
MAKING END-OF-LIFE DECISIONS:

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UNITED
CHURCH
OF
CHRIST
PERSPECTIVES

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The Council for Health and
Human Service Ministries of
The United Church of Christ

*Revised and Updated
1997*



United Church of Christ
Chaplains in Health Care

PREFACE

“The values of the Christian faith motivate our ministries of human service and must be the central values of organizational life and mission.”

This statement is a central tenet of the Philosophy and Mission Statement of the UCC Council for Health and Human Service Ministries. There can and should be continuing debate on what constitutes the “values of the Christian faith.”

However, there is one unequivocal claim of our faith which must underlie and inform all others: Namely, the claim of Christ’s victory over death. Indeed, in all its ministry and mission the Church of Jesus Christ, including church-related institutions of health and healing, must proclaim Christ’s victory over death with uncompromising passion. It is in faithfulness to the call to such proclamation that this manual is dedicated.

I suspect that at its core, this proclamation is heresy to the fundamental premises which have informed the practice of medicine for the last several decades. Careful study of the material which follows should help both care giver and receiver understand their relationship in new ways — ways which liberate us from old patterns of decision making and dependency and free us to new relationships of mutual dependence upon God. In this regard, our church institutions need to differentiate themselves in at least three ways:

1. **Our mission is to help people to live, not survive.** We are to provide an environment where persons can come to understand and express their belovedness. Thus, the most important element in healing becomes listening. The listener/healers whom we employ must understand themselves as care receivers as well as care givers and their “patient encounters” are encounters with God, rather than billable events.

2. **A primary goal of our care giving should be to minimize technological interventions.** We need to learn to ask how a given technology will enhance or inhibit a person’s quest to understand themselves as beloved of God.

3. **We must move from being workshops for medical practitioners to being workshops of the spirit.** If God is revealed among the most vulnerable, health care institutions are temples for these sacred vessels of revelation. The sick are the priests of this temple, not the managers or clergy or physicians or even the family.

As we confront end-of-life decisions, we do so in hope and in the certainty of victory. Such decisions are opportunities for faithfulness for each Christian and for the whole Church.

(BWS)

End-of-life decisions are unlike any others we make, and sometimes the advice, “Talk to your pastor,” is too general to be helpful. This publication is intended to address specific moral issues at the end of life for members of the United Church of Christ, and it may be used in two ways:

1. **As a resource for someone who is actively engaged in an ethical dilemma** and needs guidance in making end-of-life decisions; or

2. **As a study guide** for church members and clergy, to introduce advance directives as an option to be considered and to describe ethical issues in health care today.

The impetus for this resource came from passage of the resolution on “The Rights and Responsibilities of Christians Regarding Human Death” by UCC General Synod 18 (see chapter six). In addition, the changing climate of health care forces chaplains, staff, patients and families to confront each day the questions explored here. The resource was written primarily by UCC chaplains who work in health care settings and focuses primarily on advance directives and foregoing life-sustaining treatment, though there is some mention of the still-emerging debate on active euthanasia and assisted suicide. Staff members at UCC health and human service agencies and parish clergy provided valuable critique of the document, reflecting their expertise and perspective.

The information here is current as of its publication date. It cannot be equated with legal advice. For further information on end-of-life decision making, please contact staff at CHHSM or members of UCC Chaplains in Health Care. We are indebted to the United Church of Christ and members of our respective organizations for their support in preparing this manual.

(JRH/dm)

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INTRODUCTION: WHY THIS RESOURCE IS NEEDED

COMPLEXITY OF MORAL CHOICES TODAY

New knowledge and scientific technology provide abundant resources for modern medicine. These advances offer new tools for enhancing and extending human life. At the same time, they have created new and complex choices for patients and families, health care personnel, the church and society in general.

One area profoundly influenced by the "biomedical revolution" is end-of-life decision making. "Medical chemistry and technology have given us unprecedented power to prolong living. The problem . . . is that in the process of trying to prolong living we have developed the means to prolong dying, sometimes with the unintended consequences of extended pain, hopeless suffering, and loss of self-determination." <1> In such circumstances, dying may become "a drawn-out series of degenerative changes," in which some persons are preserved by artificial means with no hope of improvement or recovery.

One ethical issue is: **What is best for the person?** Should life be sustained when quality of life is nonexistent? Quality of life describes a person's ability to enjoy daily living through activities such as thinking, talking, communicating with others, eating, moving from place to place, and using one's senses of sight, touch, hearing, taste, and smell. Some persons have none of these abilities, and thus they seem to have no "quality of life." Should they be given compassionate care while being allowed to die? At what point can the treatment process be redirected from "curing" to comfort in dying?

A further issue is: **Who should make decisions about matters of life and death?** Traditionally, such decisions were made almost exclusively by the physician, with some consideration of patient and family wishes. However, in more recent years the pattern has shifted toward a more collaborative relationship between the primary caregiver (physicians and other health care staff) and the person receiving care. This new pattern is one result of the patient rights movement, which emphasizes autonomy or the right of a person to make informed decisions about their own health care. At its best, health care today is a partnership with caregivers and patients actively involved in the decision making process.

Several questions arise. Today it is often assumed that the patient is the senior member in the partnership. Should the patient's preferences override the physician's perceptions of what is best for the patient? Does the patient correctly understand the medical indications so that end-of-life decisions can be made which are consistent with the patient's beliefs? And, how are disagreements between the partners to be resolved?

COST OF HEALTH CARE AND RATIONING HEALTH CARE

Medical care, with the advances mentioned earlier, now carries a hefty price-tag (exceeding the rate of inflation in this country). Furthermore, health care resources are limited. There are gross inequalities in the expenditure of funds and in the availability of and access to medical services. **Who will tend to these issues of social and distributive justice?**

One area of concern is the high cost of dying. Over half of the health care dollar is spent on services provided during the final few months of life, with only a small percentage devoted to prenatal and well-baby care. Funds spent on exotic procedures that prolong living — and dying — for a few could be used to provide basic health care for many. A dollar spent on preventive care saves many dollars that would later be required to deliver adequate acute and continuing care.

These trends in health care — advances in medical capabilities, greater participation by patients in treatment decisions, and escalation of health care costs — create ethical concerns with which church and society must deal. On another level, each of these issues is very personal and relevant to all of us in our daily lives.

INCREASING EMPHASIS ON ADVANCE DIRECTIVES

Modern medicine's ability to prolong living and dying forces us to face our feelings about the prospect of being maintained on artificial life-supports. It is usually helpful to consider our beliefs and feelings on the matter beforehand, though our opinions may change if we are ever in a situation where life-support is needed.

Our personal preferences are given considerable weight by those who provide our medical care. This trend is clearly seen today, with physicians increasingly considering patients' stated choices and values along with medical indications and quality of life issues. For this reason, it is important for each person to make known in advance his or her own wishes concerning health care at the end of life.

The cost of dying has its personal aspect as well. Simply sustaining biological existence can be not only an assault on the dignity of the person and possibly a means of prolonging suffering, it can also create a heavy economic burden. Extended care under such circumstances could deplete money needed for other purposes. This is especially significant in our nation with 42 million citizens uninsured and a like number having inadequate health care coverage.

CASE STUDIES IN END-OF-LIFE DECISION MAKING

The following case studies will give some flesh to the bare bones of this guide, providing real life examples of the problems and approaches that will be explored.

PEDIATRIC CASE STUDY

David, 5, is the youngest son of John and Jane Smith. His older brothers, 11 and 14, have a three-wheel All Terrain Vehicle (ATV) which they use on their farm. David yearns to be like them. One day while they are at school and mother is busy, he decides to ride his brothers' ATV. As he leaves the yard, the vehicle hits a rock and he is thrown several feet in the air before he lands on the ground. The sound of the motor has brought Jane running. She finds David unconscious. A friend who has just arrived calls for help, while Jane initiates cardio-pulmonary resuscitation (CPR).

At the hospital, David is found to have a C1-C2 spinal cord injury. He also has a closed head injury. Over the first several days, David's brain swells from the injury, as expected. Studies of his spinal injury reveal a complete severance of the spinal column. David will be completely paralyzed from the neck down, will be dependent on a machine to breathe for him, and will need total care from his parents or others. Additionally, the head injury could leave him with long-term mental deficits.

As David's brain reaches the time of maximum swelling, his vital signs (blood pressure, heart rate, temperature) become erratic. Each change is met with compensating medical interventions. The physician approaches David's family and asks them to consider a "Do Not Resuscitate" decision. This means that it may be in the child's and family's best interests not to perform CPR if his heart stops beating, given the overwhelming lifelong problems which he and the family will face if he lives.

The parents' initial response is, "Do everything." However, they agree to think about what the physician has told them. The possibilities with full medical intervention are: 1. David may die anyway; 2. David may live, but never recover enough brain function to have meaningful interaction with them; 3. David may live, recover complete brain function, but be completely paralyzed and dependent on the breathing machine. It is also likely that he will experience frequent medical problems brought about by his quadriplegia, and will need long-term rehabilitation. The family has medical insurance, but it will probably not cover the range of services David will need. Their income level currently will make them ineligible for other kinds of financial resources. (HSN)

We must make our wishes regarding life-support clearly known to others. Preferably, this is done in advance of a health crisis or a potentially life-threatening illness, rather than under severe stress. Also, it is helpful to learn about and indicate the type of treatment one would prefer prior to the crisis, in the event that one should lose consciousness or become incompetent to make decisions. These preferences can be stated in advance directives, described in detail in chapter two.

Experience has shown the increasing use of advance directives is due in part to the fact that all parties tend to benefit. The person benefits by exercising the power to make important health care decisions in advance, stating which types of care they would or would not want to receive. Also, it can protect the person from the indignity and discomfort of a prolonged dying process.

The family benefits by being spared the pain, and sometimes guilt, of deciding to withhold or withdraw treatment, while not being aware of the patient's earlier wishes on the matter. The physician and other caregivers benefit because they know more clearly "what the patient wanted."

The end-of-life decision making process underscores the quality of life issues as opposed to simply the number of days "lived" on earth. This process should acknowledge death as a natural part of life. Finally, it reflects the faith that both life and death are ultimately in God's hands. (JHF/dm)



ADULT CASE STUDY

Joe Hriniak, 66, is a retired immigrant from Eastern Europe who had cardiac bypass surgery. Although he had been quite ill prior to the surgery, he initially did well after the operation. However, after leaving the surgical heart unit he developed a severe pneumonia and was admitted to intensive care. There he was placed on a mechanical respirator to support his breathing.

During two weeks on the respirator, Joe drifted in and out of consciousness. When awake, he gave signs clearly indicating he did not like being on the respirator. Once he pulled out the breathing tube; it was quickly reinserted. Sometimes Mr. Hriniak mouthed the words, "I want to die." But his apparent awareness and alertness when conscious were inconsistent. He had no written advance directives.

Joe's two sons and one daughter were distressed by his condition. One son and daughter-in-law were most available to visit him and consulted with the health care team: physicians, nurses, social worker, and chaplain. To them, after two weeks on the respirator Joe showed little improvement. They wondered if he could ever be "weaned" from the machine and breathe on his own, let alone recover genuine function of his mind and body.

Both son and daughter-in-law had heard Mr. Hriniak say before that he never wanted to be "hooked up to machines." They had also heard him say during this illness, and even before the bypass surgery, that he wanted to die. They told the staff they believed his wishes should be respected.

His physicians were opposed to the discontinuation of the respirator. Joe's cardiologist, neurologist and the attending physician (an internist) all believed he could recover, though slowly, from this illness. The neurologist believed Joe had sustained little if any brain damage from loss of oxygen. The doctors stated the respirator was a treatment that preserved Joe's life until he could recover, and without the respirator he would die in a matter of hours. Further, they recalled that, despite Joe's avowed wish to die, he had opted for the surgery when it was offered.

At a patient care conference, both the family members and staff members wondered how to proceed when Mr. Hriniak's stated wishes and his actual choices were inconsistent. (DBM/dm)

OLDER ADULT CASE STUDY

Myrtle Brown, 98, broke a hip on New Year's Eve when she fell at home. She went to a nursing home to receive therapy and learn to walk again. She was alert and active and in good spirits during her stay, though Myrtle was almost completely deaf and visitors had to write notes to her to communicate.

On Good Friday, she suffered a massive stroke and was transferred to a hospital. She was unable to speak or move and could no longer swallow. A feeding tube was inserted in her stomach to provide for artificial nutrition and hydration. Myrtle then returned to the nursing home. Her condition there neither improved nor worsened for six months. She had signed a durable power of attorney for health care two years before and gave complete decision-making power to two individuals (one relative and one friend). However, her state's law regarding these advance directives provides that only one person may be appointed as the agent (see glossary). After some careful deliberation, these two approached the doctor and nursing home staff to discuss what might happen if the feeding tube were disconnected.

The doctor had strong reservations about this action, since Myrtle was not fully comatose; she still had some responses to touch and sound and her heart and lungs were functioning well. The power of attorney holders were insistent that Myrtle would never want to live this way, because she had been such an active, vibrant person even at age 98. The nursing home ethics committee had several meetings with the family, and their discussion was informed by a recently passed state law which provided for withdrawal of life-sustaining treatment for a patient in an "irreversible condition." After a few months, the decision was made to stop the artificial feeding.

However, Myrtle did not die. Two weeks later, she was able to eat and drink by mouth, with the assistance of a nurse. Family and friends who had brooded over this decision for so long were stunned and dismayed. They requested the nursing home staff stop offering food by mouth; the staff refused to stop on the grounds that this was a comfort measure. Eventually, the people holding the power of attorney elected to take Myrtle to her own home and hired nurses to care for her there. She died after being home for three weeks. (JRH/dm)

CHAPTER ONE: OVERCOMING THE BARRIERS TO END-OF-LIFE DECISION MAKING



Definition of an ethical dilemma: A decision no one wants to make.

There are many decisions no one wants to make in health care today. Ethical dilemmas abound as individuals and their loved ones are called upon to decide whether life-sustaining treatments are appropriate for a critically or terminally ill person. Eighty percent of Americans die a so-called “managed death” in a hospital or nursing home, surrounded by institutional caregivers. Those who die a quick and sudden death are in the minority. As one approaches end-of-life decisions for oneself or others, several barriers threaten to hinder one’s ability to make ethical choices. This section may help identify and overcome some of those barriers.

FEAR OF DEATH AND DYING

Most of us are conspirators in our society’s denial of death. People generally do not like to contemplate the subject. We leave funerals with glad, quickened steps. Death is the enemy we prefer to keep invisible. Death is final and irreversible, in a world in which nearly every other natural event is cyclical or recurring. Death causes us to feel shocked, angry, hurt, and offended; it disturbs our view of the way things “should” be.

Beneath this denial is a deep fear of death itself. Christian faith can help us to overcome the fear of death and dying and free us to make decisions with peace of heart and mind. In anticipation of his own death on the cross, Jesus prepares the disciples with these words: “Do not let your

hearts be troubled. Believe in God, believe also in me.” (John 14:1) In a resurrection appearance to the disciples, his first statement is, “Do not be afraid.” (Matthew 28:10) In ministering to people in times of grief, in his own tears of compassion, and in his courageous death and triumphant resurrection, Jesus calls us away from fear and into hope.

Christ teaches that human death is not the final end of life, but an entrance into a new life. In comforting words to Martha following the death of her brother Lazarus, Jesus says, “Your brother will rise again.” Martha responds, “I know that he will rise again in the resurrection on the last day,” implying this is at least partial comfort. Jesus then affirms, “I am the resurrection and the life. Those who believe in me, even though they die, will live, and everyone who lives and believes in me will never die.” (John 11:23-26)

FEAR OF THE UNKNOWN

One of the difficult elements of decision making is not knowing exactly how a medication, procedure, prayer, or conversation may affect a person who is dying. Health care professionals may estimate “how much time the patient has left,” but ultimately life and death are beyond human control. In the words of Job, “I know that you can do all things, and that no purpose of yours can be thwarted.” (Job 42:2)

If one says “yes” to a feeding tube, will it give an opportunity for recovery to the patient, or will it start the patient on a downhill slide toward months of existence in a hospital or nursing home bed? In the latter case, what will happen if artificial feeding is eventually discontinued? (See Older Adult Case Study above.)

Because of this uncertainty, many people choose not to state a preference for or against a particular treatment until something critical happens. Then, in the midst of the crisis, the person will know what is best. But this well-intentioned strategy may not work, since even in the midst of a crisis there are many possible outcomes. (See Pediatric Case Study above.)

Illness always results in some loss of control: part of the loss comes from the illness itself; part of it comes from the realization that one’s future is in the hands of health-care providers. A mission-driven hospital or nursing home provides an environment of pastoral care and support to diminish the vulnerability and dependence of persons in their care. Patients and loved ones are entitled to every medical, emotional, and spiritual support available to help them walk through the “valley of the shadow of death.”

In this less-than-perfect world, we are often called

upon to make end-of-life decisions with insufficient information and trust that God will undergird us in the risks and choices that lead into the future. Jesus teaches us to pray for God's will to be done (Matthew 6:10) and not to be overly fearful or anxious about our lives. Worry about the unknown can distract us from making decisions based on what we *do* know. The popular adage, "Take one day at a time," echoes similar advice from Jesus: "So do not worry about tomorrow, for tomorrow will bring worries of its own. Today's trouble is enough for today." (Matthew 6:34)

GUILT

Guilt could be called "The Great Immobilizer." Guilty people spend a lot of emotional and spiritual energy feeling ashamed of something done or not done in the past or something they contemplate doing now. Guilt is usually not a helpful response when someone is dying. It may be an avoidance mechanism that allows us to dodge responsibility for our own actions and decisions in the present. Guilt may also cause us to transfer responsibility for our behavior to others, whom we believe are causing our guilt.

Clearly there are times when guilt is deserved. Then it should be confronted, confessed, and forgiven. Jesus' teachings about forgiveness are numerous, and even at his own crucifixion he said, "Father, forgive them, for they do not know what they are doing." (Luke 23:34) Burdening oneself with irrational and undeserved guilt will only cause one to be ineffective in a time of great need and/or disable one with years of emotional torment. A great advantage of having an advance directive is that it can free a person's loved ones from guilt about making an end-of-life decision if it explains clearly what is wanted by the person himself or herself.

DENIAL AND PROCRASTINATION

People often deny the need for end-of-life discussions because they don't want to believe this may ever happen to them. There are three good reasons not to procrastinate in filling out an advance directive or values history.

1. The responsibility for life and death is a sacred one, and God calls us to face up to our freedom of choice. In Deuteronomy 30:19, Yahweh proclaims, "I have set before you life and death, blessings and curses. Choose life so that you and your descendants may live." God intends the community of faith to be a place where individuals struggling to make the right decisions about life and death are guided, challenged, and supported. This manual was written to promote that experience within the United Church of Christ.

2. The court system and our civil laws have been structured so that more people will make their own decisions about life-sustaining treatment. The courts are not well equipped to resolve complex ethical dilemmas. Members of our church community and sensitive health care providers are more responsive to the intricacies of religious, medical, social and emotional factors in any given case. Very few cases involving life-sustaining treatments have to go to court; in fact, most can be resolved with cooperation of the person, their family, the health care providers, and, in some cases, an ethics committee.

3. One goal of some advance directives is that a specific person be appointed as agent or representative prior to a medical crisis. This person is empowered and entrusted to make the best decision for the patient in the event this becomes necessary. The agent then knows the patient's beliefs, preferences, and feelings about life and death through personal conversations and is prepared to accept this responsibility.

MISTRUST

A person making end-of-life decisions is usually surrounded by competing advisers. Doctors may disagree with one another; family members may argue; hospital or long-term care staff may seem to be suspect in their motives; and other significant persons may curiously keep silent. People one knows and loves — clergy, neighbors, co-workers — may offer helpful advice, but one is afraid they don't know enough about the situation to offer an informed opinion.

The best decisions arise from a combination of rigorously-questioned medical information, advice from trusted friends and professionals, and spiritual discernment. Job during his time of suffering was surrounded by well-intentioned friends who nonetheless offered no comfort to him. It was only his faith that enabled him to persevere and delivered him from his suffering. (Job 42:10-17) After these barriers to decision making have been overcome, the next step is to begin making decisions for yourself. (JRH/dm)

STUDY QUESTION:

Among your loved ones and acquaintances, what are the best examples of end-of-life decision making? What are the worst examples? Why?

CHAPTER TWO: MAKING DECISIONS FOR YOURSELF



ADVANCE DIRECTIVES

We believe life to be sacred, because God created humankind in God's image (Genesis 1:26-27). God limits our duration of life on earth. We are born, we are here for a period of time, and then we die. "For everything there is a season, and a time for every matter under heaven: a time to be born and a time to die." (Ecclesiastes 3:1-2a) When King Hezekiah became so sick he was near the point of death, Isaiah the prophet came to him and said, "Thus says the Lord: Set your house in order, for you shall die; you shall not recover." (II Kings 20:1) This was the phrase for settling one's affairs in the face of death in the days of the Hebrew Scriptures. In our time, it is equally imperative we set our affairs in order while we are healthy and competent.

If a person is competent (see definition in glossary), health care professionals do not have the right to touch a person's body or treat them without the person's consent. <2> One can protect this right of privacy and control over one's medical care while one is still competent by writing legal documents called the Durable Power of Attorney for Health Care (DPAHC) and/or the Living Will (LW). (These documents have various names in different states. For a state by state listing, contact Choice in Dying, Inc. The address is listed in chapter three.) Advance directives enable persons to avoid court proceedings if they should become incapacitated and require that others make health care decisions on their behalf, because the written directives state in advance what the person would want done. <3>

There are no federal laws for advance directives. But the Patient Self-Determination Act, effective December 1, 1991, does state any health care institution receiving federally funded Medicare or Medicaid dollars is required to inform its patients of their right under state laws to:

- execute an advance directive;
- understand the facility's policy regarding advance directives;
- and present to the facility any advance directive which has already been properly executed.

These requirements apply to hospitals (inpatients or outpatients), doctors' offices, long-term care providers, HMOs (health maintenance organizations), and home health agencies.

What type do I need?

Some professionals recommend persons should have both a DPAHC and LW. "A living will only normally addresses the issues of life-sustaining procedures for the terminally ill. . . . A durable power of attorney covers all health care decisions." <4> If both are used, they need to be consistent. However, in some states, such as Wisconsin, people are discouraged from completing both. There a DPAHC takes legal precedence over an LW. Doctor and attorney Alan D. Lieberman recommends the Comprehensive Living Will that takes the place of both DPAHC and the typical short form LW. <5> This document is detailed more in the living will section.

How do I complete an advance directive?

Once these documents are written they become legal only when they are signed and dated by the principal before unrelated witnesses. It is often recommended they be notarized. The originals are to be kept in a safe place. The documents should be reviewed every few years to ascertain whether they meet the present need. California has a seven-year limit on the DPAHC, at which time it must be rewritten. A person must usually be 18 years old and a legal adult in their state of residence when drafting advance directives. <6> State statutes establishing these rights are continually in process of change. Check current law on these rights before drafting such documents.

Before finalizing an advance directive, one should review it with one's physician to be sure that the physician has no personal or professional reasons not to honor one's wishes. If the physician has reservations about your requests

find another physician who will honor your wishes. The "Checklist of Medical Interventions" below will promote this discussion. Some states require registering a DPAHC with the county recorder where one resides. <7> Advance directives may be revoked at any time by a competent person, as described at the end of this chapter.

CHECKLIST OF MEDICAL INTERVENTIONS TO BE DISCUSSED WITH YOUR PHYSICIAN(S)

- pain medication: narcotics and other drugs administered to reduce pain
- antibiotic treatment: the use of drugs to fight bacterial infection
- blood transfusion
- simple diagnostic test: blood test, X ray, etc.
- invasive diagnostic test: a more complex test that may require cutting of the skin or the insertion of an instrument (cardiac catheterization, etc.)
- chemotherapy: treatment of cancer with drugs, which may have substantial side effects
- kidney dialysis: mechanical removal of waste from blood
- minor surgery: a minor operative procedure
- major surgery: a more difficult and potentially dangerous procedure
- organ transplantation: replacement of a diseased organ with the organ of another person
- mechanically-assisted breathing: may require the insertion of a tube into the windpipe
- cardiopulmonary resuscitation (CPR): techniques for stimulating a stopped heart
- artificial nutrition and hydration (see glossary)

What is Durable Power of Attorney for Health Care?

This document is recognized throughout the United States, so if it is created in one state it is likely to be honored in another. <8> It is called "durable" because it continues to be legally effective if and when the person who writes it becomes incapacitated (see glossary). Many states have actual forms for the DPAHC which are recommended, though others simply have statutes authorizing the use of such a document. Copies are available in libraries, health care institutions, doctors' offices, state or county offices, or through Choice in Dying.

DPAHC forms leave space for a person to individualize the document, e.g. "Under no circumstances do I wish to receive artificial feeding through a tube," or "I would like to be kept alive if I will be able to appreciate the birth of a new grandchild." Thirteen states require a person to see a lawyer when drafting a DPAHC; the rest do not.

There are two types of DPAHC forms: standard

and "springing." The standard kind becomes effective at the time the principal (see glossary) signs it or on a specified date. The "springing" type becomes effective only if and when the principal becomes incapacitated and unable to make health care decisions. Then the principal's "agent" (or successors if the primary agent is unable or unwilling to serve) will make the person's health care decisions. This agent, also referred to as a surrogate decision-maker, is the person selected by the principal and trusted to make very critical choices on the person's behalf. <9> This agent may or may not be a relative or an heir, but the agent should not be a total stranger to the person writing the DPAHC. <10> The agent accepts enormous responsibility in accepting the task. The form should be explicit in defining exactly what the person wants in health care, including the use, withholding, or withdrawal of life-sustaining treatments. The principal and agent should talk over these details with some care.

- Many states permit agents designated by a DPAHC to withdraw or withhold life support;
- Some states will allow agents to consent to medical treatment but do not specifically authorize them to allow withdrawal or withholding of life support; and
- Some states permit agents to make medical decisions, including withholding or withdrawing life support. <11>

What is a Living Will?

Competent adults can make self-determined decisions about withdrawing or withholding life-sustaining procedures as a constitutional right. <12> All but a few states have enacted LW legislation since 1976, due to the public's growing concern about death with dignity.

Incompetent persons do not have the right to refuse life support or require it to be withdrawn unless one of the following provisions applies:

- The person completed a valid advance directive while still competent.
- A court-appointed guardian makes the decision.
- A surrogate decision-maker makes the decision, as provided by law in some states (such as Illinois).

There are two kinds of Living Wills: statutory and common law. The statutory LW comes into being through a law passed by a state legislature. It can be applied only when a person is diagnosed by a doctor as terminally ill or in a persistent vegetative state. Common law LWs are the only valid LWs in states that do not have statutory LWs. They may also become valid in states with LW statutes

when an individual's LW does not comply with the state law and thus does not show clear and convincing evidence of the declarant's desires. <13>

A problem with LWs in some states is that the statutes seem to protect individual rights, but do not always "apply" to individual cases as people had expected. For instance, persons with Alzheimer's Disease, multiple sclerosis, muscular dystrophy, or AIDS often do not have their LWs honored. Their conditions are terminal, but doctors may hesitate to specify that such patients will die within a specified time period. Another problem is that statutory LWs may not grant physician immunity, causing many doctors to feel reluctant in honoring these directives. Furthermore, LWs may be valid only in the states where they are appropriately enacted. (Some states, such as Illinois, will honor a LW which has been validly executed in another state.) Some persons need to complete additional LWs when they travel or maintain residence in more than one state.

This points to the need for a document that will be legally valid in all situations in any location. The Comprehensive Living Will (CLW) was developed to meet that need.

What is a Comprehensive Living Will?

This combines the DPAHC and LW into one document. There is a place in the document to insert one's LW. The CLW defines the meaning of ambiguous terms such as "permanently unconscious," which is commonly used without definition in LWs. It details all the situations a person might experience in a terminal condition. The writer of a CLW makes choices in 11 articles to either use life support systems or withhold or withdraw them. It provides for physician immunity when the CLW provisions are followed. There is room for personal additions and remarks. Terminal conditions, such as Huntington's disease are mentioned in the CLW in a section on end-stage dementia, which is not included in short form LWs. A CLW is a more effective document than a LW to achieve withdrawal of artificial feeding tubes from non-terminal, yet severely incapacitated patients.

Three other advance directive documents are less commonly used than those described above, but serve similar purposes. They are: the Medical Care Directive; the Personal Medical Mandate; and the Values History.

What is a Medical Care Directive?

This document is written with the help of a lawyer and is oriented toward the person who is writing it. It calls for one's family to express love during the time of dying through verbal and physical sharing, such as touching. It requests that the person who is dying be informed of his or her own condition and prognosis. If the person is in a terminal condition, life-prolonging medical treatment is forbid-

den. The patient can appoint someone else to make health care decisions based on the patient's philosophy of life and religious beliefs.

The Medical Care Directive may state that the patient be kept comfortable through pain medication or that food should not be withheld. It is signed and dated by the person completing it and two unrelated witnesses. If this document is appropriately enacted it would fall under common law, making it subject to court procedure — exactly what the DPAHC and LW seek to avoid. <14>

What is a Personal Medical Mandate?

This was created by two physicians in 1989 and is a variation of the DPAHC and LW. It is designed to aid physicians in better understanding the desires of a patient when the person is incompetent. Vague terms such as "heroic measures" are omitted. It is intended to support a state's LW rather than take its place. There are many places where personal choices can be made by the writer. It has two main weaknesses when compared with the CLW: it has less detailed choices than the CLW; and it does not go to the same extent as the CLW to ensure it is appropriately enacted in both statutory and common law, so it lacks the legal strength of a CLW. <15>

What is a Values History?

One advance directive planning tool that offers a wholistic decision making process to address death and dying is called a Values History. <16> It is not legally binding, nor is a similar tool, called the Values History Form. The Values History Form gathers information about legal documents a person has completed; wishes concerning medical procedures; and attitudes about one's health, independence and control, relationships, illness, finances, and funeral. <17> Sample questions include:

1. Have you written any of the following legal documents? Living will, durable power of attorney for property, durable power of attorney for health care decisions, organ donor card? On what dates? Where are they located?
2. What are your wishes concerning specific medical procedures? Organ donation, kidney dialysis, CPR, ventilator, artificial feeding and hydration.
3. How would you describe your current health status? How well are you able to meet the basic necessities of life?
4. Do you trust your doctors to make decisions concerning any treatment you might need?
5. How important is independence and self-sufficiency in your life?

6. Do you expect that your friends, family and/or others will support your decisions regarding medical treatment you may need now or in the future?

7. What, if any, unfinished business from the past are you concerned about (e.g., personal and family relationships, business and legal matters)?

8. What activities do you enjoy? How satisfied are you with what you have achieved in your life? What goals do you have for the future?

10. What will be important to you when you are dying?

11. Where would you prefer to die?

12. How do your religious beliefs affect your attitude toward serious or terminal illness?

13. How does your faith community, church or synagogue view the role of prayer or religious sacraments in an illness?

14. How much do you worry about having enough money to provide for your care?

15. What are your wishes concerning your funeral and burial or cremation?

16. Have you made your funeral arrangements? If so, with whom?

17. How would you like your funeral and burial or memorial to be conducted?

A values history has at least two advantages. (1) It puts decisions about death and dying in the context of one's overall life and the beliefs which are most important. (2) It provides friends, family, and caregivers with much more information to guide them in times when they are likely to be feeling great stress.

It may be included in one's medical record, home files, and/or it may be used to stimulate intergenerational discussion in a family. It may be completed by anyone without the assistance of a professional. The topics are applicable for teenagers through adults, and could be helpful in schools, hospitals, long-term care facilities, community centers and churches. It would be of great help in an ethics committee consultation.

While a values history looks like a questionnaire, it is "more importantly a process of reflection and communication that can take place over a lifetime. . . . While we cannot predict our future, we can at least explain ourselves now. That explanation may help ensure that the person we are, and hope to be, is respected by others who must stand in our stead." <18>

HOW TO REVOKE AN ADVANCE DIRECTIVE:

A revocation of a durable power of attorney means you are taking away the power or authority you granted when you created the documents. A revocation of a living will means you have changed your mind in respect to your preference in the event of a terminal illness. As long as you are competent, advance directives may be revoked at any time, in one of the following ways.

1. Tear it up and inform all other persons and/or institutions who may rely on the document that it is no longer valid.

2. Revoke it verbally in front of two witnesses.

3. Revoke it in writing.

4. Create a new one and destroy old directives.

5. The DPAHC will automatically terminate in the event of the death of your surrogate, agent or proxy, unless you have made provisions for a successor agent.

A final word about advance directives:

A 1989 study shows less than 20 percent of Americans have completed an advance directive. This is unfortunate, because drafting specific directives can ease end-of-life decision making for the vast majority of us who will spend the last days of our life in health care institutions. Writing an advance directive does take time and does require us to make provisions for some unknown future date when some unknown event could significantly alter our lives. But the benefits of having done this are great: providing peace of mind for ourselves and our loved ones by making decisions that are in harmony with our faith and our beliefs about stewardship. Most of us will take the time to buy insurance and write a will to provide for our money and property at the time of our death — why then should we not take the time to provide for our own spiritual, emotional, and physical well-being by completing advance directives?

(EEW/dm)

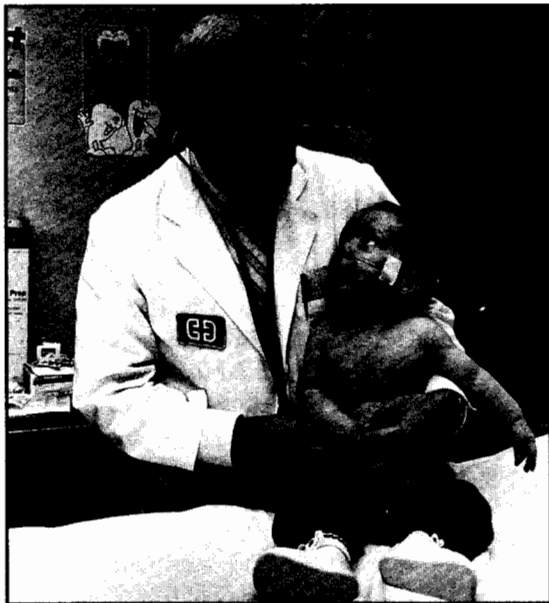
STUDY QUESTIONS FOR CHAPTER TWO:

1. Explain the difference between a Power of Attorney, the Durable Power of Attorney for Health Care, and the Living Will.

2. What next steps do I need to take to "set my house in order"?

3. What happens when an incompetent person with a diagnosed terminal illness, who has no advance directives, is rushed to a hospital in an emergency medical vehicle?

CHAPTER THREE: MAKING DECISIONS FOR OTHERS



WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT: NEONATAL AND PEDIATRIC ISSUES

Making decisions regarding continuation of human life, or allowing death to occur without further intervention, is never easy. To decide under what conditions one's own life should not be artificially supported is a difficult personal decision, one which is generally honored as the individual's own decision to make. To decide on behalf of another is more complex. When the other is an adult, then a surrogate decision maker may use his or her knowledge of the individual to infer the kind of decision the individual, if competent, would have made. When the crisis involves an infant or youth, the emotional, legal, and moral issues become significantly more complex.

"Neonatal" is the period of time usually associated with the word "newborn." A number of issues commonly present potential end-of-life decisions during this period.

Extremely early gestational age (babies born at 23-25 weeks, instead of the usual 40 weeks of pregnancy), or babies born with extremely low birth weight (one-two pounds) are at high risk for severe birth defects which are incompatible with life; complications which occur during delivery, such as anoxia (lack of oxygen) and severe neurological damage; and genetic problems — each of which may raise possible continuation of life issues which parents and staff must address. Modern medical care in a neonatal intensive care nursery comes at great monetary and emotional cost to the family, as well as the cost of pain and suffering to the infant. Parents must decide whether to begin on this path, when the outlook is bleak. (They may not always have

a choice.) Often a decision must be made in a very brief period of time. Information which is complicated, and rarely definitive, must be processed while the emotions are still stunned and shocked questions ("Did I cause this problem for my child? Is this God's punishment for . . .?") race through parents' minds. Well-meaning relatives (and sometimes hospital staff) may try to shape the decision, especially if the parents are very young.

If parents decide to pursue life-prolonging medical intervention, end-of-life decisions may still face them during the course of hospitalization, or during subsequent years if the child remains medically fragile.

Intracranial bleeding leading to severe neurological impairment, lungs too damaged to provide a good oxygen supply to the body, kidney failure, and necrotic bowel tissue are a few of the common problems. How much should be done? For how long? What is a "good outcome?" What does it mean to love your baby? Does it mean "do everything?" Or does it mean "letting nature take its course — my baby has suffered enough?" If the latter decision is made, should there be withdrawal of support? Or should a path of passive non-intervention be followed? The parent who has given life must now decide major moral questions which affect this new life.

"Quality of life" decisions are also faced by parents of older children. A nine-year-old accident victim is a ventilator dependent quadriplegic, experiencing erratic heartbeats. If cardiac arrest occurs, should resuscitation be attempted? What do parents/staff believe about physical disabilities? How far should parents decide to go with experimental treatments for their child's disease, or even with conventional treatments which are not working? There may be times when parents will not be truly free to make decisions regarding their child, based on their own moral, religious, and psychosocial beliefs. If parents decide against treatment, and the medical staff disagrees, the courts may take custody and impose treatment. Thus, end-of-life decisions do not always lie solely within the parent's control.

Spiritual, emotional, and relational issues are interwoven in these crises. The family facing end-of-life decisions for a child may be very young; they may be estranged from each other; there may be only a single parent. The family may be socially isolated, dysfunctional, or already overburdened by other demands. The child may be a long awaited child, perhaps the first "boy" or "girl" born into the family line in several generations; the child may represent hopes and dreams which are difficult to separate from the child. Helping a family make a decision which will affect their lives forever means knowing not only the medical dilemmas and the moral questions involved, but also the people who will live with the decision and how they will live with it.

One begins to ask questions of faith: "Where is God in all of this? Why does God let this happen? Will (*can*) God bring healing even in the most extreme circumstances? If I reform my behavior, will God's mind/decision be changed?" Here divine providence and human sinfulness intersect. The sacrament of baptism and other rituals may bring the comfort and assurance of God's love and care for those within the church. They may also bear unspoken hopes of changing the outcome. Parents, whether from church-going or from "unchurched" homes, often have not had the time and experience to think through these challenging faith questions. They may find that a childhood or adolescent level of faith no longer "works" for them. Feelings of abandonment and betrayal may now overshadow belief.

There is no single Christian understanding that might serve as a guide, a kind of "road map" or destination for decision making. Decisions always involve holding competing Christian values in tension. The sanctity of life as gift stands in tension with our belief that death, while grievous, is not an "ultimate." Decisions must be made in the midst of uncertainty. We are called to act responsibly, for each child is God's creation, one for whom Christ died. But respecting life and allowing death to occur are not necessarily opposites. In the Pediatric Case Study, a responsible decision must consider the best interests of the child. It must also consider the family who will live with the decision, including the older siblings who are equally loved by God and parents. In the end, the decision will affect the larger human community, who will need to participate financially and socially in the outcome. Responsible Christian people may find themselves making radically different decisions. What we can claim in the decision making process is that God is with us as we listen, reflect, and pray. God is with us, and suffers with us. And God will move with us into the future to bring renewed life: for the individual, the family, and the larger community.

The support of pastors, chaplains, and church members during this intensely painful and difficult time is crucial. When parents feel their questions and cries of anguish have been heard (not necessarily answered), when they are helped to process the meaning of medical information in the light of Christian faith and beliefs, they may then experience authentic grief and a deepening understanding of God and God's world. End-of-life decisions always reflect our beliefs. The faith community that is present and supportive also connects the family to a history of faithful people who have experienced both crisis and redemption.

"We must be Easter people, deeply rooted in the world and its pain but holding always within the same focus the God who made us and who alone makes sense of our living and our dying. . . . Right at the heart of the mystery of suffering is the grace that sustains us all, carers and cared for alike." <19>

(HSN/dm)

WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT: HOW TO DETERMINE AN ADULT'S WISHES

Making end-of-life decisions for someone else is frequently easier if one is guided by the principle of "substituted judgment." A series of judicial decisions and recent state statutes have developed legal standards for use by those who are the "proxy" or "surrogate" decision-makers. These standards are proven useful not only for surrogates acting under a court's direction but also for families and friends making decisions for incapacitated patients outside a court's jurisdiction.

Case law in this area varies from state to state (see below). **In general, substituted judgment requires trying to make the decision the patient would have made if legally competent or capable of making decisions.** The surrogate is not to decide by equating his or her own desires with those of the patient ("If I were you" reasoning). Nor is the goal to form a judgment of the patient's "best interests" based on criteria that do not consider the patient's own wishes. The highest goal is not really to "substitute" a judgment at all, but rather to convey a judgment that plausibly could have been the patient's own decision. <20> (This is what Joe's family in the Adult Case Study sought to do as they reported his statements about being "hooked up to machines.")

In the court system, a substituted judgment will follow the guidelines of case law in that state. Frequently, these decisions are made quite apart from the court setting, but most state laws assume that a health care power of attorney or agent will exercise substituted judgment.

But how do we know what another would want? Can we know at all? Courts have established standards of "proof" for substituted judgments (see below) and suggested sources of evidence that may meet those standards. Advance directives, such as a living will, may offer important guidance in making a decision, even when the patient's condition does not meet the medical criteria necessary to "operationalize" it.

Direct, clearly recalled spoken desires about a medical treatment now in question are also good guides for surrogates. For instance, the patient may have made comments about others' medical treatment; religious beliefs about life, death, and health; and/or consistently displayed attitudes and conduct regarding medical treatment. Overall values and the way one has lived one's life are also relevant information for surrogates. <21> In the Older Adult Case Study, Myrtle's surrogates supported their request to withdraw her feeding tube by citing Myrtle's former subjective experience of a zest for life, which was made possible by her relatively good health.

It is one thing to contemplate these issues and quite another to feel their emotional impact once a health crisis strikes. Making life and death decisions on behalf of another person can be painful, and the emotional strain can make decision making difficult. Seeking support from others — family, friends, fellow church members, pastor or chaplain — is vital. It is important to sort out our feelings, with the help of a sensitive other's listening ear, if we are to think clearly about the decision at hand.

One value of referring to substituted judgment at such a time is that it keeps the focus on what the patient would have wanted, and reminds the decision-maker that he or she is the "agent" of the patient's desires rather than his or her own wishes or needs. This recognition may relieve the pressure of feeling that it is I, the surrogate, who must "decide" about another's life and death. In fact, in most cases it is the patient's physical decline that is truly "decisive" and thereby is the primary "cause" of death, rather than someone else's decision about the death-delaying use of medical technology. Realizing this may not only bring a degree of comfort or relief from guilt; it may also help a decision-maker to be clear-sighted in sorting through the medical options and seeing them through the patient's eyes. (DBM/dm)

Where to get help: Ethics Committees

Ethics committees are found in many health care institutions. They provide education, policy review, and case consultation or review that addresses the ethical issues involved in a particular situation. <22> Patients, residents, family members, physicians, or hospital/long-term care staff usually have the right to request a consultation by the ethics committee. They may contact the institutional administrator or pastoral care department for information.

Committees vary depending upon the nature of the care provided by a facility or agency: long-term or short-term, skilled or intermediate, institutional or home care. Ethics committee education is focused on the needs of the staff, patients, family members and friends, volunteers, and the wider community. Educational topics may include different understandings of the approach of death, legal issues, policy questions, or consequences of the withdrawal of life-sustaining treatment. <23>

In large medical centers the ethics committee may be composed of several multidisciplinary teams which are constantly at work daily and on call for consultation emergency situations. <24> Another model in some hospitals is to provide one or two ethics consultants who are on call. Often, hospitals conduct ethics "rounds" involving case review by doctors and other staff. In long-term care settings the ethics committee may meet every three months to consider policy and once a month or weekly to hear resident issues and problems.

Ethics committee members can include doctors, nurses, administrators, social workers, ethicists, chaplains,

and lawyers. In addition, many committees include patients or long term care residents, family members, board members, resident advocates, dietary staff, nurses' aides, and/or community clergy. <25> **The approach of such a committee is wholistic**, pursuing concerns for the whole person: physical, emotional, social, and spiritual well-being. <26>

The ethics committee does not diagnose. This is the physician's task, often performed in consultation with other specialists. Ethics committees consult, rather than making decisions. "They provide a process so key decision makers can make their best, most well-informed decisions." <27> The committee reviews the case, considers the ethical issues, and makes recommendations to the decision makers, considering the risks and consequences. The ethics committee also reviews policies of the institution to ensure that respect, privacy, and confidentiality are reflected in the care that is provided.

Typical ethical issues considered in the hospital setting are resuscitation, intubation, artificial feeding and hydration, pain management, neonatal life support, autonomy and self-determination related to advance directives, decisions about limiting routine treatments, withdrawing or withholding life-sustaining treatment, and economic issues such as the cost of care and constraints imposed by managed care.

Ethical issues in long term care include most of the above as well as: whether or not treatment should include hospitalization, roommate selection, privacy, table-mate assignments, sexual or affectional involvements, and admission/discharge policies.

Ideally, the multidisciplinary team which constitutes the ethics committee should demonstrate mutual respect and professionalism among its own membership. However, there is some danger that persons representing the different disciplines could become opponents instead of friends working together in cooperation for the benefit of the patient. This could severely damage the health care institution and should be prevented, for the sake of the patients' well-being. <28> (EEW/dm)

STUDY QUESTIONS:

- 1. What are the three tasks performed by an ethics committee?**
- 2. What disciplines should a person look for in an ethics committee?**
- 3. What are the dangers present within the power structure of an institutional ethics committee?**
- 4. What, for you, would be the key issues if faced with the need to be a decision-maker?**

Where to get help: Court Cases

The court system can be a source of help in resolving disputes or clarifying legal standards for treatment at the end of life. When in doubt, patients and others can consult an attorney for legal guidance about case and statutory law, advance directives, and the option of seeking guardianship through the courts.

Courts across the country have issued many and varied rulings on cases involving life-sustaining treatment since the Quinlan ruling in 1976. The Quinlan case was initiated by the parents of Karen Quinlan, a young adult who was in a persistent vegetative state. They sought through the courts to turn off the ventilator which was keeping their daughter alive, with little quality of life. Other court rulings have addressed such matters as: the determination of death (brain death); the definition of life-sustaining treatments (e.g. mechanical respirators, renal dialysis and artificial feeding and hydration); "who decides" — physicians, ethics committees, families or court-appointed guardians — when the patient cannot; and standards for surrogate decisionmakers to follow (i.e., "best interests" or some form of "substituted judgment"). The Quinlan case established the right of a surrogate decision maker to make a substituted judgment for an incompetent patient in requesting removal of life-prolonging treatment.

The 1990 U.S. Supreme Court decision in the Cruzan case is of special interest because it is the first case in which the Court ruled on a patient's life-sustaining treatment. Like Karen Ann Quinlan, Nancy Cruzan was a young woman in a persistent vegetative state. Her parents were seeking to discontinue artificial feeding and hydration. In this case the Court upheld a patient's "liberty interest" in retaining the option to refuse life-sustaining treatment. At the same time, the Court allowed states the right to set their own standard of proof regarding what constitutes sufficient evidence, once a patient is incompetent, of that patient's previously expressed or inferable wishes to refuse treatment. By implication the majority opinion in Cruzan treated medically administered nutrition and hydration as a form of life-sustaining treatment that, like other such treatments, could be withheld or discontinued when reasonably established state safeguards were observed.

As noted in chapter two, nearly all states now permit a competent patient to execute a legally binding "advance directive" regarding his or her care if the patient becomes decisionally incapacitated and/or certain medical circumstances (such as a terminal illness) arise. In addition, most states recognize the right of patients to have decisions made for them by guardians or other proxy decision makers on the basis of the patient's own desires as directly expressed or implied while the patient was competent.

In the past the recognized standard for such decision making was normally the patient's best interests, understood in terms of broad categories such as physical risks, harms, and benefits. Typically, best interests judg-

ments have been conservative. They have tended to prefer life (of whatever quality) over death, and have considered effects of treatment on physical health rather than emotional or spiritual factors. Note that, from a legal perspective, the family's interests are not a relevant consideration in treatment decisions. (Thus, when the Pediatric Case Study suggests the best interests of David's family might be served by forgoing CPR, this possibility would probably be disregarded by a court deciding the case.)

Where questions have arisen about the certainty of the incapacitated patient's previously expressed desires, courts and legislatures have had recourse to two standards of evidentiary proof: "preponderance of evidence" and "clear and convincing evidence." The "preponderance of evidence" test is a looser one that may be met by reference to general statements of the patient or appeals to the patient's characteristic attitudes about life, death or medical treatment.

The "clear and convincing evidence" standard requires evidence of a direct expression by the patient regarding the specific medical treatment now at issue. For this test, the "substitution" of others' judgment about what the patient "would have wanted" is insufficient unless it is accompanied by clear "subjective" evidence directly attributable to the patient. So far courts have stopped short of requiring a written advance directive in order for this test to be met, but advance directives obviously can be a useful means for meeting the standard.

Weighing Benefits and Burdens

Sometimes an incapacitated person's treatment wishes are not known, or a surrogate lacks full confidence in his or her ability to infer those wishes. In such cases the surrogate may resort to a form of "best interests" determination by weighing the prospective benefits of treatment against the prospective burdens.

We may wonder, "What counts as a 'benefit' or 'burden'?" In general, benefits may be of two kinds: "objective" and "subjective." **Objective benefits** are measurable or observable. Examples include reversals of the disease process, improvements in physical function, prolonged life, decreased symptoms of pain, or observably improved mental functioning. In the Older Adult Case Study, Myrtle's physician appealed to such objective benefits of treatment as preservation of her observed responsiveness and her overall viability.

Subjective benefits are those that are actually experienced as "benefits" by the patient. They may encompass objective benefits since an objective benefit may be experienced as subjectively rewarding or helpful. Achieving a better "quality of life" or "meaningful life" are subjective benefits. Prolonged life in itself may or may not be a subjective benefit. Pain relief, on the other hand, is almost always a subjective benefit as well as an objective one. In contrast with the physician, Myrtle's surrogates cited what

they considered her subjective criteria for a life worth living. Treatment that could not promise a return to this kind of life would not truly "benefit" her, in their view.

"Burdens" are the opposite of benefits and may be either objective or subjective. The "burdens" under consideration are those introduced by the treatment itself, not those already imposed by the patient's condition. Life-sustaining treatments may impose added pain or suffering, they may weaken the patient, or they may reduce the patient's quality of life. If these and other burdens clearly surpass the benefits, a benefits-burdens determination to forego life-sustaining treatment may be considered.

It is important to note that an aspect of "substituted judgment" may enter a benefits-burdens calculation. In assessing subjective benefits and burdens, the surrogate may draw on his or her best sense of what the patient would feel as a benefit or a burden.

Life-sustaining treatments seek to yield the objective benefit of prolonging life. This benefit will sometimes be the only one to be weighted against the burdens imposed by the treatment. Further, those burdens will often be coupled with the burdens already imposed by the patient's medical condition. If the only achievable benefit is extended life, a surrogate may find it difficult to estimate burdens of the treatment without also considering the existing burdens of the patient's condition. (DBM/dm)

Where to get help: Professional organizations

The following groups may provide assistance in coping with particular health issues, offering educational materials, support groups, and/or lobbying efforts.

AIDS

Office of Public Affairs
U.S. Public Health Service
Room 721-H
200 Independence Ave., SW
Washington, DC 20201
(800) 342-AIDS

American Association of Retired Persons

601 E Street, NW
Washington, DC 20049
(202) 434-2277

American Diabetes Association

1660 Duke Street
Alexandria, VA 22314
(800) 232-3472

American Heart Association

7272 Greenville Avenue
Dallas, TX 75231
(214) 373-6300

American Lung Association
432 Park Avenue South
8th Floor
New York, NY 10016
(212) 889-3370

Cystic Fibrosis Foundation
6931 Arlington Road
Bethesda, MD 20814
(800) FIGHT-CF

Muscular Dystrophy Association

Patient Services
342 Madison Avenue
New York, NY 10017
(addresses various muscular disorders, including ALS)
(212) 689-9040

National Hospice Organization

1901 N. Moore Street
Suite 901
Arlington, VA 22209
(703) 243-5900
Help Line: (800) 646-6460

Alzheimer's Association

919 N. Michigan Avenue
Suite 1000
Chicago, IL 60611-1676
(800) 272-3900

American Cancer Society

1599 Clifton Road, NE
Atlanta, GA 30329
(404) 320-3333

American Health Care Association

1201 L Street, NW
Washington, DC 20005-4014
(202) 842-4444

American Hospital Association

1 N. Franklin
27th Floor
Chicago, IL 60606
(312) 442-3000

Choice in Dying

200 Varick Street
New York, NY 10014
(212) 366-5540
FAX (212) 366-5337

Huntington's Disease Society of America
140 W. 22nd Street, 6th Floor
New York, NY 10011-2420
(212) 242-1968

The National Hemophilia Foundation
The SoHo Building
110 Greene Street, #303
New York, NY 10012
(212) 219-8180

National Cancer Institute
Publications Order Service
P.O. Box 24128
Baltimore, MD 21227
(800) 4CANCER

(EEW/dm)

STUDY QUESTIONS FOR CHAPTER THREE:

In Chapter One, three ethical foci were discussed: What is best for the person? Who should make decisions about life and death? Who will tend to issues of social and distributive justice?

1. In light of the facts given in each of the three cases, what should be done? Discuss each case from (a) the patient's perspective, (b) the family's perspective, and (c) the physician's/nursing home staff's perspective. (If a physician or other health care provider is a member of the group, ask him/her to play the role of the staff.) What theological understandings support each perspective? What Christian values compete with each perspective?

2. Who should make the decisions needed?

3. Discuss the financial cost of caring for these individuals. Should this impact the decision making process? If so, how should it affect the decision? If not, why not?

CHAPTER FOUR: ETHICAL APPROACHES



Christians value the moral guidance our faith gives us. However, most literature in the field of bioethics (which relates ethics to biology, medicine, and health care <29>) describes issues from a “secular” or non-religious perspective. Whatever our feeling about this development, contemporary bioethical discussion does offer moral wisdom that can aid our decision making. There are vital connections between the secular guidance of bioethics and the guidance we find in the Judeo-Christian tradition.

One widely accepted bioethical framework identifies four key principles that shape ethical decisions. The principles are:

1. autonomy
2. beneficence
3. nonmaleficence and
4. justice <30>

No one claims that these principles by themselves are sufficient to tell us how to act in particular situations. The principles can, however, structure our thinking and sensitize us to critical moral issues.

Respect for Autonomy

The principle of respect for autonomy may be the best known of the four principles. “Autonomy” or self-determination is our capacity to govern our lives, to shape and carry out our “personal plans for life.” <31> This capacity is often said to deserve respect because it is at the heart of our humanity, and because its exercise is crucial to

our creative engagement with life.

Thus respect for autonomy depends, first, on the presence of “competence” or the capacity to be autonomous. It is generally agreed that legally incompetent or decisionally incapacitated patients (including most minors) need others to make decisions in their behalf (see chapter three). The uncertain capacity of Mr. Hriniaik in the Adult Case Study made it difficult for the hospital staff and physicians to accept his “wish to die” as a truly autonomous expression.

Respect for autonomy depends, second, on an understanding of “respect.” In current practice, respect for autonomy most often seems to mean following the patient’s wishes and not intervening in his or her choices. This view sees respect primarily as a duty not to “interfere.”

Clearly, the rise of this form of respect for autonomy has protected many patients against what might have been done “for” them but against their will, especially in the realm of life-sustaining treatments. It has also been a moral driving force behind today’s emphasis on the patient’s informed consent to (or refusal of) treatment, as well as the emergence of the advance directives discussed above.

Beneficence and Nonmaleficence

The principle of beneficence generally refers to a duty to do good, confer benefits, and prevent or remove harm when we can. For health caregivers, beneficence toward patients is a duty central to their professional role. Physicians since the time of Hippocrates have pledged themselves to benefit their patients and protect them from harm. Mr. Hriniaik’s physicians felt duty-bound to continue their life-prolonging efforts, especially since they believed that benefits beyond merely extending his life were also likely.

Clear thinking about medical beneficence requires that the goals of treatment (the benefits sought) be clear. Sometimes the goals of medicine conflict: prolonging life, for example, may be at odds with relieving or avoiding suffering. In such instances priorities have to be set and treatment choices made. Goals or values of patients may differ from those of medical caregivers or families. A conflict between others’ “paternalism” and patient autonomy may arise, a conflict in which different views of the patient’s welfare are at work. Respect for autonomy may then function as a limit on the scope of beneficence.

From another perspective, the principle of nonmaleficence also sets a limit on beneficence. Nonmaleficence is the caregiver’s duty not to inflict harm. As the Hippocratic tradition puts it, “Above all, do no harm.” Myrtle’s physician in the case study did fear — rightly or wrongly — that removing the feeding tube would

violate his overriding duty of nonmaleficence. Not only does this duty bar physician involvement in active euthanasia, but it also requires the beneficent doctor to weigh prospective benefits against the likely burdens of a given medical treatment. Of course medical care often involves pain, discomfort, and a degree of risk. Nonmaleficence pledges that the intent to benefit is primary and the physician will carefully weigh the probable outcomes.

Justice

Justice can have many meanings in health care, especially in the domain of public policy. In patient care the principle of justice holds that each person should receive what is due her or him. More specifically, similar cases should be treated in similar ways while dissimilar cases should be treated in accord with their differences.

What needs to be determined in each case is just what similarities and differences are relevant to decisions about treatment. Is the age of the patient, for instance, a decisive or even a relevant criterion in determining whether to offer or to continue life-sustaining treatment, as with 98-year-old Myrtle in the case study? The principle of justice also presses us to be consistent in selecting and applying our criteria from one case to the next.

What about Conflict?

If these principles come into conflict, some way to resolve the conflict must be sought. The "facts," medical and otherwise, of a particular case are important information in conflictual situations. In the Pediatric Case Study, the certainty of quadriplegia and the strong possibility of severe brain damage are important data for David's family and the medical personnel to consider in weighing the ethical options for his care. Given the facts insofar as they are known, some prefer to resolve conflicts by appealing to the consequences (for the patient, or for all affected) that might result from various courses of action. David's physician seems to be thinking primarily of consequences — mostly unfavorable ones — when he asks the family to consider the advisability of CPR if David's heart stops.

Others try to weigh the relative claim they believe the principles make on the participants in the situation. For example, many today feel the claims of patient autonomy take precedence over the claims of medical beneficence if the two conflict. Facts, such as a patient's doubtful decision making ability, might modify that judgment.

The initial "do everything" response of David's parents probably reflects their sense of their son's claim on their protection and support in the face of death. Further reflection might lead them to view their son's claim as a claim on their love and care, which may be expressed through various courses of medical action. Possibly David's

parents could make a loving decision to "let go" of the effort to prolong his life with its likely limitations and suffering, or make a loving decision to "hang in" with him in the hope of his survival and eventual rehabilitation.

Christian Perspectives

We might wish for a one-to-one correspondence between such secular principles as respect for autonomy or beneficence and such Christian moral guides as "Love your neighbor as yourself," or "Honor your father and mother." However, application of these biblical commands may not be clear in situations created by modern health care and its life-sustaining technology.

Nevertheless our tradition — Scripture, the historic experience of people of faith, and the church's theological reflection — does shed light on the principles and issues identified above. **Much in the biblical story, for example, raises questions about the modern view of autonomy when it treats persons as isolated individuals rather than members of families and communities (including the church).** <32>

The stinging indictment of Israel because "all the people did what was right in their own eyes" (Judges 21:25) might apply equally to much modern individualism. Thus, although the prophetic justice of Amos and Hosea would surely condemn any sacrifice of vulnerable patients to some "common good," the communal emphasis of Scripture does suggest that the impact of health care decisions on families and the community is a factor to consider.

In fact, respect for autonomy does not exclude such considerations. It is, after all, a principle aimed at others' responses to the patient, not a principle that either prescribes or limits the factors the patient as decisionmaker should take into account. We may agree that others should respect the conscience of the patient as the instrument of that person's unique calling and ultimately mysterious relationship to God. <33>

Such respect does not mean that all efforts to influence the patient's conscientious deciding are unwarranted, or that patients should have to make decisions without the moral support of those who are there for them. Indeed, empathic engagement with the other's moral struggle may be at the heart of genuine "moral support": "You shall not oppress a resident alien; you know the heart of an alien, for you were aliens in the land of Egypt." (Exodus 23:9)

Beneficence, too, can be qualified by attention to our tradition. An emphasis on "benefits" stresses outcomes of a tangible, usually physical, kind. This emphasis is not foreign to Scripture, but the Bible also stresses care for persons, especially the vulnerable. **The duty — and, more, the opportunity — to care extends beyond our ability to confer benefits. We are to care even when we cannot cure.** <34> In Matthew 25:31-46, the king recognizes the acts of

care of those who welcomed strangers, who offered food and water — and “took care of” the sick. Sometimes genuine care may even mean relinquishing our efforts to prolong life, particularly when those efforts bring further suffering in their wake.

A traditional concept from Catholic moral theology, that of ordinary and extraordinary means of treatment, is relevant in this regard. In this view, no patient is obligated to accept extraordinary means; they are optional. Extraordinary means are any treatments which do not promise reasonable hope of benefit and/or impose excessive cost, pain or inconvenience. <35> The condition of the patient, not just the inherent nature of the means used, helps to determine whether the means are ordinary or extraordinary. In the Pediatric Case Study, David’s prognosis, both for continued life and for recovery, would be a decisive factor in assessing whether the existing life-sustaining treatments and possible CPR are extraordinary (and therefore optional) means of treatment.

A second Catholic concept, the principle of double effect, is relevant to our understanding of nonmaleficence when terminal illness is involved. Double effect holds that some “evils” can be allowed when they occur as an indirect and unintended side effect of actions that bring about a significant good.

This principle may ease the conscience of those who feel at moral risk in giving terminal care. Caregivers may hesitate to administer adequate doses of pain medications which depress respiration, because death sometimes results. They fear that they will “cause” death in such a case. Double effect would allow the medically indicated administration of these drugs because (a) the intent is not to bring about death, but to ease pain, and (b) the drug, not the patient’s death, is the means of pain relief.

The ongoing conversation of Christians with the Scriptures and with each other offers much more that is relevant to the four principles and their application to life-sustaining treatment. For example, our biblical and theological heritage richly supplements — and challenges — secular views of justice. The discussion offered here is therefore intended as a beginning, not a final word. Readers are urged to consult the bibliography for other works that explore the relationship between our faith and ethical issues at life’s end.

(DBM/dm)

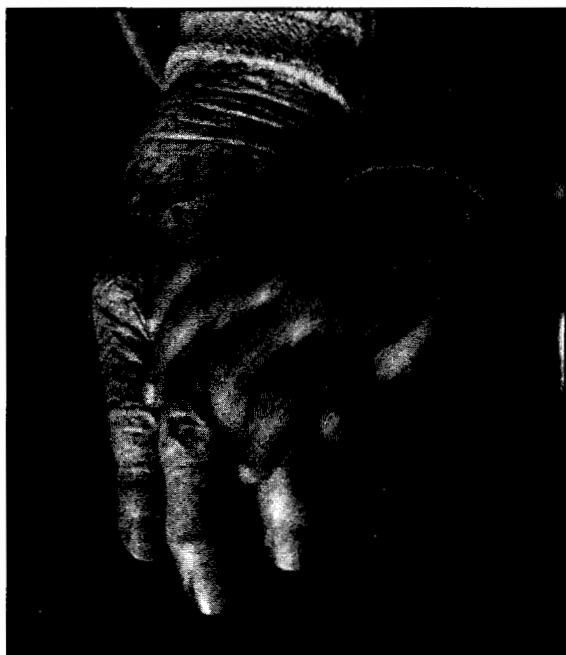
STUDY QUESTIONS FOR CHAPTER FOUR:

1. How should we “honor our father and mother” when life-sustaining treatment is at issue? By respecting their wishes concerning such treatment, or by acting to promote their welfare and “best interests” even if we act without their approval or consent?

2. Are the needs and interests of families — including the economic impact on families of life-sustaining treatment and its possible long-term aftermath — a legitimate factor to consider in making decisions about such treatment?

3. In the Adult Case Study, is the respirator an ordinary or extraordinary means of treatment for Mr. Hriniak?

CHAPTER FIVE: U.C.C. PERSPECTIVES



Relevant General Synod Statements

At the national level, three General Synod statements address issues of stewardship, life support technologies, and euthanasia:

General Synod 9 (1973) adopted **The Rights and Responsibilities of Christians Regarding Human Death**, a statement originally reported by the Council for Christian Social Action. It acknowledges that progress of medical technology has created new possibilities and new problems in the care and perpetuation of human life; affirms the right to die and execution of living wills; supports the right to die with dignity through termination of extraordinary measures used to keep a terminally ill, unconscious patient alive; calls for more effective consultation between physician, family, and clergy when death is imminent. It does not address the question of euthanasia at a conscious patient's request.

General Synod 12 (1979) passed an action on **Legal Recognition of Living Wills**. This statement supports legal recognition of advance directives with appropriate safeguards; and directs the Office for Church in Society and the Conferences to urge state legislation.

General Synod 18 (1991) adopted another resolution titled **The Rights and Responsibilities of Christians Regarding Human Death**. This raises the ethical dilemmas of euthanasia and suicide in cases of painful, lingering death or the prospect of a debilitating or terminal disease and calls for further examination of the problem. It also

affirms the right of individuals "to die with dignity and not have their lives unnecessarily prolonged by extraordinary measures" and calls upon Christians "to offer love, compassion, and understanding to those who are faced with difficult life-ending decisions." The resolution further recognizes the need for "safeguards to protect persons who cannot make life and death decisions for themselves." The full text of this document is included at the end of chapter six.

Self-Determination

The American Hospital Association's "Patient's Bill of Rights" underscores the right to self-determination. These rights are affirmed: the right to have all pertinent information regarding diagnosis, treatment, and prognosis; the right to give "informed consent" prior to any procedures being performed; and pertinent to this booklet, the right to "refuse medical treatment." The General Synod's statements are all consistent with this right. They also show a willingness to struggle with difficult issues.

From a responsible Christian perspective the question looms for us: **What will be my choices if and when I am confronted by end-of-life decisions?** It is argued by many in the health care system that people often change their minds when confronted with the "real thing," that bravery in declaring that we wish not to utilize all of the technology at our disposal evaporates when one is confronted with death. It often seems as if this is an argument used by those practitioners who do not wish to have their options limited when technology choices are imminent.

It is all the more reason for us as thoughtful Christians to consider what our wishes are, to express those to our physicians and those who know us best, so we can make the most responsible decisions. Thinking about such a serious issue beforehand, even declaring one's wishes, in no way means one cannot change one's mind. Without such advance consideration, the determination of one's medical destiny may not be one's own.

Stewardship of Life Issues

The use of sophisticated technology in medicine is for the purpose of providing a "window of opportunity" for the severely injured or diseased patient to make a comeback and survive. This has not always been the case. Fifteen years ago, it was widely held that once a ventilator was used with a patient it was morally impermissible to discontinue its use. Now it is generally held, but not always practiced, that when a patient has had that window of opportunity and has not progressed, it is poor stewardship to continue life-

sustaining treatment, including artificial feeding. The treatment may be judged to be futile.

As more people complete advance directives they seem to be motivated by a fear of becoming captives to medical systems and having their dying prolonged beyond their wishes. Resolving the conflicts between self-determination and a physician or family member's desire to "save life" has created many stressful situations for patients and families, as illustrated in the case studies above.

Stewardship of life and life-support technologies presents two opportunities. First, one can discuss wishes and preferences with family and complete advance directives. This would be of some help in avoiding inappropriate and futile overtreatment. Second, one can decide whether or not to be a donor of one's organs or body. This may present the possibility that out of death will come a greater opportunity for survival for others. Organ or tissue donation is a form of continued stewardship of the gift of life.

There are stewardship issues to address in the area of overtreatment. It is worth noting that in any insurance group six percent of the members utilize more than 60 percent of the monetary resources of the total group. High utilization by a small number of people drives group rates higher, creating a crisis in which businesses consider dropping health care coverage for all employees.

Another area of overtreatment is suggested by the statistics indicating that a disproportionate amount of health care expenditures are devoted to the last six months of a person's life. Much of that care is unwanted, and often unnecessary treatment is not terminated in a timely way. The evidence suggests that current practices tend to lead to inappropriate overtreatment.

Euthanasia and suicide

It is crucial to distinguish between withholding or withdrawing life sustaining treatment, which means allowing a person to die, and the very different choices of active euthanasia and assisted suicide (see glossary for definitions). This section addresses the latter two issues, which are considerably more controversial than the former. More public forums and bioethics journals now openly consider these topics, which have also become the subject of much-publicized litigation. As a result of recent Federal court decisions overturning state laws against assisted suicide, as of this writing the Supreme Court is expected to rule on the constitutionality of such laws in 1997. What are the reasons behind this sudden and surprising discussion?

First, Americans wish to have more control over what happens in their lives, even to the point of decisions about their dying. As Bette-Jane Crigger wrote in the March-April 1992 issue of *The Hastings Center Report*, "Do the canons of self-determination and respect for persons compel us to honor the choices of those who request active

assistance in dying? Can we coherently argue that physicians' professional obligations to alleviate suffering extend so far as to taking life on request?" <36> That is the question.

Second, we would not be discussing euthanasia and suicide at all if it were not for the difficulty of intense suffering which some of the dying experience. Suffering is more than just physical at times and involves intense anguish for some who have lost control of their bodies and must be completely dependent upon others.

This appeal to suffering is probably the only motivational force strong enough to get physicians to consider assisting someone to become free of their suffering. In an article presented as a "Sounding Board" to other physicians in *The New England Journal of Medicine*, three physicians present the following compelling vignettes.

"Consider the following patients: a former athlete weighing 80 lbs. (36 kg) after an eight year struggle with the acquired immunodeficiency syndrome (AIDS), who is losing his sight and his memory and is terrified of AIDS dementia; a mother of seven children, continually exhausted and bed-bound at home with a gaping, foul-smelling, open wound in her abdomen, who can no longer eat and who no longer wants to fight ovarian cancer; a fiercely independent retired factory worker, quadriplegic from amyotrophic lateral sclerosis, who no longer wants to linger in a helpless, dependent state waiting and hoping for death." <37>

Third, opinion polls show that approximately 62 percent of the American public is in favor of some kind of assistance in dying.

Fourth, many physicians who are opposed to active euthanasia have less difficulty with deaths that fall under the principle of "double effect", as when morphine or sedatives provided to alleviate pain have the unintended side effect of depressing respirations and causing death.

Fifth, those who argue against some kind of assistance for those who wish to die do so on three grounds. (1) Some fear that there is a "slippery slope" which will lead to indiscriminate killing of people such as happened in Nazi Germany. That is, if American culture moves even slightly in the direction of assisted dying, for supposedly merciful reasons, it may lead to more widespread evils and temptations for less beneficent reasons. (2) Many in the medical field find euthanasia totally inconsistent with the medical mandate to preserve life. (3) Those in the religious community may argue from the commandment, "Thou shalt not kill."

One cannot say on such sensitive issues what "the United Church of Christ says" on every point. But UCC members are engaging in discussion fiercely. Consensus may not result soon. But clearly there will be consequences for many of us in the future as a result of our debates and decisions.

(RE/dm)

STUDY QUESTIONS FOR CHAPTER FIVE:

- 1. How comfortable are you with organ donation? Do you see this as a community/stewardship issue?**
- 2. Have you created advance directives for yourself?**
- 3. How does our Christian faith inform our decisions about organ donation and advance directives?**

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CHAPTER SIX: CHALLENGE TO THE CHURCH



INTRODUCING ADVANCE DIRECTIVES IN THE CHURCH

In order to educate church members about advance directives, resources will include people, printed materials, films, and videos. Below are numerous suggestions which your church may find helpful.

1. Enlist the support and participation of church members who have training in medicine, law, nursing, social services or chaplaincy. Ask them to serve on a panel or conduct a forum on advance directives. They can help church members fill out advance directives and help familiarize people with the forms used in your state. For a directory of UCC chaplains in your area, write to the president of UCC Chaplains in Health Care.

2. Utilize resources in your community. Ask the local medical society, hospital or nursing home to provide speakers on advance directives and medical ethics. Colleges and universities are also a good source of information and speakers.

3. Use the resources of your denomination. A seminary or denominational college is a good place to look for speakers, books and articles. UCC publications and General Synod statements may be used as discussion starters. The CHHSM office in Cleveland and the United Church Board for Homeland Ministries have staff and resources which may be helpful to you. Think about sponsoring a retreat using denominational staff, faculty members, and this resource. The retreat may be designed for a specific group such as

couples or senior citizens.

4. Keep a supply of advance directives, instructions, and interpretive material in the church office. Make them available upon request. Take time to sit down with those who request the forms and help complete them.

5. Write articles on medical ethics, stewardship of resources, and advance directives for the church newsletter. Find a guest author, if necessary.

6. Preach on themes which probe issues related to the quality of life, such as human dignity, free will, ethical decision-making, resurrection, abundant life, and social responsibility.

7. Form study groups to examine books on the subject. Many titles are listed in the endnotes and bibliography of this manual. Two books which may be especially appropriate are Joseph E. Beltran's *The Living Will and Other Life-and-Death Medical Choices* (Nashville, Thomas Nelson, 1994) and David John Doukas and William Reichel's *Planning for Uncertainty: A Guide to Living Wills and Other Advance Directives for Health Care* (Baltimore, Johns Hopkins, 1993).

8. Provide inspirational materials, booklets, and pamphlets. "Care Notes" from Abbey Press, One Caring Place, Hill Drive, St. Meinrad, IN 47577 are excellent resources for use in pastoral ministry. One of their new Care Notes is titled Planning Now for Tough Medical Choices You May Face in the Future, by Mark O'Keefe, OSR. Also, the Channing L. Bete Company, South Deerfield, Mass. 01373, has produced a short booklet titled About Advance Medical Directives (available in English and Spanish). Items from both companies can be ordered in quantity for a fee.

For churches and agencies, the American Hospital Association (address in chapter three) offers a resource titled Put It in Writing: A Guide to Promoting Advance Directives, also for a fee.

9. Video tapes are available on this subject. Check with your local library or church resource center. The American Hospital Association has a video called "Advance Directives: Guaranteeing Your Health Care Rights." Other educational videos can be rented or purchased from Fanlight Productions, 47 Halifax Street, Boston, Mass. 02130 (1-617-524-0980). Some of their titles include: "Help Me Die," exploring ethical issues raised when a terminally ill patient asks for assistance in dying; "Code Gray: Ethical Dilemmas in Nursing;" and "A Fate Worse Than Death," a documentary about several families who must decide about

withdrawal of life support from a loved one who is permanently unconscious.

10. **Encourage pastors and lay leaders to participate in continuing education** in disciplines such as pastoral ministry, chaplaincy, and medical ethics. Often community hospitals and long-term care facilities offer seminars and workshops for church members.

Ours is an age in which many people feel powerless. Advance directives enable us to exercise some personal power. Expressing one's opinions about being resuscitated, fed through a tube, or placed on a respirator indicates respect for oneself and one's family. This manual should assist in gaining confidence in the decisions one has made with the help of God and the community of faith which is the church.

(GRR/dm)

TASKS FOR UCC HEALTH AND HUMAN SERVICE AGENCIES

The member institutions of CHHSM have professed "an obligation to contribute our particular talents, resources, and perspectives toward the furtherance of the human service mission of the UCC and the whole church of Jesus Christ." The challenge of making end-of-life decisions with faithfulness and integrity requires an open, informative, and supportive environment. The church's health care institutions have a major role to play in the creation and sustenance of spaces and systems where clinicians, counselors, patients, and families can risk the proclamation of Christ's victory.

At a minimum we need to be about five tasks:

1. We must be scrupulous, comprehensive, and sensitive about **providing persons with information about advance directives and recording their directives**. A brochure in the admissions packet won't do it! A culture of comfort around these issues must be developed which encourages inquiry and genuine response from patients and caregivers at all levels.

Helpful materials for general and professional education (in written and video format) are available from Choice in Dying (address in chapter three). Their materials are geared for specific audiences, including acute or long-term care, residents, families, or staff.

2. A properly authorized, representative, and fully resourced **ethics committee is essential**. It must be understood that the role of such a committee is to deliberate and counsel, not to judge.

3. The undergirding Christian religious tradition of the institution should receive unapologetic witness, while affirming that **respect for the ideals of religious freedom** is integral to this tradition. Where the patient and/or caregivers' desires conflict with the fundamental values of the institution, seek alternatives without being judgmental.

4. **Contribute our perspectives to the ongoing societal struggle** to reconcile issues of cost of care, quality of life, and the equitable distribution of finite health care resources.

5. Finally, leaders of our institutions should acknowledge that all of this is messy. **We will never be able to adequately deal with end-of-life issues through policies, procedures, and protocols**. These are issues which go to the very heart of our reason for being: to be places of healing for body, mind, and spirit. Can we acknowledge and embrace human finitude and rejoice in those times when we heal by allowing the spirit to fly from the body? Perhaps as we become able to answer "yes" to this question, we will also discover the depth of meaning and purpose in being a Christian institution.

(BWS)

(The material in section one of this chapter was previously published in the May/June 1993 issue of The Christian Ministry under the title of "The Pastor, the Parish, and Advance Directives" by George R. Robie.)

UCC GENERAL SYNOD RESOLUTION (1991):

WHEREAS, we live in an era of complex biomedical technologies, with various means to maintain or prolong physical life and postpone inevitable death;

WHEREAS, there are ever-increasing anxieties about a prolonged dying process with irreversible deterioration, and its potentially devastating effects on the dignity of the dying person, the emotional and physical well-being of families, as well as the responsible Christian stewardship of resources;

WHEREAS, technology advances more quickly than public policy, and public opinion is often ahead of legislative enactment;

WHEREAS, individuals have increasing responsibilities in these life and death decisions, but often lack adequate information regarding available options;

WHEREAS, life is sourced in God, and recognizing that our faith calls for commitment and work for the quality of human life with mercy, justice, and truth;

WHEREAS, affirming that the gift of abundant life is more than the avoidance of death, and that overregard for the body, without proper concern for the needs of the person and the human spirit, can become a kind of biological idolatry; we are convinced that what is required is a balanced appreciation of the whole person;

WHEREAS, General Synod 12 of the United Church of Christ has supported the legal recognition of living wills and General Synod 9 addressed the rights and responsibilities of Christians regarding human death; and

WHEREAS, we support the right and responsibility of individuals to choose their own destiny, and recognize the need for safeguards to protect persons who cannot make life and death choices for themselves.

THEREFORE, BE IT RESOLVED, the 18th General Synod supports the rights of individuals, their designees and their families to make decisions regarding human death and dying.

BE IT FURTHER RESOLVED, the 18th General Synod affirms the right of individuals to die with dignity and not have their lives unnecessarily prolonged by extraordinary measures if so chosen.

BE IT FURTHER RESOLVED, the 18th General Synod calls on Christians to offer love, compassion and understanding to those who are faced with difficult life-ending decisions.

BE IT FURTHER RESOLVED, the 18th General Synod calls upon the churches to study and discuss life-ending issues with resources provided by the United Church Board for Homeland Ministries, the United Church Board of World Ministries, the Office for Church in Society, and the Council for Health and Human Service Ministries.

BE IT FURTHER RESOLVED, the 18th General Synod calls upon the United Church Board for Homeland Ministries, the United Church Board for World Ministries, the Office for Church in Society, and the Council for Health and Human Service Ministries to report to General Synod 19 (1993).

BE IT FURTHER RESOLVED, the 18th General Synod encourages the enactment of legislation safeguarding these rights, including the rights of those who are unable to make decisions for themselves.

GLOSSARY

ACTIVE EUTHANASIA: An action that deliberately brings about the death of another person in order to relieve pain or suffering.

ADVANCE DIRECTIVE: A written instruction, such as a living will or durable power of attorney for health care, recognized under state law and describing the medical care or naming the surrogate a person would want in the event that he or she became unable to make and/or communicate their own health care decisions.

AGENT: See "Surrogate/Agent/Proxy."

ARTIFICIAL FEEDING AND HYDRATION: When a person is unable to eat or be fed orally, liquid nourishment may be administered through peripheral and central intravenous lines (IVs), by tubes inserted through the nose to the stomach (NG tubes), and/or by a tube connected directly to the stomach (G tubes).

ASSISTED SUICIDE: Self-inflicted death that makes use of the assistance of another person (e.g., by providing pills or another means to cause death).

AUTONOMY: Each individual's capacity and right to make moral judgments affecting their own body and overall health.

BRAIN DEATH: Complete and irreversible cessation of total brain function, including that of the brain stem.

COMATOSE: A person who cannot be aroused by external stimuli; a deep stupor occurring in illness or due to an injury.

COMPETENT: Able to make decisions for oneself, as judged through due process in a court of law. Persons must be over the age of 18 and generally have the ability to understand who they are, what is happening to them, and what would be the consequences of their decisions.

DEFICITS: Lack of normal function in some part of the body, e.g. the inability to hear, see, process mental decisions, move one's arms and legs, control one's bowel and bladder.

DNR: Acronym for "Do not resuscitate," which may be a physician's order for a patient who does not wish to receive cardiopulmonary resuscitation in the event of an arrest. Sometimes called "DNAR" (Do not attempt resuscitation), "No CPR," or "No Code" orders.

EUTHANASIA: From the Greek literally meaning "Painless, happy death." The act or method of causing or providing for a painless death for a person suffering and/or dying of an incurable disease.

GENERAL SYNOD: The national voting body of the United Church of Christ which is convened every two years.

GUARDIAN: The court-appointed caretaker of a disabled individual with authority over personal and/or financial decisions.

INCAPACITATED/INCAPABLE: This refers to a person's ability to make a given medical decision. An incapacitated person cannot: understand the proposed treatment, its predicted effects, and the available alternatives to the proposed treatment; communicate verbally or nonverbally their understanding and wishes regarding the treatment; and identify what day and time it is and where they are. Capacity is determined by one's physician. If a person is judged to be incapacitated, a surrogate decision-maker must be found.

INCOMPETENT: A person who does not fit the qualifications of a "competent" person as defined above, and is declared incompetent in a court of law.

INTUBATION: Placing a tube through the nose or mouth to a patient's larynx or trachea, producing an open airway to allow breathing.

IRREVERSIBLE OR INCURABLE CONDITION: A disease in which the prognosis cannot be changed with medical treatment; beyond cure.

PASSIVE EUTHANASIA: Allowing a person to die without making an active intervention to either prevent or hasten their death; generally made possible by allowing the disease process to take its course; may involve discontinuing artificial life support, treatments, and/or medication.

PERMANENT UNCONSCIOUSNESS: The state of being insensible or without conscious experience, unaware. This condition usually results from a persistent vegetative state.

PERSISTENT VEGETATIVE STATE (PVS): An unconscious state in which the person has no cognitive abilities and has ceased to experience the surrounding environment. PVS is often an "eyes-open" unconsciousness in which the person goes through sleep-wake cycles. If provided with artificial nutrition and hydration and other supportive care, PVS patients can live for prolonged periods.

PHYSICIAN-ASSISTED SUICIDE: A form of assisted suicide in which the lethal means is provided by a doctor.

PRINCIPAL: The person who by informed, voluntary choice gives authority to another (an "agent" or "proxy") to act on his or her behalf in making personal and/or financial decisions.

PROGNOSIS: A professional judgment regarding the likely course of a patient's disease and their probability of recovery or death; forecast of disease course.

PROXY: See "Surrogate/Agent/Proxy."

QUADRIPLEGIC: A person who is paralyzed from the neck down, partially or totally unable to use arms and legs.

RESPIRATOR: See "ventilator."

SELF-DETERMINATION: The ability to decide for oneself without outside intervention.

SURROGATE/AGENT/PROXY: The person who receives authority and assumes the responsibility of acting on behalf of another, according to the terms and limitations established in the empowering agreement and/or provisions of the law.

TERMINAL CONDITION: A disease process that has a prognosis of death. Some — not all — definitions of terminality specify a life expectancy of six months or less.

UNRESPONSIVE: Unable to respond to external stimuli.

VENTILATOR: A mechanical device for artificial ventilation of the lungs; covers mouth and nose and requires intubation.

WITHDRAWING LIFE-SUSTAINING TREATMENT: Discontinuing a form of life support, such as a ventilator or artificial feeding.

WITHHOLDING LIFE-SUSTAINING TREATMENT: Not providing a form of life support, such as refraining from the use of a ventilator when a person cannot breathe independently. (HB/dm)

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