



“You hem me in, behind and before...”

Faithfully Facing Dying



Preface

“Dying is at once a fact of life and a profound mystery.”[1]

Dying – it is not something any of us wants to think about, but it is a fact of life. And, of course, we all will, one day, die. But, dying is not as “simple” as it used to be. Up until the 1950’s, most people died at home. Death was a part of living. People who died were laid out in the “parlor” until it was time for their burial. Pneumonia was the “old man’s friend” because there were no antibiotics to fight the infection and there were no “life support” machines to help us get over the “hump” of an infection or other illness. With the discovery of antibiotics and the invention of various “life-saving” machines in the early 1960s, death moved out of the home and into the hospital and went behind closed doors.

And here we are, 50 years later: “Medical technology has been a factor in increasing both longevity and quality of life. We are called to celebrate medical technology as a manifestation of God’s aim at healing and wholeness and a continuation of Jesus’ healing ministry. Nevertheless, we must also recognize that many persons today have fallen victim to the technology aimed at helping them.”[2]

Technology has brought us to a place where we have to make what can be very painful decisions concerning loved ones. We wonder whether or not we should continue to provide life sustaining treatment when the quality of our loved one’s life might not be ‘meaningful’ (a threshold that is different for each of us). Should we use these life-sustaining technologies just because they are available? After all, “There is no indication in scripture that God prefers longevity over quality of life.”[3]

There are no right or wrong answers in these situations and when our loved one suddenly becomes ill or has an accident, of course we want to keep them “alive” as long as possible. But does there come a time when ‘alive’ should mean more than having machines breathe and maintain a heartbeat, providing artificial nutrition through a feeding tube, and using dialysis to clean the blood?

Decisions these days are often not cut and dried, and there are so many options that need to be considered. But, when people tell their loved ones what is most important for their life to have meaning, what their ‘bottom line’ is, it makes it a bit easier for loved ones to make those decisions. All my years as a professional hospital chaplain, watching people having to make decisions for loved ones when there had been no conversations about the patient’s wishes, have led me to believe that the greatest gift we can give those we love is to let them know our wishes about how we want our body treated as we near the end of our life here on earth. After all my years as a professional chaplain in a hospital, watching people having to make decisions for loved ones when there have been no conversations about the patient’s wishes, has led me to believe that the greatest gift we can give to those we love is letting them know what our wishes are as to how we want our body treated as we near the end of our life here on earth.

According to a recent article in *The Annals of Internal Medicine*, those who became a surrogate decision maker by default described the surrogate role as ‘profoundly burdensome.’ A ‘substantial minority’ of these decision makers reported ‘feelings of guilt and self-doubt about whether they made the right decision.’ [4] (Surrogate laws, which vary from state to state, specify who makes the decision when a patient has not appointed a decision maker or specified treatment wishes in writing.)[4]

So, I encourage you to read this booklet, which can help you educate yourself about the various end-of-life issues that may arise. Then you can give your loved ones the gift of knowing what your wishes are and how you want your body to be treated as you near the end of your life. Your loved ones will be able to concentrate on spending quality time with you, without trying to figure out what you might have wanted or perhaps fighting over treatment decisions.

I also encourage you to consider that there are different kinds of healings – not just physical healing. When physical healing is no longer possible, spiritual healing, relational healing, healing of hurts and angers, healing of broken promises and grief over unfulfilled dreams, the healing of forgiveness sought and forgiveness given, and healing of one’s relationship with God are all possible outcomes. Jesus did more than cure people of their illnesses; he healed them. So, use whatever time you may have to allow healing to take place.

Lastly, I strongly encourage you to invite God to the table when you have these discussions with yourself and with those you love. Be ever mindful that Jesus is right by your side and will not be going anywhere, for whether you live or you die, you belong to God.

My deepest thanks to the Working Group that spent many, many months together by phone and email as we discussed with open minds and open hearts how each person felt around these not easily contemplated end-of-life issues. I have great respect for each of them as they explained their “side” with patience and with love and with God’s presence before them. It has been a blessing to work with each of them over the past three years. I am the better for it and you will become,

hopefully, the well-educated recipient of our labors.

Blessings and Peace,



Rev. Dr. Martha R. Jacobs, BCC, Editor
June 2011

Footnotes:

[1] Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, Washington, DC, National Academy Press, 1997, 1.

[2] Bruce Epperly and John Mills, *A Word to the Church on End of Life Care: Theological, Spiritual, and Ethical Reflections* The United Church of Christ Science and Technology Taskforce, 2009 [accessed 4/13/2010. Available from <http://www.ucc.org/science/pdf/microsoft-word-end-of-life-care-with-theological-ethical-spiritual-resources.pdf>, 5.]

[3] *Ibid.*, 7.

[4] David Wendler, Annette Rid. “Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others.” *Annals of Internal Medicine*, 3/1/11, Vol 154, Issue 5, 336-346.



Lord, You have searched me and known me. You know when I sit down and when I rise up. You discern my thoughts from far away... You search out my path and my lying down and are acquainted with all my ways... (Ps. 139:1-3)

Introduction

For most of us, there will come a time when we will need to confront our own fears around our dying and death. Some of these fears are grounded in concerns that our dying may be prolonged or our remaining life cut short. Some of these fears come from our sense of not having control over what happens to our bodies as we move through the dying process. Some of these fears come from the amazing technology that is available to us today that can prolong life but also requires us to consider at what cost both to our bodies and to our limited resources. And, as technology becomes more and more sophisticated and can prolong life for what may seem like an indefinite period, we need to be educated about these issues so that we, and those who love and care about us, will know what our wishes are, in case something happens to us that prevents us from voicing those wishes ourselves.

Conversations around end-of-life issues are not easy for most of us. We each have our beliefs and our own sense of what is “right” for us. Our society allows us choices, and that is what conversations about end-of-life issues are about – knowing what choices are available and how you can be an educated “consumer” so that you can make the choices and decisions that are “right” for you.

This booklet has been prepared for your use as a guide to being informed prior to something happening to you physically. As a denomination, the UCC affirms our need to be mindful about our resources, our equality, and our justice issues, in terms of all being given the same information and all being able to make use of that information in ways that will be helpful to us as we are confronted by the inevitability of the end of our own life. Those

suffering at the end-of-life are especially vulnerable, so caring for them is a matter of justice, as it is with any vulnerable or oppressed group.[1,2]

Below is the history that prompted this booklet and our greater awareness of the need to know what one’s options are when illness strikes. Following that will be sections on various end-of-life issues and conditions that people are most likely to have to confront as we continue our journey on this earth.

At the end of the booklet you will find a wealth of resources that are available to you should you wish to learn more about any of the issues we are raising here. The Lenten Series upon which this booklet is based is also available to you on the Justice and Witness Ministries page of the UCC website. The Working Group encourages you to use this resource within your church and your family because “our calling as Christians is to provide loving care and spiritual support for the most vulnerable members of our community.”[3]

Prior Resolutions Passed at General Synod

Below are all of the Resolutions that have been passed at General Synods (since 1973) that deal with issues around dying and death.

General Synod 9 (1973) adopted *The Rights and Responsibilities of Christians Regarding Human Death*, which acknowledged that the 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; and calls for more effective consultation between physician, family, and clergy when death is imminent. It did 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*, which supports legal recognition of advance directives with appropriate safeguards and directs the Office for Church and 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*, which raises the ethical dilemmas of euthanasia and suicide in cases of painful, lingering death or the prospect of a debilitating terminal disease and calls for further examination of the problem. It also affirms the rights 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.” It further recognizes the need for “safeguards to protect persons who cannot make life and death decisions for themselves.” The resolution originally submitted to General Synod (GS) endorsed “the right of persons under hopeless and irreversible conditions to terminate their lives and emphasize[d] that Christian understanding and compassion are appropriate with regard to suicide and euthanasia.” This language was not included in the resolution approved by GS.

Following GS18, a group of professional chaplains who were members of the UCC Chaplains in Health Care (now the United Church of Christ Professional Chaplains and Counselors) wrote the booklet, *Making End-of-Life Decisions: United Church of Christ Perspectives*, 1993. It was revised and updated in 1997 by Rev. Dr. David McCurdy, and was supported both times by the Council for Health and Human Service Ministries (CHHSM).[4]

Recent Resolutions Presented at General Synod

At GS 26 (2007) a resolution was presented from the Northern California/Nevada Conference titled *Legalization of Physician Aid in Dying*. An amended resolution was adopted. It did not make a direct recommendation about legalization of physician aid in dying, but called on the church to study a proposal favoring legalization. Subsequently a Working Group was tasked with developing a recommendation to bring to GS 27 (2009). You will find the text of this resolution (as well as a similar one submitted to GS 27 from the Central Atlantic Conference and also incorporated into the work of the Working Group) in the Resources section at the end of this booklet.

The Working Group was unable to reach a consensus, and so came to GS 27 with a recommendation that, as a denomination, we use the time between Ash Wednesday and Holy Week in 2010 to study the issues around physician aid in dying as well as other end-of-life issues. A follow-up survey would be taken to determine where the members of our denomination stand on various end-of-life issues. This information would then be utilized to formulate resolutions on the issues for presentation to GS 28 (2011). Unfortunately, the number of survey responses was too small to be statistically valid, so the report to GS 28 (2011) indicated that the Working Group had “no recommendation regarding adoption of the proposal contained in “Legalization of Physician Aid in Dying,” the related resolution “In Support of Physician Assistance in Dying,”[5] or some amalgam of the two.” [6]

Without a consensus, the Working Group thought it appropriate to still continue to educate our members on end-of-life issues, hence the creation of this booklet.

We pray that you will find this to be a helpful resource so that you can make educated decisions about how you would hope to have your body treated when you are nearing the end of your life.

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Footnotes

- [1] Frank Brennan, Daniel B. Carr, and Michael Cousins, "Pain Management: A Fundamental Human Right," *Anesthesia and Analgesia* 105, no. 1 (2007): 205-21.
- [2] Allyn L. Taylor, Lawrence O. Gostin, and Katrina A. Pagonis, "Ensuring Effective Pain Treatment: A National and Global Perspective," *JAMA* 299, no. 1 (2008): 89-91.
- [3] Epperly, Bruce and John Mills, *A Word to the Church on End-of-Life Care: Theological, Spiritual, and Ethical Reflections*, UCC STN – The United Church of Christ Science and Technology Taskforce, 5.
- [4] A copy may be obtained at: www.aclergyguidetoendoflifeissues.com.
- [5] The Central Atlantic Conference had submitted to General Synod 27 a new resolution entitled "In support of Physician Assistance in Dying." Since this proposed resolution was very similar to the GS 26 resolution as originally presented, it was referred by the Executive Council to the existing JWM Working Group to be part of the study process they were already developing.
- [6] From the Report entitled: "Study of Proposal to Support Legalization of Physician Aid in Dying Working Group Report to the Committee of Reference, March 31, 2011."
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Even before a word is on my tongue, Lord, you know it completely... You hem me in behind and before and lay your hand upon me. Such knowledge is too wonderful for me, it is so high that I cannot attain it... (Ps. 139: 4-6)

Section 1: Advance Directives/Advance Care Planning

Advance Directives came to public awareness when Congress passed the Patient Self Determination Act in 1991. This legislation requires health care institutions to disseminate written information to patients at the time of their admission to a hospital or nursing home about the patient's rights under state law to refuse treatment and to prepare an advance directive.[1]

An Advance Directive is usually a written statement made by a competent person about choices for medical treatment or selecting a substitute medical decision maker. The advance directive normally takes effect *only* if the person should become unable to make such decisions or communicate them at some time in the future. It makes our preferences known to health care providers and others who know us and care about us. The two most common forms of advance directives are Health Care Proxies (or Durable Power of Attorney for Health Care) and Living Wills. Do Not Resuscitate (DNR) Orders are another form of Advance Directive that is written in the hospital or when under Hospice care. Some states have developed Do Not Resuscitate Order forms that serve as advance directives because they are signed by both patient and physician.

The time to let others know what your wishes are is while you are able to discuss and communicate them clearly. It is important to communicate your wishes to the person whom you designate as your Health Care Agent/ Durable Power of Attorney for Health Care. However, it is easier on everyone when people hear directly from a person what their wishes are concerning how they want their body treated as they near the end of their life. There are several different ways you can have these

conversations. One of the best ways is with all of your family present at the same time, so they all hear it at once. These are not easy conversations and many children (even adult children) will not want to discuss this. You might consider sitting around the kitchen or dining room table with those who are closest to you. Over coffee or tea, and after offering a prayer, begin to talk about what the important aspects of your life are – talk about what is important in order for your life to have meaning for you. Here are some guiding questions:

- What is a meaningful life for you?
- What does “living” mean for you?
- Are there things that you **MUST** be able to do in order for your life to have meaning? For example:
 - Must you be able to communicate?
 - Must you be able to take care of your bodily functions by yourself?
 - Must you be able to interact with family and other loved ones?
- What is **MOST** important to you? For example:
 - Spending time with family and loved ones?
 - Seeing your children or grandchildren grow up?
 - Going to church and taking walks in the woods?
- Do you want everything done to keep you alive, no matter what the quality of your life is?
- Where is God in your decisions about the kind of medical care you wish to receive when you are critically ill or at the end of your life?
- Do you think that God would want you connected to machinery that was keeping your body functioning even if you were unable to move or respond and had no hope of improvement or recovery?
- Do you want your organs/tissue to be used for organ donation, if viable?

- Are there family considerations that might affect your wishes about medical treatment if you become very ill?
- Another factor to consider is that there may be ways for you to continue to live a fruitful and meaningful life even if you cannot speak, walk, eat, breathe or take care of your bodily functions by yourself. You may be able to use a motorized wheelchair, other technology, and home care services to help you live life to the fullest. It is important to think about these issues in the broader context of your whole life.

There are other resources available to guide you if you want a step-by-step process to follow. You will find resources at the end of this booklet on places where you can find set formats and questions that some people have found helpful. Also, there are several different Health Care Proxy/Durable Power of Attorney for Health Care forms that you can use, which are available on-line (links are included in the Resources section). Forms may also be available at your doctor's office or local hospital.

Below are the various types of forms that can be used in order to give someone the authority to act on your behalf. In order for any of these advance directives to take effect, someone must be determined to not have capacity. "Capacity" is often confused with "Competence." "**Competence**" is a legal term. People are presumed competent unless found incompetent by a court. Whether someone is "incompetent" is determined by a judge, who looks at whether or not one has basic cognitive and functional capacity to participate in decision-making.

"**Capacity**" is a medical term. Doctors (e.g., physicians and psychiatrists) determine the extent to which one is able to understand the information concerning a treatment decision and appreciate the reasonably foreseeable consequences of a decision or lack of a decision. When one has capacity, one can complete a Health Care Proxy, sign or consent to a Do Not Resuscitate Order, and/or

make any and all other health care decisions. It should be noted that mental illness or a diagnosis of depression does not automatically render a patient "incompetent" or incapable of making medical decisions.

A Health Care Proxy/Durable Power of Attorney for Health Care is the form that addresses the widest range of situations, yet it does not need to include any specific wishes (except in New York and Missouri where there must be specific wording about use of nutrition and hydration). This form allows you to select an individual (and a secondary person) to make healthcare decisions for you when you can no longer make them for yourself. As your representative, that person is allowed to view medical records, sit in on care-conferences and discuss medical treatment with all health care providers who are tending to your health care needs. The Agent is expected to act in accordance with your wishes. Therefore, the person you select should be prepared to make the decision that YOU want made, not what they want for you. If they are not willing to abide by your wishes, you should consider appointing someone else. Hopefully, you and the individual(s) you selected will have ongoing discussions over the years as you age and your priorities shift and medical technology evolves.

Most Health Care Proxies/Durable Power of Attorney for Health Care forms don't require a lawyer, nor do they need to be notarized in most states. Be sure to check the form and follow the directions for your state so that you can ensure that the form does not get in the way of your wishes.

Living Wills (LWs) specify what you want or do not want done in the event you become incapacitated or unable to participate in the discussions about your medical treatment decisions. A living will can be as specific or general as you wish. One of the problems with living wills is that they often do not cover everything that could happen to a person. Some living wills include an opportunity to appoint a Proxy. In some states, for example, Illinois, (a) the LW doesn't

become operative until the patient is determined to be terminally and irreversibly ill and death is imminent, and (b) the document essentially addresses only life sustaining (“death-delaying”) treatments and comfort care. People may add other preferences in writing, but the death-delaying treatments are the focus of the text supplied in the statutory form. Because the LW may be interpreted or used differently in different states, it is important to check your state’s particular laws. (You will find links to the forms in the Resource section at the back of this booklet.)

Surrogate Decision Making/Substituted Judgment is allowed in some states, particularly if there has not been a health care proxy/durable power of attorney for health care form completed. In this scenario, the person tries to determine, based on knowing you, how you would want your treatment to proceed. The surrogate uses your life history and known preferences, values, goals and objectives in order to make the best decision he or she can make, taking “you” into account and not their own preferences for your care decisions.

The law of a given state may establish categories of eligible surrogates and may prioritize among them. Usually spouses are the first eligible category, followed by adult children, siblings, etc. If there are multiple family members in a category, such as adult children, they may disagree about what should be done for the patient. Because a state may resolve this issue through a ‘majority rules’ provision, advance discussion among family members is desirable. But this, in turn, argues again for the creation of a written advance directive, preferably a Health Care Proxy/Durable Power of Attorney for Health Care, followed by the kind of family discussion suggested earlier.

Some states allow a “substituted judgment standard,” which enables someone who is close to the patient to make decisions that the patient would make were that person competent. If that is not possible, then a decision-maker should be guided by the “best interests” standard in which the person

“considers the highest net benefit to the individual in question, given the available options and the person’s known preferences and values.”[2]

Do Not Resuscitate Orders (DNR)

Do Not Resuscitate Orders are physician Orders often written in hospitals when a patient’s medical condition warrants them and/or or when the patient requests that resuscitation not be performed. A DNR Order in the medical record precludes the use of resuscitative measures, including chest compressions, artificial respiration, defibrillation, and cardioactive medications in the event of cardiopulmonary arrest—if a patient’s heart stops or he/she stops breathing. In other words, a “code” is not called and attempts to resuscitate are not begun. However, all other treatments continue, e.g., antibiotics, pain medication, bathing, turning, etc.

Some states have created Do-Not-Resuscitate Orders that are legally recognized as another form of Advance Directive. These orders typically extend beyond the hospital into settings such as hospice care, nursing homes, and even the patient’s home. They alert emergency personnel not to attempt resuscitation if the patient suffers an arrest.

Do Not Intubate Orders (DNI)

It is also possible in some states for a physician in the hospital to write a Do-Not-Intubate Order, in which a patient who experiences breathing difficulties (sometimes a sign of an impending cardiac arrest) will not have a breathing tube inserted down his or her throat. Typically, in the hospital this Order also means that if the patient suffers a full cardiopulmonary arrest, no ‘code’ will be called and resuscitation will not be attempted.

Some states have instituted a Do-Not-Intubate Order as another kind of Advance Directive. In contrast to standard hospital practice, in the event of a full arrest these orders sometimes permit, or even require, a modified form of resuscitation that may include all of the ‘code’ elements *except* the use of a

breathing tube. Most clinicians believe this “partial” resuscitation is ineffective and advise against its use. Also, many states have not authorized official DNI Orders. You may check your state health laws to find out whether or not your state has this form of advance directive. You will find the link in the Reference section.

Some hospitals do not actually ask patients or family members to “sign” a DNR, but take their oral consent as agreement.

When a person is under hospice care, an out-of-hospital DNR Order (typically a form provided by the state) may be signed, usually by the patient and the physician, so that death is allowed to happen as a natural result of the progression of the illness and without emergency interventions.

Allow Natural Death (AND)

The Allow Natural Death (AND) form started in Texas where they believe that when one signs a paper to “not” do something, one is allowing the natural progression of the illness to occur. To not “code” the person is allowing nature to take its course. AND has been receiving very positive feedback especially since, to the patient/family member who is signing it, it feels like they are doing something positive by allowing death to take its natural course without human intervention.

Studies have shown that patients who did not have conversations with their loved one, then by default became the surrogate decision-maker, had a more difficult time resuming their life after making a decision for their loved one. For a substantial period of time after the death of that loved one, the person still wondered if they made the “right” decision, often suffering from guilt and second-guessing. Because of this, once again, we reiterate, the greatest gift you can give to your family is to let them know what your wishes are regarding how you want your body treated as you near the end of your life.

Other End-of-Life Concerns

Artificial Nutrition and Hydration (ANH)

Artificial nutrition and hydration (fluids) is not “food and water” as we commonly know it. Artificial Nutrition is a medically supplied, chemically balanced mix of nutrients and fluids. It provides nutrition and hydration to people who are unable to chew, swallow, or otherwise consume food and liquids in the “normal” manner. ANH may be given for a short time intravenously; long term administration of nutrition and hydration is through a “feeding tube.” There are several types, some of which are inserted into the stomach by a minor surgical procedure. ANH is not provided solely to patients at the “end-of-life.” ANH enables some patients with chronic conditions to lead active lives.

Foregoing Life-Sustaining Interventions

Patients may choose to forego treatment with or without an advance directive in place. It is the choice of the patient and/or family member to have life-sustaining interventions withheld or to withdraw interventions previously started (if allowed by state law). Types of interventions that may be foregone include, but are not limited to: placement in intensive care units; cardio-pulmonary resuscitation; intubation and ventilation (being put on a respirator to assist with breathing); any drug therapy regimen; dialysis; blood transfusions; intravenous fluids and feedings; radiation; chemotherapy; surgery. Patients may continue or begin to receive adequate pain medication so that the patient is as free from pain and anxiety as possible. This choice may be reversed at any time. Courts have ruled that competent patients may forego life-sustaining interventions, including artificial nutrition or hydration.

It is important for the patient and family members to understand that death will probably follow this refusal of life-sustaining interventions. At the same time, it is worth remembering that the real ‘cause’ of death is not the refusal of these interventions, but rather

the underlying illness. Family members may find comfort in this fact.

Life Sustaining Treatment

Life sustaining treatment may be defined as “any medical intervention that would have little or no effect on the underlying disease, injury or condition, but is administered to forestall the time of death or to reinstate life when death can be regarded as having occurred.”[4]

Organ Donation

In the late 1960s, the Uniform Anatomical Gift Act became public policy in the US. It has encouraged individuals to donate one’s organs or tissues after one’s death so that someone else might benefit from the transplanted organs and/or tissues. In the mid 1980s, in an attempt to increase donations, families became the focus for consent and laws were passed that required “the” question (about donating the patient’s organs) to be asked of all families. The need for organs is very real and the chance for someone to continue to live, even as someone else dies, can be a real “gift” to that person and their family.

Decisions about organ donation after a diagnosis of brain death can be heart wrenching for families. Often the cause of the total brain failure has been a sudden accident, injury, or body “malfunction.” As a result, just when the family is only starting to deal with the pain of their loved one’s death, they are also being asked to give the “gift of life” to someone else – usually a stranger – who may be a match. Because time is of the essence (viable organs need to be removed as soon as possible in order for the recipient to have the best chance of survival), family members may feel pushed to make the decision. This possibility is why it is important for you to have this conversation with your family. Your wishes concerning donating organs or tissues can make their decision that much easier once they know how you want your body treated when your life ends.

Quality of Life

“A phrase that, used in its broadest sense, refers to an assessment of those economic, social, physical and psychological conditions or possibilities that make life pleasant and ‘livable.’”[5] Health care quality of life assessments “focus on the physiological and mental conditions that limit or enhance the patient’s life experiences.”[6] If decisions need to be made about whether or not continuation of a particular life-extending medical intervention is in the patient’s “best interests,” quality of life is considered (e.g., does the possible positive outcome outweigh the burdens for continuing to “live”?). Today, many believe that “quality of life” is a judgment to be made primarily, if not exclusively, by the competent patient himself or herself.

Ventilator/Respirator

“An automated machine used to deliver breathable air to and from the lungs of an individual who is unable to breathe or whose breathing capacity is not sufficient to maintain adequate oxygen supply to the body.”[7]

Voluntary Stopping Eating and Drinking (VSED)

“Voluntary Stopping Eating and Drinking, referred to as VSED, (is) the option to forgo food and fluid, while receiving supportive comfort care until death arrives.... VSED (is) accepted by current law and medical practice norms in every state.”[8]

Footnotes:

[1] Lawrence O. Gostin, “Deciding life and death in the courtroom: from Quinlan to Cruzan, Glucksberg and Vacco – A brief history and analysis of constitutional protection of the ‘right to die,’” *Journal of the American Medical Association* 278, no. 18, November 12, 1997, 1524.

[2] Phillip M. Kleespies, *Life and Death Decisions: Psychological and Ethical Considerations in End-Of-Life Care*, Washington, DC, American Psychological Association, 2004, 69.

- [3] <http://www.hhs.gov/ocr/privacy/hipaa/faq/about/187.html>, accessed 10/5/09.
- [4] Kleespies, 56-57.
- [5] James B. Tubbs Jr., *A Handbook of Bioethics Terms*, Georgetown University Press, 2009, 137.
- [6] Tubbs, 138.
- [7] Tubbs, 182.
- [8] American Public Health Association, *Gerontological Health Section Newsletter*, Spring 2009.
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Where can I go from your spirit? Or where can I flee from your presence? If I take the wings of the morning and settle at the farthest limits of the sea, even there your hand shall guide me and your right hand shall hold me fast.... (Ps. 139:7, 9-10)

Section 2: Palliative Care, Hospice, Suffering and Pain Control

Palliative Care

Palliative Care is a medical specialty that is both a philosophy of care and a process for delivering care. The term “palliate” means to “relieve or lessen without curing; to mitigate; to alleviate.” Palliative care focuses on relieving suffering and reducing the severity of disease symptoms for persons with serious illness as well as improving the quality of life for patients and their families. While the purpose of palliative care is not to halt or delay the disease progression or cure illness, it can be delivered along with curative treatment at any time during the course of a person’s illness. Palliative Care is helpful when a person has a life-changing illness or diagnosis. The goal of Palliative Care is to match the goals of care to the goals of the patient.

In order to address the complex needs of patients and their families, palliative care is generally delivered through an interdisciplinary team of health care professionals. These professionals are in hospitals and in nursing homes and can come to your private home, through hospice care. The team includes professionals from medicine (the primary physician), nursing, pastoral care, and social work.

Palliative care involves attention to, assessment of, and attempts to relieve pain and other symptoms that a patient may experience so that the patient’s quality of life is improved. Some of these symptoms are results of the injury or disease process; others are results of the medical treatments themselves. Because “human life is profoundly relational,”[1] relief of suffering is a matter of justice. Keep in mind that not all palliative care

is hospice care, while all hospice care is palliative care.

Hospice

Only 24.9 percent of Americans die at home even though more than 70 percent say they wish to do so.[2] Approximately 2.5 million people die in the United States each year. Approximately 80 percent have a protracted illness before death and yet less than 20% use hospice or palliative care.[3] In the last years of life, health care costs are more profound. “One recent study found that, for those alive at age eighty-five, one-third of life-time health costs are still ahead.”[4] According to CMS (Centers for Medicare and Medicaid), about one-fourth of total Medicare spending occurs in the last year of life. This amount has remained generally constant for the past 20 years. The majority of Medicare end-of-life costs are from inpatient hospital expenditures.[5]

So, while the majority of people want to die at home, the reality is that only about 25% of people have their wish fulfilled. There are many reasons for this, not the least of which is our desire as human beings to live as long as possible. This desire often leads us to utilize the life sustaining equipment talked about in Section One. This modern technology may enable us to stay alive longer, but it may also rob us of the chance to die at home.

Hospice provides patient-centered palliative care for people who are terminally ill. It combines emotional, spiritual and social support with expert medical and nursing care delivered by an interdisciplinary team of specially trained health professionals and volunteers. Hospice provides support for the entire family. Hospice care is palliative care, that is, comfort care, for those who forego curative treatment and have a life expectancy that can be measured in months.

So when is the “right” time to ask for a Hospice consultation?

To be eligible for the Medicare hospice benefit, beneficiaries must be certified by their attending physician, and the hospice physician, as being terminally ill with a life expectancy of

six months or less if the disease follows its “normal course.”

Some believe that you should investigate hospice while you are healthy so that you can know ahead of time what your options are, particularly checking your health plan to see if hospice is covered. Medicare and Medicaid do cover hospice, with at least partial payments for hospice. The best way to find out is to either contact your local hospice or ask your health insurance carrier. Many people have assumed that their medical plan included hospice only to find out that it is not covered, or is not 100% covered.

Hospice should be considered as an option when you receive a “terminal” diagnosis – that is, a diagnosis that would lead to death within about six months. If your doctor does not suggest it, it is quite appropriate for you to ask about it. Some doctors are hesitant to suggest hospice because it means that you will not receive aggressive care that seeks to “cure” your terminal illness. Also, some doctors may feel that they have “failed” you if they cannot cure you, and may steer you away from options other than aggressive care. But considering hospice is an individual’s choice, and a legitimate option. You should learn about ALL of your options before making any decisions about “aggressive” care or “comfort” care.

What are the benefits and burdens of Hospice?

Hospice care can be provided in a variety of settings including a private residence, a long-term care facility such as a nursing home, or a residential care facility such as an assisted living facility. Some hospice providers also operate a dedicated inpatient unit or freestanding hospice facility. According to NHPCO (the National Hospice and Palliative Care Organization), most hospice patients die in their own residence or the “place they call home.”[6]

The benefit of hospice is that the hospice team works with you and your family, seeking to assure that you will have the kind of

“good death” that you desire. Hospice care also provides respite care for family members. This service provides them temporary relief from their caregiving responsibilities. However, 30% of hospice patients are introduced to hospice shortly (less than 7 days) before they die, when it is too late for the patient and family to benefit from the wonderful care that hospice has to offer.

A burden of being on hospice is that it can put a lot of pressure on family members who are the basic caregivers, 24/7, unless your health insurance covers homecare services. Even with respite care, this can become a burden, albeit a loving burden, on a family. If you don’t have family members who are able or willing to take this on, there are residential hospices available in most areas of the country, where you can go and live for the rest of your life, being taken care of, as if at home, in the comfort of a place that is not a hospital and will provide on-going 24-hour care.

Another “burden” or possible drawback is that you cannot receive aggressive or curative care when you are in hospice. However, you can change your mind and withdraw from hospice and return to curative care at any time. You can receive palliative care, such as radiation to shrink a tumor that is causing you pain, but you would not be able to continue chemotherapy. On the other hand, you could still receive dialysis since it is considered palliative treatment. Check with your local hospice if you want to know more about hospice.

Long-Term Care

Long-term care is “a variety of services that includes medical and non-medical care to people who have a chronic illness or disability.”[7] It can be provided at home, in the community, in assisted living facilities or in nursing homes. It meets health or personal needs and is designed “to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom.”[8]

Pain Management

Pain management includes careful attention to patients' description and understanding of the meaning of pain; evaluation of the history and current status of the disease process that is likely causing the pain; thorough physical examination of the places where it hurts; discussion with the patients and their families about options for pain relief; establishment of an individualized pain care plan; use of pharmacological (medicines) and non-pharmacological methods (such as heat or repositioning) to provide relief; regular reassessment of pain to determine effectiveness of methods used; changes in dosages or combinations of medicines in response to patients' needs; attention to breakthrough pain or new kinds of pain; and prevention of unnecessary pain, such as the procedural pain of blood tests when the answers really will not matter anymore.[9, 10]

Suffering and Pain Control

Is there something good and holy about enduring severe pain? Margaret Mohrmann discusses this issue in her book *Medicine as Ministry: Reflections on Suffering*. She says that the old idea that pain strengthens character has been generally misused. When there were no medicines that could be safely used to reduce or prevent pain, and, if the pain was unavoidable, or the situation that created the pain was unavoidable, if persons were to keep their integrity, persons would have an opportunity to grow in character by developing endurance. However, in the context of healthcare in this age, especially care at the end-of-life, when effective pain control is usually possible, it is wrong to use the suffering of heroes in the Bible to justify one's own or another's suffering from injury or disease. Mohrmann says, "Although Jesus asked some interesting questions of his patients, he never suggested to them that they would be better off just bearing their pain. Jesus' consistent willingness to relieve physical suffering adds a necessary qualifier and counterbalance to any discussion of the glorious endurance that suffering can produce." [11] When caregivers neglect adequate treatment of symptoms, patients and families may have the impression

that moderate to severe pain is inevitable. Professional caregivers who have not learned about the latest methods of pain assessment and treatment may believe that pain is inevitable. However, most of the time, it is not inevitable. [12,13,14] Pain can be safely managed in most cases, including in the emergency room [15] or the intensive care unit.[16]

In our society, there are cultural mores that tell some that the expression of pain is not appropriate; they are used to suffering in silence. However, they need not suffer in silence. It is rare that physical pain cannot be reduced to acceptable levels. Spiritual and emotional pain, if present, needs to be discussed and not ignored, unless the patient does not want to deal with it. Ultimately, it is the patient's decision, or in some cases the health care proxy's decision, about what measures to take. However, patients and families need to have complete information. For example, many people (including some clinicians) believe that high doses of drugs like morphine can hasten death. As a result they tend to use lower, less effective doses. But when pain is carefully assessed and morphine seems to be the most appropriate and effective medicine to use and when physicians very gradually increase the dosage until relief is attained, there is little danger of depression of the respiratory system bringing about an early death.[16,17]

The rare instances when pain medication might contribute to an earlier death are addressed by the principle of the "double effect." "Double effect" seeks to explain those circumstances in which it is morally acceptable to perform an action that will predictably lead to a desired good consequence or effect even though it will also predictably result in an evil consequence or effect." [18] There are four conditions necessary to meet the criteria for proper use of this principle: (1) the action must not be intrinsically wrong; (2) the agent must intend only the good effect, not the bad one; (3) the bad effect must not be the means of achieving the good effect; and (4) the good effect must be "proportional" to the bad one,

that is must equal or outweigh it.[19] For example, morphine is used to manage pain and suffering. However, morphine can slow respirations. Therefore, if a patient receives additional morphine, it may hasten his/her death. Some might consider this euthanasia. However, it is the intention which makes the difference. If the intention is to relieve pain and suffering, then more morphine is appropriate. If the intention is to hasten death, then it is not appropriate. Some pain relief experts point out that, in competent pain management, the double effect isn't an issue because the patients' distress can be carefully assessed and medication increased very gradually, thus achieving relief before respiratory depression occurs.[20, 21,22]

In rare cases, when pain is intolerable or does not respond to treatment, imminently dying patients may be offered the option of palliative sedation, which may mean that they are sedated somewhere on a continuum between light sedation and sedation to unconsciousness, depending on the extent of their suffering.

“Terminal Sedation”

For some dying patients, the profound pain that may occur when dying may not be relievable by any other means than terminal sedation. Terminal sedation uses sedatives that make the patient unconscious until death occurs from the underlying illness.[23] “Some prefer to call this process ‘palliative sedation,’ since it aims at relieving pain rather than bringing about death itself.”[24]

Footnotes:

[1] Bruce Epperly and John Mills, *A Word to the Church on End of Life Care: Theological, Spiritual, and Ethical Reflections* The United Church of Christ Science and Technology Taskforce, 2009 [accessed 4/13/2010]. Available from <http://www.ucc.org/science/pdf/microsoft-word-end-of-life-care-with-theological-ethical-spiritual-resources.pdf>.

[2] *Means to a Better End: A Report on Dying in America Today*, November 2002.

[3] Phillip M. Kleespies, *Life and Death Decisions: Psychological and Ethical Considerations in End-Of-Life Care*, Washington, DC, American Psychological Association, 2004, 143-44.

[4] Joanne Lynn, “Living Long in Fragile Health: The new demographics shape end of life care,” *Improving End of life Care: Why has it been so difficult? Hastings Center Report Special Report* 35, no 6, 2005, S15.

[5] Congressional Research Service (CRS), *End of Life Care: Services, Costs, Ethics and Quality of Care*, http://assets.opencrs.com/rpts/R40235_20090223.pdf, accessed 12/3/09.

[6] NHPCO Facts and Figures, 2008.

[7] U.S. Government Health and Human Services Web site:

<http://www.medicare.gov/LongTermCare/static/Home.asp>, accessed 2/9/09.

[8] *ibid.*

[9] Nessa Coyle and Mary Layman-Goldstein, "Pain Assessment and Pharmacological Interventions," in *Palliative Care Nursing: Quality Care to the End of Life*, eds. Marianne LaPorte Matzo and Deborah Witt Sherman, New York NY, 2006, pp. 345-405.

[10] Betty Ferrell, Michael H. Levy, and Judith Paice, "Managing Pain from Advanced Cancer in the Palliative Care Setting," *Clinical Journal of Oncology Nursing* 12, no. 4 (2008): 575-81.

[11] Margaret E. Mohrmann, *Medicine as Ministry: Reflections on Suffering, Ethics, and Hope*, Cleveland OH, 1995, .

[12] Allyn L. Taylor, Lawrence O. Gostin, and Katrina A. Pagonis, "Ensuring Effective Pain Treatment: A National and Global Perspective," *JAMA* 299, no. 1, 2008: 89-91.

[13] Betty Ferrell, Michael H. Levy, and Judith Paice, "Managing Pain from Advanced Cancer in the Palliative Care Setting," *Clinical Journal of Oncology Nursing* 12, no. 4, 2008, 575-81.

[14] Nessa Coyle, and Mary Layman-Goldstein, "Pain Assessment and Pharmacological Interventions," in *Palliative Care Nursing: Quality Care to the End of Life*, eds. Marianne LaPorte Matzo and Deborah Witt Sherman, New York NY, 2006, pp. 345-405.

[15] Timothy Rupp, and Kathleen A. Delaney, "Inadequate Analgesia in Emergency

Medicine," *Annals of Emergency Medicine* 43, no. 4, 2004, 494-503.

[16] Richard A. Mularski, Kathleen Puntillo, Basil Varkey, Brian L. Erstad, Mary Jo Grap, Hugh C. Gilbert, Denise Li, Justine Medina, Chris Pasero, and Curtis N. Sessler, "Pain Management within the Palliative and End-of-Life Care Experience in the ICU." *Chest* 135, no. 5, 2009, 1360-9.

[17] Margaret L. Campbell, "Treating Distress at the End of Life: The Principle of Double Effect," *AACN Advanced Critical Care* 19, no. 3, 2008, 340-4.

[18] James B. Tubbs Jr., *A Handbook of Bioethics Terms*, Georgetown University Press, 2009, 42.

[19] Phillip M. Kleespies, *Life and Death Decisions: Psychological and Ethical Considerations in End-Of-Life Care*, Washington, DC, American Psychological Association, 2004, 63.

[20] Portenoy, Russell K, Una Sibirceva, Randall Smout, Susan Horn, Stephen Connor, Ronald H. Blum, Carol Spence, and Perry G. Fine, "Opioid Use and Survival at the End of Life: A Survey of a Hospice Population," *Journal of Pain and Symptom Management* 32, no. 6, 2006, 532-540.

[21] Margaret L. Campbell, "Treating Distress at the End of Life: The Principle of Double Effect," *AACN Advanced Critical Care* 19, no. 3, 2008, 340-4.

[22] Richard A. Mularski, Kathleen Puntillo, Basil Varkey, Brian L. Erstad, Mary Jo Grap, Hugh C. Gilbert, Denise Li, Justine Medina, Chris Pasero, and Curtis N. Sessler, "Pain Management within the Palliative and End-of-Life Care Experience in the ICU." *Chest* 135, no. 5, 2009, 1360-9.

[23] Tubbs, 156-7.

[24] James J. Walter, "Terminal Sedation: A Catholic Perspective," *Update* 18, no. 2, 6, cited in David F. Kelly, *Medical Care at the End of Life: A Catholic Perspective*, Washington, D.C.: Georgetown University Press, 2006.



For it was you who formed my inward parts;... I praise you for I am fearfully and wonderfully made; ... that I know very well.... In your book were written all the days for me when none of them as yet existed... (Ps. 139: 13-14, 16b-17)

are real fears that physician-assisted death could be used as a detour that avoids effective palliative care or as a way to eliminate the suffering of vulnerable patients by eliminating the sufferer.”[2]

Section 3: Physician Aid in Dying, Euthanasia, Brain Death, Persistent Vegetative State, Minimally Conscious State

Physician Aid in Dying

Physician Aid-in-Dying (PAD) refers to a practice in which a physician provides a competent, terminally ill patient with a prescription for a lethal dose of medication, upon the patient's request, which the patient intends to use to end his or her own life.[1] As of the printing of this booklet, Washington Oregon and Montana are the only three states in the United States where physicians can legally provide a prescription for a lethal dose of medication. It should be noted that many call this process “physician-assisted suicide.” Others favor “physician aid in dying” because “suicide” is often associated with moral disapproval, and also because the term “suicide” may obscure the fact that an underlying terminal condition, often accompanied by much suffering, is present. Still others worry that “physician aid in dying” may actually include the option of euthanasia, since euthanasia is another way in which a physician could “aid” a patient’s dying.

“The public remains deeply divided on the question of whether to permit physician-assisted death. In most surveys, approximately two-thirds of the population of the United States approve of it as an option for terminally ill patients with intractable suffering. But when the question of legalization comes to a vote, it is usually closer to 50/50. This split probably reflects the inherent tensions in the debate. On the one hand, most people know of cases of severe suffering, even with excellent palliative care, where the need for some predictable escape is very compelling. On the other hand, there

There are very strong opinions as to whether or not PAD should be allowed (hence the Working Group’s inability to reach a consensus on this issue). If you want more in-depth information that engages both sides of this debate fairly, go to the UCC Justice and Witness webpage and download sessions 4 and 5 from the *Faithfully Facing Dying Lenten Series*. (See link in the Resources section at the end of this booklet.)

Euthanasia

Since there has been confusion as to what the difference is between PAD and euthanasia, below is a definition of euthanasia. This information is included so that you will understand that euthanasia is NOT allowed in the U.S., nor is it supported by those who are proponents of PAD within the UCC.

Euthanasia (from the Greek for “good death”), has been defined as “[t]he practice of intentionally bringing about the death of an individual in a relatively peaceful or painless manner to prevent extended suffering or a prolonged dying process.”[3] Euthanasia involves the introduction of a new lethal process by an outside agent (e.g., a physician or family member) in order to hasten the person’s death. Euthanasia of human beings is illegal in the United States, including states which have legalized physician aid in dying. The difference between PAD and euthanasia is that in PAD, the person who wants to die must actively take the dose himself, while Euthanasia is the act of someone else providing the means to die.

Brain Death (or Whole Brain Death)

“Brain death is loss of function of the entire cerebrum and brain stem, resulting in coma, no spontaneous respiration, and loss of all brain stem reflexes. Spinal reflexes, including deep tendon, plantar flexion, and

withdrawal reflexes, may remain. Recovery does not occur.”[4] In short, the ‘brain dead’ patient has died. Even though breathing and heartbeat continue, it is only because they are artificially supported by machines and medications. “Brain death” is the determination of death by neurological criteria, just as death may be determined by cardiopulmonary criteria. A few states allow for a religious or moral objection to this neurological definition of death. Brain death is therefore distinct from a Persistent Vegetative State (see below).

Persistent Vegetative State (PVS)

“A state of prolonged unconsciousness and unawareness, sometimes following a coma, in which the individual has lost higher brain functions (such as thinking ability and awareness of surroundings) but maintains basic functions such as breathing, heart regulation, and normal sleep cycles. Someone in a PVS may exhibit spontaneous movements or responses.”[5] A patient in a PVS remains alive, unlike a patient who is determined to be “brain dead.” Patients in a PVS are sustained nutritionally by a feeding tube and, with attentive nursing care; some live for a number of years but almost never recover higher brain function.

“The persistent vegetative state was first described in 1972 in a landmark article in the British journal *The Lancet*. It described PVS as a state of ‘wakeful unresponsiveness’ in which the eyes are open, but there is no awareness of self or others. Patients who are vegetative do not have cognitive or higher brain functions, such as the ability to think and reason. But they do have autonomic functions, such as the direction of cardiac and respiratory function and sleep-wake cycles, which originate in the brain stem—the lower part of the brain just above the spinal cord. Vegetative patients may also have a startle reflex, but this behavior is not intentional and involves only brain stem activity.”[6]

“The vegetative state is often confused with a coma by non-clinicians. This is an important error to correct. Although comatose and vegetative patients are unresponsive and

unarousable, there are important differences. Coma is an eyes-closed state, while the vegetative state is an eyes-open one. Moreover, coma is the initial presentation of severe brain injury and is self-limited, usually lasting a couple of weeks. A coma can progress in a number of ways, from brain death to complete recovery. The most ominous of comas progress to brain death, defined as the death of the whole brain, including brain stem and higher brain functions.”[7]

Please note that the word ‘vegetative’ is not a term we prefer. Patients in a PVS are still persons, not “vegetables.” The term is used in this resource because it is the currently accepted medical terminology.

Minimally Conscious State

There have been cases where people say that someone who was in a PVS for many years suddenly recovered. Recent studies have shown that these individuals were actually inappropriately diagnosed. They were actually in what is known as a Minimally Conscious State (MCS).

MCS is a new clinical designation that has its origins in the Aspen Criteria published in the journal *Neurology* in 2002. Unlike the vegetative state—with which MCS may be confused—MCS is a state of consciousness. MCS patients demonstrate unequivocal but fluctuating evidence of awareness of self and the environment. They may say words or phrases and gesture. They also may show evidence of memory, attention, and intention. However, these behaviors may be fleeting. The inability to reproduce telltale signs of awareness is part of the biology of MCS and an expected and confounding part of the clinical picture.[8]

“Arkansan Terry Wallis emerged from MCS in 2003, bringing international media attention to this phenomenon against the backdrop of the evolving Schiavo saga. Wallis regained fluent speech after lingering for some 19 years in a nursing home after sustaining traumatic brain injury in a motor vehicle

accident. During that time he had been labeled erroneously as being in a coma or vegetative state, although he was most certainly minimally conscious and recovered fluent speech from that prognostic milestone. In July 2003, he began to speak. His first words were “mom” and “Pepsi.” In his mind it was still 1984, and Ronald Reagan was still president.”[9]

Footnotes:

[1]

<http://depts.washington.edu/bioethx/topics/pad.html>.

[2]

<http://www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2202>

[3] James B. Tubbs Jr., *A Handbook of Bioethics Terms*, Georgetown University Press, 2009, 54-55.

[4] The Merck Manuals Online Medical Library, <http://www.merck.com/mmpe/sec16/ch212/ch212d.html>.

[5] Tubbs, 124.

[6] Joseph J. Fins, “Brain Injury: The Vegetative and Minimally Conscious States.” The Hastings Center, *Briefing Book*.

<http://www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2166>. [7] Ibid.

[8] Ibid.

[9] Ibid.

Resources:

General Synod 26 Resolutions

THEREFORE, BE IT RESOLVED that the Twenty-sixth General Synod calls upon the local churches, conferences, and Justice and Witness Ministries in consultation with UCC Disabilities Ministries, Council for Health and Human Service Ministries (CHHSM), UCC Professional Chaplains and Counselors, UCC Faith Community Nurses and Physicians to study the following proposal and report their views through Justice and Witness Ministries

to the Twenty-seventh General Synod for further consideration and action: that on the grounds of compassion and choice, if strict safeguards to prevent abuse are followed, a terminally ill and mentally competent adult should have a legal right to request and receive medication from a willing physician to hasten death if the patient finds his or her suffering to be unbearable.

General Synod 27 Resolution

THEREFORE LET IT BE RESOLVED, that the Twenty-seventh General Synod supports physician assistance in dying, under very specific guidelines as determined by each State, when for an adult patient:

- (1) who has a terminal/incurable debilitating illness or condition
- (2) is expected to die within six months
- (3) who has periods of severe, unrelenting and intolerable physical discomfort or pain, without prospect of significant improvement, which is unacceptable to the patient
- (4) who is legally competent to make medical decisions and
- (5) is expressing a voluntary and personal choice to die

Faithfully Facing Dying – A Lenten Study Guide on Critical Decisions Surrounding Dying and Death

<http://www.ucc.org/justice/health/faithfully-facing-dying/>

Websites for state Health Care Proxy and Living Will forms

This website will enable you to download a form that is acceptable for your specific state. <http://www.caringinfo.org/stateadownload>

Websites for other advance care planning documents:

Caring Conversations

Center for Practical Bioethics

<http://www.practicalbioethics.org/cpb.aspx?pglD=986>

Finding your Way

Sacramento Health Care Decisions

<http://www.sachealthdecisions.org/finding.html>

Five Wishes

<http://www.agingwithdignity.org/5wishes.html>

Respecting Choices

An advance care planning system from
Gundersen Lutheran Medical Foundation

<http://www.respectingchoices.org/>

Ethical Wills

Offers a way to leave your legacy by writing
down your values and beliefs.

www.ethicalwill.com.

Information about Organ Donation:

<http://www.organdonor.gov/>

<http://www.donatelife.net/>

<http://www.organtransplants.org/>

Books:

Jacobs, Martha R. *A Clergy Guide to End-of-life Care*, Cleveland: The Pilgrim Press, 2010.

Other Resource:

Epperly, Bruce and John Mills on behalf of The
United Church of Christ Science and
Technology Taskforce. *A Word to the Church
on End of Life Care: Theological, Spiritual, and
Ethical Reflections*

<http://www.ucc.org/science/pdf/microsoft-word-end-of-life-care-with-theological-ethical-spiritual-resources.pdf>

