethical decision making, one cannot lose sight of the fact that the physician is an integral agent in moral acts that take place in healthcare. Therefore, physicians should not be compelled to violate ethical convictions or religious beliefs at the request of a patient or the patient’s caregiver. When a patient indicates requests or desires for interventions that may violate the physician’s own conscience or ethical standards, the physician should recognize and discuss these differences at the outset. When a patient and physician are at odds regarding proceeding with care that the patient requests, the patient should seek another healthcare provider and the physician should assist and support the transition.17

Spiritual Issues and End-of-Life Care

Physicians frequently hesitate to ask their patients questions about spiritual issues, yet spirituality may become central to a patient near the end of life. Spirituality may span affirmation of specific religious beliefs to simply making sense or identifying meaning in life. It has been recognized that patients at the end of life could experience significant spiritual growth. The physician should explore the patient’s past and current spiritual life, whether the patient would value a visit from a clergy person, and the importance of religious rituals to the patient. Physicians should be aware of how important religion may be to a specific patient, and physicians should facilitate available resources to aid their patients in spiritual care.18
Comments

Physicians, patients, and caregivers are confronted with many ethical dilemmas at the end of life. Many of these ethical dilemmas can be avoided with good dialogue between the patient, physician, and caregivers as well as effective advance care planning. The central role of patient self-determination, upholding the ethical principle of autonomy, is critical to good end-of-life care; however, the role of the physician as a moral agent must not be excluded. Withdrawing and withholding interventions at the end of life are morally equivalent and certainly acceptable when consistent with the patient’s values and goals. The ethical principle of the double effect provides a basis for appropriate pain management for patients at the end of life. Physician-assisted suicide will alter the integrity of the patient-physician relationship, which has been to care and comfort, not to take life. It is likely to diminish society’s resolve to provide good care for dying patients. Osteopathic physicians and other healthcare professionals should promote good care for dying patients as an alternative to the societal acceptance of physician-assisted suicide. Recommendations for ethical care at the end of life are presented in Figure 2.

References

Del Greenfield had endured repeated bouts of cancer over four decades, yet kept working as a peace activist in Portland, Ore., into her 80s. “She was a powerful force,” said her daughter, Bonnie Reagan.

But in 2007, Ms. Greenfield was struggling. She had been her husband’s caregiver until he died that year at 97, never telling her family she was feeling miserable herself. She’d lost much of her hearing. She required supplemental oxygen.

When she fell and broke an arm, “that was the final straw,” her daughter said. “She was a real doer, and she couldn’t function the way she wanted to. Life wasn’t joyful anymore.”

At 91, Ms. Greenfield told her family she was ready to die. She wanted a prescription for lethal drugs, and because she had active cancer, she might have obtained one under Oregon’s Death with Dignity statute for people with terminal illnesses.

Then her son-in-law, a family physician who had written such prescriptions for other patients, explained the somewhat involved process: oral and written requests, a waiting period, two physicians’ assent.
“I don’t have time for that,” Ms. Greenfield objected. “I’m just going to stop eating and drinking.”

In end-of-life circles, this option is called VSED (usually pronounced VEEsed), for voluntarily stopping eating and drinking. It causes death by dehydration, usually within seven to 14 days. To people with serious illnesses who want to hasten their deaths, a small but determined group, VSED can sound like a reasonable exit strategy.

Unlike aid with dying, now legal in five states, it doesn’t require governmental action or physicians’ authorization. Patients don’t need a terminal diagnosis, and they don’t have to prove mental capacity. They do need resolve.

“It’s for strong-willed, independent people with very supportive families,” said Dr. Timothy Quill, a veteran palliative care physician at the University of Rochester Medical Center.

He was speaking at a conference on VSED, billed as the nation’s first, at Seattle University School of Law this month. It drew about 220 participants — physicians and nurses, lawyers, bioethicists, academics of various stripes, theologians, hospice staff. (Disclosure: I was also a speaker, and received an honorarium and some travel costs.)

What the gathering made clear was that much about VSED remains unclear.

Is it legal?

For a mentally competent patient, able to grasp and communicate decisions, probably so, said Thaddeus Pope, director of the Health Law Institute at Mitchell Hamline School of Law in St. Paul, Minn. His research has found no laws expressly prohibiting competent people from VSED, and the right to refuse medical and health care intervention is well established.

Still, he pointed out, “absence of prohibition is not the same as permission.” Health care professionals can be reluctant to become involved, because “they want a green light, and there isn’t one of those for VSED,” he added.
The question grows much murkier for patients with dementia or mental illness who have specified VSED under certain circumstances through advance directives. Several states, including Wisconsin and New York, forbid health care surrogates to stop food and fluids. (Oregon legislators, on the other hand, are considering drafting a bill to allow surrogates to withhold nutrition.)

The question intrigues bioethicists. Can your current competent self cut off nutrition and hydration for your future demented self? In a handful of court decisions, judges have declined to enforce such directives.

Can VSED be comfortable and provide a peaceful death?

“The start of it is generally quite comfortable,” Dr. Quill said he had found, having cared for such patients. The not-eating part comes fairly easily, health professionals say; the seriously ill often lose their appetites anyway.

Coping with thirst can be much more difficult. Yet even sips of water prolong the dying process.

“You want a medical partner to manage your symptoms,” Dr. Quill said. “It’s harder than you think.”

Keeping patients’ mouths moistened and having aggressive pain medication available make a big difference, health professionals say.

At the conference, the Dutch researcher Dr. Eva Bolt presented results from a survey of family physicians in the Netherlands, describing 99 cases of VSED. Their patients (median age: 83) had serious diseases and depended on others for everyday care; three-quarters had life expectancies of less than a year.

In their final three days, their doctors reported, 14 percent suffered pain, and smaller percentages experienced fatigue, impaired cognition, thirst or delirium.

Still, 80 percent of the physicians said the process had unfolded as the patients wanted; only 2 percent said it hadn’t. The median time from the start of their fasts
until death was seven days.

Those results mirror a 2003 study of hospice nurses in Oregon who had cared for VSED patients. Rating their deaths on a scale from 0 to 9 (a very good death), the nurses assigned a median score of 8. Nearly all of the patients died within 15 days.

The slower pace of death from fasting, compared with ingesting barbiturates, gives people time to say goodbye and, for the first few days, to change their minds. Several conference speakers described patients who had fasted and stopped a few times before continuing until death.

That’s hard on families and caregivers, though. And slowness won’t benefit people who are dying with severe shortness of breath or pain. “Two weeks is a lifetime in that situation,” Dr. Quill said.

Other obstacles could restrict VSED. A quiet choice in a private home, it could be derailed in nursing homes and assisted living facilities where administrators fear lawsuits or regulatory sanctions. Physicians might decline to participate; home care aides might quit.

Moreover, major religious groups have yet to declare whether they consider VSED an acceptable act of self-determination or a suicide, anathema in most faiths.

Phyllis Shacter and her husband, Alan Alberts, a computer scientist who received a Alzheimer’s disease diagnosis in 2011, had few doubts, however. VSED allowed him to escape the disease that had slowly killed his mother.

No state allows a person with dementia to use a “death with dignity” law, but with support from his wife, doctor and two caregivers, Mr. Alberts, 76, died peacefully at home in 2013 after a nine-day fast.

“I’m glad my husband fulfilled his desire not to live into the final stages of Alzheimer’s,” Ms. Shacter said.

On the other hand, Judith Schwarz, clinical coordinator of End of Life Choices New York, told of an 81-year-old attempting VSED with inadequate pain medication, crying out to his wife at night, “I’m dying of thirst.”
“And of course, he was, but slowly,” Dr. Schwarz said. “This was a horror show.”

Del Greenfield fared better. “She didn’t use any medicines, just some oxygen,” her daughter said. Ms. Greenfield’s children, grandchildren and great-grandchildren came to see her, and “she was completely peaceful, chatting and joking and telling people she loved them.”

She announced that she had one regret. “We all leaned in,” Bonnie Reagan said. “And she said, ‘I wish I’d seen the Rolling Stones the last time they came to Portland.’”

On the fifth day of fasting, “she just fell asleep,” and died about 36 hours later.

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Family faces 'decade of torture' if bid to withdraw life support from vegetative Gulf War hero fails

The Telegraph
By Henry Bodkin

27 November 2016, 7:05 PM

The family of a Gulf War veteran left in a coma after a road accident say they face a decade of “torture” if their legal bid to remove his life support fails.

Lindsey Briggs is campaigning for doctors to allow her husband Paul to “pass away with dignity”, 17 months after he collided head-on with a car using the wrong lane while riding his motorbike.

The 43-year-old police officer has been diagnosed as being in a permanent vegetative state.

A medic consulted by the family has said this could continue for another 10 years before the father of one dies, if he remains on life support.

Mr Briggs is unable to speak or make informed decisions and has no independent control of his body, however his medical team at Walton Centre in Liverpool are understood to believe that he could become more responsive in the future.

A spokesman for his family said he “Would not have wanted to carry on” being kept alive purely on life support.

Mrs Briggs, who has secured legal aid funding to challenge the NHS hospital in the Court of Protection, has described witnessing her husband’s unresponsive state as “beyond torture”.

The 26-year-old driver who struck Briggs was jailed for a year in July.

During the sentencing hearing, Mrs Briggs said the impact of her husband’s injuries meant the situation was “much worse than if he had died at the scene”.

He was left with bleeding on the brain, five fractures to his spine and bruising to internal organs.

“While Paul remains in a horrific state, it is beyond devastating and affects every aspect of all our lives for the worse,” said Mrs Briggs.

“We have to endure seeing him like this every day, for many long, difficult months now.”

She added: “I never knew that states worse than death existed until this happened to Paul.”
PC Briggs had been riding on the Birkenhead flyover on July 3 2015, ahead of a night shift, when he was killed  CREDIT: BRIGGS FAMILY

On Thursday Mr Justice Charles ruled that Mrs Briggs, 40, is eligible for non-means-tested legal aid for the four-day trial starting in Manchester on Monday November 27.

She had indicated that without the financial support she might have been forced to represent herself.

A spokesman for her solicitors, Irwin Mitchell, said Mr Briggs, who served with Merseyside Police, “Has been in a minimally conscious state in hospital for 17 months”.

“Mr Briggs is a veteran of the Gulf War and has been a dedicated policeman who lived an active life,” he said.

Mr Briggs, in common with the vast majority of people, did not leave any written instructions detailing what should happen in circumstances such as those he now faces.

Mathieu Culverhouse, a lawyer at the firm, added: “She [Mrs Briggs] firmly believes that the withdrawal of treatment is in Paul’s best interests given his previously expressed wishes, injuries and his current condition and prognosis.”

Where a patient lacks the capacity to make a decision about treatment or to communicate it, it is his or her doctors who have the final say.

Compassion in Dying, which advises people on how to plan ahead in case of illness, says only four in 100 people leave written advance instructions regarding future treatment.

The group described Mr Briggs’s case as “heartbreaking but all too familiar”, and urged people with “strong feelings” about how they might be treated to plan ahead.

A spokesman for the Walton Centre NHS Foundation Trust, said: “This is an extremely complex case and the trust empathises with Mr Briggs’s family.

“Mr Briggs’s care has always been out top priority.
“It is now a matter for the Court of Protection and we await the outcome.”
Where Is Death’s Sting?

Woody Allen is supposed to have said, famously, that he is not afraid of death – he just doesn’t want to be there when it happens. Indeed nothing quite prepares us to watch another person die, at least the first time, and especially if it is someone we love. For death does not necessarily happen the way we picture it, or as it is sometimes shown in movies – with a sudden collapse followed by enough of a reprieve to utter last words before fading away in neat, orderly fashion. Given the reality of death, Advance Directives are a Godsend that at the very least give all persons involved in end-of-life situations a foundation - a chance to manage as best possible in such trying, draining circumstances. But for a few practical reasons, Advance Directives are not always a panacea by themselves.

Many health lawyers know the details of making Advance Directives that are clear and enforceable. This brief article is not about such details. Rather, this discussion aims to fill out a lawyer’s emotional intelligence, a capacity that can enhance the quality of counseling provided to clients and stave off conflicts that might otherwise arise in the stress of the moment. Substitute decision makers and other survivors can be well served by some advance thought and communications.

A few realities that people might encounter include these:

First, the decision maker can expect providers to ask if the patient changed his/her mind or elaborated further upon provisions in the AD on record. A surrogate’s being able to answer with clarity and confidence, not to mention accuracy, is valuable.

Emotional strength is important. Even with clear decisions already made by the patient, dying can be emotionally fraught. This might be more true if the patient has indicated that treatment other than comfort care is not desired. The surrogate may experience guilt and fear about not doing more for the patient, or that he or she is wronging the patient. (After all, grief is involuntary, colors everything, and does not follow rules or documents.)
If the patient’s dying is somewhat protracted and even volatile, a unique kind of fatigue sets in for those attending the patient that blurs one’s sense of time and reality. Doubt can also set in. Is the palliative care truly working? How do we know especially if the patient is not speaking? Is this really what the loved one intended? Is this right? Pacing oneself, taking some breaks (a meal; walks etc..) improves evenness of temperament and ability to provide satisfying patient support.

Not all palliative care service providers are alike. In the end, there might not be a choice of where and by whom the palliation is given. How and when pain medication is administered and its effects, how hydration is achieved (especially if not intravenously), the effect of administering oxygen (note that use of a respirator is different from oxygen) - these subjects and questions can and should be discussed with a patient’s healthcare provider at the time of making arrangements to sign an Advance Directive. What is the reality of the dying process? It is not a subject most of us want to focus on at any time.

Communications with providers might be tested as time and (psychic) pain drags on. A tension can develop naturally between the need of healthcare staff to be able to do their jobs (especially when they are overworked) and family emotion (especially when family feels helpless and must just wait). Establishing in advance agreed upon lines for effective, regular or appropriate communication that will suit both is desirable to the extent practically possible. (Nagging staff does not do anyone any good but staff also should remember where apparent criticisms sometimes come from and absorb them as best possible).

Equally important is the ability to field family communications especially with those who are afar and unable to be present. The waiting and uncertainty (uncertainty because hope has a way of springing eternal) is hard on everyone.

Think about what spiritual support would be helpful and consider asking for it. There was a time when hospitals had religious ministers readily available to talk with and support patients and families in their hours of need. That
might not be as much the case now and if so, a possible detriment to all. Ministers have been effective “problem solvers” and peacemakers who can remind persons of their most deeply held values and beliefs. (When speaking of ministers, the term is meant to include priests, rabbis, imams and other spiritual counselors.)

While there may not be conflict and a need for dispute resolution at the bedside in every or even in most end of life scenarios, bear in mind the effect of fatigue, of the “barometric pressure” of different personalities entering the room, individuals needing some “personal attention” or urgently wanting to communicate with the dying patient. Be aware that one emotion can masquerade as another and create miscommunication. The bottom line is that all will want to remember the main point: to help the patient pass away peacefully, comfortably and well, and the survivors to manage their grief in a way that will eventually allow some peace and some closure.

In July 2016, the ABA’s Health Law Section Conflict Management Task Force sponsored a webinar titled, “Conflict Over End of Life Care.” One speaker, Dr. Douglas White of Pittsburgh Medical Center, discussed a recent policy statement (January 2015) issued by the American Thoracic Society that 5 critical care societies contributed to concerning standards and principles for communications and handling of disputes developing at this stage of medical treatment. The program and the policy statement were geared toward actual dispute about a patient’s course of treatment (or decisions not to treat the patient). Dr. White presented the gist of the policy statement as including three recognizable phases or stops that should be planned and provided for if need arises: Intensive communications (to prevent treatment disputes from escalating), expert consultation and finally, a dispute resolution process.

Perhaps some of the above-described realities of death and dying further support the recommendation that intensive communication processes should be available and used to comfort individuals, iron out rough edges and incipient conflicts, and help everyone serve the main point. It may do
some good for lawyers and neutrals to be aware of the what and why of such communication opportunities and urge clients to expect and use them.

Jeanne F. Franklin

August 2016
Religious Groups’ Views on End-of-Life Issues

In the following summaries, religious leaders, scholars and ethicists from 16 major American religious groups explain how their faith traditions’ teachings address physician-assisted suicide, euthanasia and other end-of-life questions. (For an in-depth look at public opinion on end-of-life issues, see “Views on End-of-Life Medical Treatments.” And for an overview of the political, legal and ethical dimensions of the end-of-life debate, see “To End Our Days.”)

Assemblies of God

The Assemblies of God, the largest Pentecostal denomination in the United States, opposes physician-assisted suicide and euthanasia. The denomination teaches that life is a sacred gift and that only God should determine when life ends. “We simply feel that it is not our prerogative to end life,” says Edgar R. Lee, chairman of the church’s Commission on Doctrinal Purity. “God is the giver of life, not us.”

At the same time, the church allows that life need not be sustained at all costs when there is no hope for recovery. “We leave room for people to [reject] artificial means of life support,” Lee says. Indeed, he adds, the church “does not frown on” the use of pain medication to alleviate suffering, “even in cases where it might contribute to hastening death.”

For more information:
(http://ag.org/top/Beliefs/topics/contempissues_18_euthanasia.cfm)

Buddhism

According to Damien Keown, emeritus professor of Buddhist ethics at Goldsmiths College, University of London, Buddhists generally oppose assisted suicide and euthanasia. Buddhism teaches that it is morally wrong to destroy human life, including one’s own, he says, even if the intention is to end suffering. Buddhists are taught to have a great respect for life, Keown says, even if that life is not being lived in optimal physical and mental health.

However, he says, Buddhists also believe that life need not be preserved at all costs and that one does not need to go to extraordinary lengths to preserve a dying person’s life. This means, for instance, that while a terminally ill person should not be denied basic care, he or she could refuse treatment that might prove to be futile or unduly burdensome. “The bottom line is that so long as there is no intention to take life, no moral problem arises,” Keown says.
Catholicism

The Roman Catholic Church strongly opposes physician-assisted suicide and euthanasia. The church teaches that life should not be prematurely shortened because it is a gift from God, says John A. Di Camillo, staff ethicist at the National Catholic Bioethics Center in Philadelphia, Pa. “We don’t have the authority to take into our hands when life will end,” he says. “That’s the Creator’s decision.”

Catholic thinkers like Di Camillo contend that the decision to take one’s own life often comes as a result of issues like poor pain management, despair and loneliness, or the feeling of being a burden on family and others. These conditions, he believes, can be addressed with better palliative and psychological care. “We don’t give enough attention to people near the end of life because we’re afraid of the end of life and don’t want to come to grips with it,” Di Camillo says.

At the same time, the church recognizes that a dying person has the moral option to refuse extraordinary treatments that only minimally prolong life. “The predominant distinction or criteria for legitimate refusal of treatment is whether the treatment in question is considered proportionate or disproportionate,” Di Camillo says. This means patients can legitimately forgo “treatment that doesn’t give a reasonable hope of physical or spiritual benefit, such as resuscitating someone who is at the very end of life,” he says.

Church of Jesus Christ of Latter-day Saints (Mormon Church)

The Church of Jesus Christ of Latter-day Saints opposes physician-assisted suicide and euthanasia, believing that taking one’s own life or the life of another violates God’s commandments and his plan for each person. “While acknowledging the suffering experienced by many, we firmly believe in the sanctity of human life and in its role in God's plan,” says Lyman Kirkland, a spokesman in the church’s public affairs department.

However, the church teaches that when someone is dying, it is acceptable to forgo excessive or extraordinary therapies. “The church does not believe that allowing a person to die from natural causes” – removing a patient from artificial life support, for example – “falls within the definition of euthanasia,” Kirkland says, adding that “families should not feel obligated to extend life by unreasonable means.”

Evangelical Lutheran Church in America

The Evangelical Lutheran Church in America (ELCA) opposes physician-assisted suicide and other efforts by medical professionals to speed a patient’s death. Destroying life created in God’s image is contrary to core church teachings, says the Rev. Roger Willer, the ELCA’s director of theological ethics. “Life is a gift from God, to be received with thanksgiving, and there is an integrity of the life process that should be respected,” he says.
At the same time, Willer says, the church teaches that there is no requirement to take extraordinary steps to keep a dying person alive a little longer. “Allowing something to happen is different than actively hastening death,” Willer says.

For more information:

Episcopal Church

In 1991, the Episcopal Church passed a resolution against assisted suicide and other forms of active euthanasia, stating that it is “morally wrong and unacceptable to take a human life in order to relieve the suffering caused by incurable illness.” According to Timothy Sedgwick, a professor of Christian ethics at Virginia Theological Seminary, this teaching comes from the church’s broader view “that one should never take a life, even your own.” At the same time, Sedgwick says, there is a sense within the church that hard-and-fast rules on end-of-life issues may not fit every circumstance. “Although we have a clear moral norm against the taking of human life, there may be cases that stand beyond judgment,” he says.

The church also teaches that it is justified to stop medical treatment, including artificial nutrition and hydration, when that treatment brings significantly more burdens than benefits to a person. Such decisions also should be informed by the moral norm against taking life, Sedgwick says. “The dividing line here is the difference between the intent to take life and withdraw[ing] treatment.”

For more information:
Episcopal Church Resolution. 1991. “Establish Principles With Regard to the Prolongation of Life.” (PDF)

Hinduism

While there is no formal Hindu teaching on assisted suicide or euthanasia, there is a general concern in Hinduism that prematurely ending a person’s life could negatively impact their karma, says Deepak Sarma, a professor of South Asian religions and philosophy at Case Western Reserve University in Cleveland. The concept of karma centers around the belief that good and bad occurrences in one’s life are caused by actions taken in past lives, since Hindus believe in reincarnation. “We believe that whatever suffering you experience now is because of something you did in the past,” Sarma says. “So if you circumvent karma by taking some action to stop suffering, you will pay for it later.” In fact, Sarma says, the act of delaying suffering may further increase bad karma in the next life.

At the same time, some Hindus believe there are circumstances that could justify a hastening of death. “There are some who believe that if you have reached a stage in your life when you can no longer worship properly [due to illness or infirmity], then you are justified in asking your doctor to hasten your death,” Sarma says. Most Hindus, however, would probably not subscribe to this view, he says.

For more information:
BBC. 2009. “Euthanasia, assisted dying, and suicide.”
Nimbalkar, N. “Euthanasia: The Hindu Perspective.” (PDF)

Islam
Islamic teachings oppose physician-assisted suicide and euthanasia. “Muslims believe that life is sacred and comes from God; therefore it is a sin to take life,” says David Stephen Powers, a professor of Near Eastern studies at Cornell University in Ithaca, N.Y.

Islam also teaches that God alone decides how long someone will live and when they will die, according to Ayman Shabana, a visiting fellow at the Islamic Legal Studies Program at Harvard Law School in Cambridge, Mass. “There is this reluctance … to make any kind of decisions that would end life prematurely because it is believed that [these decisions] are solely in the hands of God,” Shabana says.

Islam’s views on such issues as assisted suicide and euthanasia also are influenced by the belief that suffering and other difficulties might be beneficial, Shabana says. “There is this notion that you don’t always know what’s good for you,” he says, “so it may be right that you should go through some kind of difficulty that tests your faith.” Indeed, Shabana says, “in the Islamic tradition, end-of-life suffering is seen as a way to purify previous sins so that by the time you meet God, you do so in a [more pure] state.”

While Islamic thinkers oppose hastening death, they also generally believe that the terminally ill need not employ extraordinary means and technologies to delay dying. “We are basically talking about the difference between a conscious decision to end life, which is wrong, and life ending by itself,” Shabana says, adding that the line between the two is not always clearly defined.

For more information:

Judaism

Under Jewish law, the directive to preserve human life generally outweighs other considerations, including the desire to alleviate pain and suffering. According to Rabbi Leonard A. Sharzer, associate director for bioethics at the Louis Finkelstein Institute for Religious and Social Studies at The Jewish Theological Seminary in New York City, Judaism teaches that life is a precious gift from God. A person’s life belongs to God, he says, and therefore deciding when it ends should be left to God.

All three major Jewish movements in the United States – Orthodox, Conservative and Reform – prohibit suicide and assisted suicide, even in cases of painful, terminal illnesses. “There are some minority views – that suicide might be permissible in rare, certain circumstances – but the majority view among all [movements] is that it’s not permissible to take one’s own life under any circumstances,” says Sharzer.

At the same time, Sharzer says, Jewish teachings do allow a person to forgo medical treatment if that person’s life is about to end and if he or she is suffering. “Jewish thinkers are pretty united in believing that a person who is near the end of [life] can stop treatment,” he says. “If that treatment is just going to give another month or two of life, and if that time is just going to bring more suffering, most Jewish rabbis and philosophers would say no one is required to endure that.”

According to Jewish teachings, doctors and caregivers should not do anything to hasten death and generally must work to keep people alive as long as possible. However, Sharzer says, in dire cases “there is a distinction made between active and passive euthanasia, between killing and allowing to die.” So, for example, most Jewish religious and ethical thinkers would agree that Judaism would allow for the cessation of life-prolonging treatment in the case of a dying person who is in a coma or vegetative state, he says.
National Baptist Convention

The National Baptist Convention, the largest historically black Protestant denomination in the United States, does not have a specific teaching on physician-assisted suicide or euthanasia. “This isn’t an issue that we’ve considered,” says Charles Brown, a professor of Christian ethics at Payne Theological Seminary in Wilberforce, Ohio. However, he says, broader church teachings are in opposition to practices such as suicide and euthanasia because they prematurely end life. “Within the traditional teachings of our church – and black churches in general – there is this notion that the length of one’s life is the providence of God, and you let it take its course,” he says.

At the same time, Brown adds, there is no requirement that patients near the end of their lives continue treatment just to extend life a little longer. “I’ve had people in my congregation who have made that choice [to forgo treatment], and I didn’t offer biblical warrants against that,” says Brown, who previously served as a senior pastor at several National Baptist churches.

Presbyterian Church U.S.A.

The Presbyterian Church U.S.A. has examined theological questions related to end-of-life issues, but the denomination has not taken specific positions or provided guidance on assisted suicide or euthanasia. However, broader church teachings – including a belief in the intrinsic value of human life, the sovereignty of God and the need for health care workers to do no harm – would imply opposition to assisted suicide and active euthanasia or hastening death, according to Abigail Rian Evans, a Presbyterian minister and bioethicist. While Presbyterians “don’t categorically rule out euthanasia and physician-assisted suicide, the burden of proof rests with the person taking the position in favor of these things,” Evans says.

According to Evans, a senior scholar at the Edmund D. Pellegrino Center for Clinical Bioethics and an adjunct professor in the Department of Family Medicine at Georgetown University Medical Center, refusal or withdrawal of treatment in cases involving a terminally ill patient would be viewed as more acceptable by her church. Forgoing treatment in such cases is different from assisted suicide or active euthanasia, she says, “because it is the illness, rather than the withdrawal of treatment, that is ending life.”

Seventh-day Adventist Church

In 1992, the Seventh-day Adventist Church issued a statement opposing euthanasia and assisted suicide. This opposition is rooted partly in the Adventist belief that the physical body and the soul are permanently linked and that both will be resurrected after death, according to Roy Branson, associate dean of the School of Religion at Loma Linda
University, an Adventist institution in Loma Linda, Calif. “We believe that there will be a bodily resurrection in the near future, and that heightens our value of each human life.” He adds, “Like many traditions, we put great value on life because life is a gift of God.”

At the same time, Branson says, the church does not believe “everything possible” must be done to keep someone alive, “particularly when the dying patient doesn’t want to be alive” or is in severe pain. For example, the church’s position statement on care for the dying states that patients are not obligated “to accept medical interventions whose burdens outweigh the probable benefits.”

For more information:

Southern Baptist Convention

The Southern Baptist Convention, the nation’s largest Protestant denomination, has issued a number of resolutions on physician-assisted suicide, euthanasia and related topics. The resolutions are not calls to action but rather “expression[s] of opinion or concern,” according to the denomination’s website. The church believes that because life is created by God, it is sacred from conception until natural death and that suicide is self-murder, says C. Ben Mitchell, a professor of moral philosophy at SBC-affiliated Union University in Jackson, Tenn. “We believe that [physician-assisted suicide] is a usurpation of God’s prerogative because he is our creator and sustainer,” Mitchell says. As an alternative, a dying person’s doctors, family and community have a duty to alleviate factors such as physical pain and psychological despair that often drive people to consider taking their own lives, he says.

At the same time, Mitchell says, the church recognizes that there is “an appropriate time to stop” medical treatments. Although the SBC generally opposes any action that may hasten death – including stopping regular medical treatment and the cessation of food and water – medical treatments that prolong the dying process are not obligatory. For instance, Mitchell says, an older person who is dying of kidney failure, is not a candidate for a transplant and has been reacting very badly to dialysis treatments should have the option to cease treatment. He asks: “Must that person continue dialysis despite its ravaging effects on their body? No, not in my view and not in the view of most Southern Baptists I know.”

For more information:

United Church of Christ

The United Church of Christ supports the right of terminally ill patients to make their own decisions about when to die – including whether to hasten death. This position is in keeping with broader church teachings that stress the importance of respecting individual conscience and choice, according to the Rev. Timothy Tutt, a senior minister at Westmoreland Congregational United Church of Christ in Bethesda, Md. “We believe that each of us approaches God on our own terms, and this includes at the end of our lives,” he says.

According to Tutt, the church also supports the right of families to discontinue treatment for incapacitated loved ones who are near death or in a vegetative state. “Once again, this is a decision of conscience,” he says, adding that families should base their decisions on what their minds and hearts tell them is best for their loved ones. Says Tutt: “We encourage people to ask: Am I being a wise or unwise steward of my parent’s life by keeping her alive to the very end?”
Unitarian Universalist Association

In 1988, the Unitarian Universalist Association of Congregations (UUA) passed a resolution advocating “the right to self-determination in dying.” As a result, the church supports laws such as those in Oregon and Vermont that enable terminally ill patients, under carefully defined circumstances, to seek physician assistance in hastening their own death, says Gary Kowalski, interim minister at the Community Church of Chapel Hill in North Carolina. Unitarian Universalists also support the right of a legally designated proxy to make life-and-death decisions for a patient, including withdrawal of life support, in cases in which the patient is unable to make such choices.

The UUA position on end-of-life issues is grounded in the church’s teachings on the individual. “Ours is a faith that honors the sanctity and integrity of the individual conscience,” Kowalski says. “These ultimate questions of life and death belong with the person most intimately affected, not with the church, a legislative committee or a bureaucratic panel.”

United Methodist Church

The United Methodist Church opposes physician-assisted suicide. The denomination teaches that “dying well” is an integral part of Christian life, says James Thobaben, a professor of bioethics and social ethics at the Asbury Theological Seminary in Wilmore, Ky. “We believe that in dying, we must do the best we can to proclaim Christ’s glory,” according to Thobaben. With this in mind, he says, it is important for Methodists to show their family, friends and others that they remain believing and committed Christians even if they are suffering “on the deathbed.” Trying “to control death in a late, modern, hyper-individualistic way, or [being] afraid of pain” is contrary to what the church considers its great tradition, Thobaben says.

The church also opposes euthanasia, although there is no requirement that the terminally ill avail themselves of every possible treatment as long as their actions are not intended to hasten death. “There is a difference between not needlessly extending the dying process and accelerating it,” Thobaben says.

For more information:

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