

# A Word to the Church on End of Life Care:

Theological, Spiritual, and Ethical Reflections

Rev. Dr. Bruce Epperly, Lancaster Theological Seminary
Rev. John Mills, UCC Hospice Chaplain
UCC STN – The United Church of Christ Science and Technology Taskforce

## 1) Introduction

The story is told of a servant who came to his master trembling in fear. "Master," he begged, "Lend me your fastest horse. I have seen Death walking in the Baghdad bazaar, and Death made a threatening gesture toward me. I must ride to Samarra where I will be safe." Being a generous man, the master loaned his servant his fastest horse. Being both curious and brave, the master went searching for Death in the bazaar. When he saw Death walking among the booths, he confronted the Death and demanded that he respond to his question, "Why did you threaten my servant today?" Death replied, "I did not make a threatening gesture at your servant. When I saw him at the bazaar in Baghdad, I was so surprised that I made an involuntary gesture. You see, I have an appointment with him tonight on the road to Samarra."

As persons and as a culture, we do our best to dismiss the reality of death. We hide the aging process through surgery and cosmetics. We mask the inevitability of death through medical language and euphemisms. We prolong life through unnecessary medical interventions. Although, as C.S. Lewis notes, the great world religions arose before the invention of pain relievers, death is seldom addressed in the church, apart from funerals and memorial services. The location of death has changed from the home to the hospital. Persons live longer and their deaths are more likely to be prolonged than sudden in nature. Although the causes of death have changed since the time of Jesus and even in the past fifty years, the mortality rate remains 100%. We need guidance to face our dying and the mysteries that lie beyond the grave.

The universality of death challenges the church to become a leader in creative and sensitive theological, spiritual, and ethical reflection. In the United Church of Christ, we affirm that "God is Still Speaking" in our world. Universal and intimate in nature, God's ongoing revelation pertains to every aspect of our lives, including the pastoral and medical care for persons at the end of life. Despite its reticence to discuss end-of-life issues in Christian education settings and in the pulpit, the church has been a leader – and needs to reclaim its leadership - in bioethical and spiritual reflection, especially as this relates to the vocation of health care professionals and ethical decisions made by persons facing the deaths of themselves or their loved ones.

Martin Luther once noted soberly that "in the midst of life, we are surrounded by death." Ultimately, we can neither deny, nor avoid, our mortality. But, in light of God's presence in Jesus of Nazareth, we can also affirm, with Luther, that "in the midst of death, we are surrounded by life." Today, the church is challenged to affirm that "God is still speaking" in end of life issues. This calls the church to think theologically about issues surrounding patient care. It also calls the church to explore 21<sup>st</sup> century spiritual practices, or "arts of dying," for persons at the end of life. From the intersection of theological reflection and spiritual formation, we can articulate an evolving and sensitive vision of health care and bioethics to respond to our technological advances.

The church is also called to explore creative and life-affirming images of immortality that will shape our medical, congregational, and personal care for persons at the descending edges of life. In so doing, we embody the gospel mandate to rescue the perishing and care for the dying, for as we have done unto the least of these, we have done unto Christ. (Matthew 25:40)

## 2) Theological Reflections

The church is at its best when it wrestles with challenging theological and ethical issues. We cannot assume uniformity, nor can we assume that any theological position is final, as we respond to the spiritual, pastoral, intellectual, and relational needs of persons with serious illnesses and their families. Still, we can assume that, in light of God's ongoing and evolving revelation in nature and human experience, we will find enough common theological insight to respond to the crucial issues of our day.

The church is called to explore the meaning of end-of-life theology in a pluralistic age. Although the scope of this paper cannot include interfaith dialogue on end-of-life issues, we believe that Christian theology today must take into account the insights, spiritual practices, medical perspectives, and ethical viewpoints of other religious traditions. Our theological treasures are found in "earthen vessels." This reminds us that as we boldly affirm our faith, we must also maintain an attitude of openness and humility toward other faith affirmations. This is especially true within Christianity today, where the "culture wars" have prevented Christians from creatively encountering the diversity of Christian viewpoints on issues such as genetic technology and cloning, abortion, and end-of-life issues. We need to recognize, as UCC theologian Reinhold Niebuhr once noted, "the truth in our neighbor's falsehood, and the falsehood in our own truth."

In the quest to respond to issues in medical care, Dr. Edmund Pellegrino, one of the parents of bioethics, suggested that we should ask three important questions:

What is wrong? What can we do? What ought we to do?

Each of these questions has a theological, social, medical, and communal context. While we cannot address the many contexts of end-of-life care in detail, it is important that we explore the divine-human relationship as it relates to medical care. Theological reflection is guided by the dynamic and evolving interplay of scripture, reason, experience, tradition, and culture. The omnipresent and omni-active God is still speaking and new insights are constantly emerging that inform our ethical decision-making.

First, theological reflection must consider God's presence in the world. Scripture, tradition, experience, and reason give us many images of God's presence and power. But, among the many possible images of God, we lift up the following trajectories as most helpful in Christian reflection on end-of-life issues:

- 1) God is dynamically present in our lives, constantly inspiring us in light of our current situation. God is constantly bringing forth new possibilities and calling us to transform our vision of ourselves and reality in light of God's ongoing revelation.
- 2) Divine inspiration is lively, contextual, and evolving. We must update our understandings of bioethics, for example, in light of the challenges of technological advances and social situations.
- 3) God has a personal relationship with each one of us that calls us to be particularly mindful of our unique ethical responsibilities in light of the broader ethical context.
- 4) God seeks abundant life for all creation and each individual.
- 5) God, according to the Biblical tradition, has a bias toward justice and care for the most vulnerable members of our society.

Second, theological reflection must consider the image of humankind as it relates to issues of bioethics. While we recognize that there is no *one* Christian image of humankind (for example, within Christianity, we have body-affirming creation theologians and body-denying Manicheans, this-worldly liberation theologians and heaven-centered fundamentalists), we lift up the following images of human life as significant for end-of-life care.

1) Human life, like all creation, is created "good" by God. Every essential aspect of our lives - such as creativity, interpersonal relationships, embodiment, and sexuality - reflects divine wisdom, love, and goodness. While these all may be misused by humankind, they are inherently good as divine creations.

- 2) Humankind is described in terms of psychosomatic wholeness. Body, mind, and spirit, interpenetrate one another. Our bodies are inspired and our spirits are embodied. Nephesh, God's breath, energetically flows through us, giving us life and health.
- 3) Human life is profoundly relational. There are no isolated, self-made individuals. We are made for relationship and find fulfillment in healthy and life-supporting relationships and communities. We are part of the body of Christ, in which our joys and sorrows are one.
- 4) We are called to be God's partners in the creative process. As stewards of life, we are responsible to God for the care of our bodies and the bodies of others. Medical care is an inherently spiritual practice. Our living and dying have spiritual and ethical implications.
- 5) We find joy and fulfillment, and contribute to the well-being of others, through responding to God in each situation. We are truly on holy ground, whether we are in the waiting room, operating room, hospice, or laboratory.

Third, theological reflection must consider the importance of ethical relationships in promoting wholeness at the personal and social levels. Again, there is no *one* biblical or Christian ethic on the majority of bioethical issues; nor does scripture and the Christian theological tradition give guidance to many of the bioethical issues raised by modern technology. Still, the Christian tradition provides insights that guide end-of-life care.

- 1) Ethics has a bias toward care for the helpless and vulnerable.
- 2) Leaders, that is, professionals, politicians, corporate managers, have inherent ethical responsibilities in terms of just allocation of resources, care for the vulnerable, and promotion of personal well-being. Persons come before profits in health care and resource allocation.
- 3) Ethics is concerned with promoting wellness, relieving suffering, and supporting life.
- 4) We are called to promote the value of life.
- 5) All life is to be reverenced and to be treated with great care including persons unable to speak for themselves (for example, persons in persistently vegetative states.)
- 6) Persons are called constantly to make decisions in the divine-human adventure, especially in terms of our quality of life as it relates to our health care and treatment.
- 7) Autonomy is balanced by interdependence in all ethical settings. Our lives are ultimately relational. Ethical decisions must take into account personal choice, but personal choice always exists in the context of creating healthy relationships, families, and communities. Rights are mated with responsibilities. Although there is a bias toward autonomy in medical decision-making, autonomy is contextual and relational, not absolute.
- 8) Every moment involves the divine call and human response. Although we believe that God is not the source of illness, divine wisdom is revealed in illness as well as in health. How we die and our end of life choices have ethical and theological implications.

While we do not claim that our theological reflections are exhaustive or final, they provide broad guidelines for responding to end of life issues. They remind us that God is present in every moment of life and that God's loving care embraces persons at every stage of life's journey. Death and suffering are realities that we must face, but even here God is working to promote healing and wholeness. As God's partners in creation, we are challenged to support persons at every stage of life and to provide humane care, spiritual guidance, and technological resources that will enable persons to face their mortality with hope and faith.

## 3) Technological Challenges

We must admit that all human achievements are ambiguous in nature. The technologies intended to help us may end up harming us, if we do not provide appropriate ethical and spiritual guidance. Many of today's bioethical challenges are the result of our successes, and not our failures. Medical technology has been a factor in increasing both longevity and quality of life. We are called to celebrate medical technology as a manifestation of God's aim at healing and wholeness and a continuation of Jesus' healing ministry. Nevertheless, we must also recognize that many persons today have fallen victim to the technology aimed at helping them.

The growing interest in physician-assisted suicide, including the notoriety of Dr. Kevorkian, is, in part, the unintended result of medicine's successes. Many persons fear medicine's "manifest destiny," that is, if we can use a particular life-saving technology, then we must employ it in patient care, even if it does not improve the patient's quality of life. Despite "advance directives" and "informed consent," patients and their families still recognize the realities of power imbalance, objectification, and dehumanization within the institutional setting and the physician-patient relationship. With greater longevity comes the reality of chronic illness, dementia, Alzheimer's disease, and drawnout terminal illness. Patients also fear unrelenting pain and debilitation in institutional contexts committed to the prolongation of life.

The disturbing spectacle of Terry Schiavo, played out before millions, is a reminder that we must prepare in advance for our dying and medical care. We must also support institutions, such as hospices, whose primary purpose is the spiritual care and appropriate palliation of dying persons and the support of their families and loved ones.

Sadly, liturgies, sermons, and Christian education have often neglected life's most difficult questions – mortality, sexuality, family violence, and unjust economic practices. Today's churches are called to be leaders in spiritual reflection and practical guidance in the areas of death and dying and end of life care. The traditional spiritual "arts of dying" need to be revived and revised for a technological age.

While we recognize that a diversity of opinions exist within congregations on end-of-life issues, we believe that the church is called to provide resources that will enable persons to make critical end-of-life decisions, based on their understanding of

God's presence and purposes for their lives. The church is also called to be a community of hospitality and support for dying persons and their families and loved ones. Our calling as Christians is to provide loving care and spiritual support for the most vulnerable members of our community. To this end, regions, associations, and seminaries of the United Church of Christ are called to be resources in the areas of death and dying, bioethics, and congregational health and parish ministries.

# 4) The Ethics of Care

A plaque at the College of Physicians in Paris states that "we are the dying caring for the dying." Truly this is the nature of life. Matthew 25 recognizes this reality in its call to care for the least of these. I Corinthians 12 describes the intricate interdependence of the body of Christ and affirms that our joys and sorrows are communal, rather than individual in nature. When one suffers, all suffer. When one rejoices, all rejoice.

Our goal in Christian bioethical reflection and pastoral care for persons at the end of life is to provide wise and supportive care. While there is no *one* particular definition of care, Christian care surely involves responding to the needs of the whole person - body, mind, spirit and relationships. It involves fidelity in personal and communal support. Positively speaking, care involves promoting well-being in body, mind, spirit, and relationships through spiritual friendship, pastoral companionship, prayer, comfort, pain relief, and appropriate medical interventions. Care for dying persons involves responding creatively and sensitively to issues of pain, debilitation, and dignity in order that persons may be able to prepare for their dying, experience companionship, and grow spiritually.

Caring for the dying begins long before the diagnosis of a terminal illness. It begins with education and spiritual formation within the congregation. Congregations are called to be places where life and death issues are discussed without denial or judgment. One trajectory of this calling involves preparing people spiritually to embrace dying, death, and the afterlife. Drawing upon resources of Christian theological reflection and spiritual experience, congregations can remove the taboo of death and integrate it into spiritual life. Further, practical issues such as advance directives, long-term health care insurance, durable health care power of attorney, and hospice care, can be addressed in light of broader Christian understandings of God, humankind, stewardship, life after death, and ethical behavior. The goal of these educational initiatives is not uniformity of belief or action, but well thought-out preparatory responses. Our calling is to enable persons to reflect on their deepest desires and make decisions regarding appropriate health care as they face their own deaths. This is the meaning of love in action.

### 5) The Ethics of Action

Today, end of life issues, like genetic and beginning of life issues, have been obscured by sound byte theology and "culture wars" that characterize popular ethical reflection. One of the reasons congregations fail to address ethical issues at the end of life is fear of disagreement that will divide congregations. Yet, virtually every

congregation contains diverse opinions of significant ethical issues. Accordingly, church leaders are called to model and facilitate difficult conversations in the context of congregational pluralism. The open spirited theology of the "God is Still Speaking" campaign must encourage theological and ethical diversity, along with ethnic, lifestyle, and gender diversity. Conservatives and liberals alike can learn from one another if they listen with love and honor the deepest experiences of their dialogue partners.

End-of-life issues have been polarized by the growing interest in physician-assisted suicide and voluntary euthanasia. The State of Oregon has legalized physician-assisted suicide. Holland implicitly supports physician-assisted suicide, although it has not become a matter of law. Clearly, congregations must challenge any form of involuntary euthanasia (that is, the killing of persons without their explicit permission). As Christians, our bias is toward affirming life, without absolutizing longevity. Neither suffering nor death is the greatest evil, for as Romans 8:39 proclaims, "nothing [not even suffering and death] can separate us from the love of God in Christ Jesus our Lord."

Briefly put, the growing interest in euthanasia (be it self-administered or involving pharmaceuticals provided by a physician) is based on a number of factors, including: 1) the desire to avoid unredemptive and unnecessary suffering of mind, body, or spirit and 2) mercy toward persons who are experiencing deep suffering. Interest in euthanasia also reflects the modern need to be in control and avoid the indignity of dependence and vulnerability. Proponents of euthanasia and physician-assisted suicide assert that the relief of suffering is an essential aspect of care. When unendurable suffering cannot be relieved by medical procedures, then, it is asserted, persons have the right to end their lives voluntarily. They believe that euthanasia is not a denial of life, but an affirmation of the importance of the quality of our lives. Further, while scripture challenges the killing of innocents, voluntary dying (martyrdom and suicide) is not prohibited in scripture. While it is true that God is the ultimate giver of life, there is no indication in scripture that God prefers longevity over quality of life. Some proponents of euthanasia believe that relieving suffering, even if it means the ending of one's life, is in alignment with God's will under certain circumstances. They assert that it is the most loving and life-affirming action possible, albeit in a difficult and complicated situation. There is no biblical or ethical mandate to sustain life when pain and indignity are constant realities.

Opponents of euthanasia and physician-assisted suicide note that legalization and normalization of these behaviors may contribute to a "slippery slope" in which voluntary euthanasia will eventually lead to involuntary euthanasia and the medical abuses that characterized Hitler's Germany. While they recognize the importance of relieving intolerable suffering and the place of mercy in responding to dying persons, they see these individual merciful choices as having negative social effects. Some opponents see euthanasia as "playing God," that is, interfering with God's prerogative in life and death issues. While they recognize that the desire to relieve unremitting suffering is at the heart of the euthanasia movement, opponents of euthanasia point out that appropriate palliative care, employed, for example, by hospices and physicians trained in pain relief for dying persons, relieves the majority of personal suffering. Further, the indignities that many

persons fear in advance may be relieved by the commitment and presence of loving communities of faith and caring medical institutions. Vulnerability and interdependence are the nature of life. We are called to accept our limits and allow others to care for us at the end of life.

Today, most Christians recognize that there are limits to medical interventions. Bioethicists assert that there is a profound difference between what we can do and what we ought to do in responding to life-threatening illness. The consensus among bioethicists is that medical care should ultimately be determined by the patient's condition, values, and spiritual commitments rather than the available medical technology. We can legitimately refuse certain medical treatments when 1) their purpose is solely to extend life without attendant quality of life, 2) they bring greater hardship than comfort, and 3) they provide no significant medical value. What might be ordinary and ethically mandated treatment for a healthy adult or child (for example, antibiotics for the treatment of pneumonia) may be excessive or extraordinary treatment for an elderly resident of a nursing home (pneumonia is often described as the "old person's friend") or a person is already in the final stages of the dying process. An omission of treatment, even though it will hasten death, is not a deliberate form of killing. Further, the utilization of pain relievers is not considered killing the patient even though morphine and other pain relief will likely shorten a person's lifespan. Here, according to the traditional principle of "double effect" the goal our actions is pain relief, not euthanasia, despite the fact that our actions may end in the death of the patient. Life is not prolonged; nor is death directly hastened.

Proponents of euthanasia recognize the distinctions between ordinary and extraordinary care. They also agree that medical interventions must be seen in light of the whole person, mind, body, and spirit, and not merely her or his physical condition. Both opponents and proponents of euthanasia share common ground in their respect for patient autonomy, their recognition of quality of life factors in health care, and their affirmation that death is not the ultimate evil. While they may continue to disagree on the area of intentional ending of life, both groups within the church are called to remain in dialogue as a means of bringing greater light to the care and medical treatment of dying persons. The main point of contention at this point involves differing understandings of the impact of euthanasia on the social order and the distinction between omissions that lead to death and intentional and voluntary actions that also lead to death, albeit sooner. Still, despite the strong disagreements, there is significant common ground in the desire to provide compassionate care for dying persons.

### 6) Hospices and Wholeness

Today's congregations are challenged to take seriously the reality of death and dying. Congregations are places of advocacy and referral. Pastors and lay leaders can help to insure that parishioners receive the best care possible. In addition, they can help persons navigate the labyrinth of social services and medical insurance, and advocate for universal health care.

Pastors and lay persons are called to support the hospice movement. Hospices seek to provide spiritual guidance and appropriate palliation for persons diagnosed with terminal illnesses. Hospices ground their practice in the affirmation that there is always something more that can be done to care for persons, when medical intervention is no longer helpful or effective. When we cannot cure certain persons, we can support them in their healing process, that is, their relationship with God and other persons. We can combine high touch (personal comfort and companionship) with hi-tech (palliation) in our support of persons with serious illnesses.

Along with congregational health and parish ministries, congregations should provide information regarding hospice care through sermons, seminars, and ethical discussions. Hospice chaplains are eager to resource the broader community. Education on hospice care, both in-patient and home care, can be integrated into Stephen Ministry, Called to Care, and other lay ministry programs. Hospice complements the church's calling to be God's healing partner in our world.

# 7) Ethics in Light of Eternity

Progressive and mainstream theology has often failed to present convincing visions of survival after death. While there are many possible visions of the afterlife, we must articulate a vision that is congruent with the graceful and healing ministry of Jesus as well as the church's concern for social justice. We can affirm the value of creation and this lifetime along with an affirmation that God continues to speak creatively in the afterlife. Sadly, many mainstream and progressive pastors have reacted to dualistic, heaven-hell, other-worldly, and saved-unsaved images of the afterlife by eliminating any constructive reflection about survival after death altogether. Faith lives by what it affirms about God's presence in the world, and not what it denies. Accordingly, a church that believes in ongoing revelation must reclaim and reform images of the afterlife that reflect our pluralistic and scientific age as well as the wisdom of tradition.

The vision of everlasting life, articulated by the images of resurrection and the loving reign of God, shape our bioethical reflection and medical practice by reminding us that: 1) death is not final, 2) each person, sharing in divine eternity, is due reverence and respect at every stage of life, and 3) death and suffering are not the ultimate realities, but are relativized in light of God's eternal care. In light of eternity, we can face death, knowing that while each person deserves the best medical care possible, we do not have to sustain physical existence at all costs. We face the death of loved ones and our own death with the affirmation that "nothing can separate us from the love of God in Christ Jesus our Lord."

### 8) Final Reflections

We have not attempted to be exhaustive in this "word to the church" on end of life issues. Our goal is to promote conversation and to remind the church that its calling is to

enable persons to be faithful to God in life's most painful situations. Spiritual guide Margaret Guenther suggests that spirituality deals with life's "unfixables." In a time of ethical flux and polarization, the church needs to be house for hope at life's descending edges; a place of learning where persons integrate theological reflection with bioethical action; a community of care for vulnerable persons; and an agent of advocacy for social transformation that reflects God's vision of wholeness and shalom. We believe that God is still speaking within the United Church of Christ and that we as a denomination have a vocation to provide creative end-of-life bioethical guidance in our time.