

***Faithfully Facing Dying: A Lenten Study Guide on Critical Issues and Decisions
for the Members of the United Church of Christ***

To Facilitators:

Dear Sisters and Brothers in Christ –

Thank you for being willing to join with others in our denomination as we take this Lenten journey through dying and death. We know that this is not an easy topic for most people to contemplate, let alone talk about, so we appreciate your willingness to facilitate these sessions.

The Task Force that created *Faithfully Facing Dying: A Lenten Study Guide on Critical Issues and Decisions for the Members of the United Church of Christ*, would like you to know that we are available to answer any questions you might have as you work your way through this. Our contact information will be at the end of this section. Know that we are not in agreement on some of the topics that are being covered, but we have tried our best to present a balanced guide so that our UCCers can make their own educated decisions concerning their options in living and dying.

Each session (except for the 6th) has a similar format. It starts with a prayer. We then recommend using Psalm 139 (without verses 19-22) to help remind people that God is present and has been since before we were born. Next will be the definition of the session's topic, as provided in the Introduction, followed by a scenario or two to help people discuss "real life" possible situations and not just "theory." Next comes a set of questions, based on the scenarios, which we ask you to discuss for about half the session. After that follows the "Information" section, which will give the specifics about the various issues that are being discussed. There is a closing prayer for you to use after the information section. There is also a "resource" section as well as the footnotes, if any, from that session. We are assuming that you will be able to have 90 minute sessions. Clearly, if you can go longer than that, it would be preferable since there is a great deal of information that needs to be disseminated.

Please know that we relied on God as we journeyed through creating this guide and know that God will be with each and every one of you as you lead your congregation/association/conference through this. When in doubt remember that God is still speaking to us and through us, even when we talk about our dying!

With gratitude and much grace, we will be praying for you and your congregation, Association and Conference during this Lenten season.

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Notes for the Group Leader to Help Facilitate these Sessions

When you are planning these sessions, you might want to consider the following:

If a member of your congregation, association or conference is a chaplain or social worker, ask him/her to be involved in these sessions. It might also be helpful to have a physician and/or nurse available. In sessions focusing on advance directives, chaplains and social workers are generally familiar with advance directives and, by the very nature of their jobs, have to set aside their own biases when talking with patients and family members about them. If a member of your congregation, association or conference is a lawyer who is knowledgeable about advance directives, it might be helpful to have him/her present as well. However, no one person's real or perceived expertise should dominate the session. Try to make sure you get through all of the information for each session so that you can move on at the next session. You might start the next session asking if there are any questions or issues that arose for people from the previous week before starting the new session. If you are limited to 90 minute sessions, you may need to contain that discussion to some degree.

For the first session, we strongly recommend that you have copies of your state's Health Care Proxy/Durable Power of Attorney for Health Care form so that you can distribute them to those present. If your church is willing to be a repository for copies of the completed forms, be sure to let your congregants know that you are willing to keep a copy at the church in the event that it is needed and that only the pastor and _____ (whoever you feel is appropriate to have access) will have access to the file and can bring it to the hospital, if needed, in an emergency.

When you plan the third session, you might want to consider inviting an administrator from your local hospice.

Please do your best to familiarize yourself with all of the documents for each session prior to that session. We anticipate that the session on Physician Assisted Death is going to be the hottest topic, since this issue is what prompted this Lenten series. Please be sure to read all of the materials, try to put aside your own opinions, and be prepared to give information from both "sides" of the issue. We have extended this topic into the beginning of session #5 because the materials, even though they have been condensed, are still "heavy."

The final session will be a wrap-up and a time to reflect, as well as ascertain how your congregation, association and/or conference feels about various issues that were covered. Some of the questions in the final session will appear in the survey that we will be sending out in late April/early May. So please make notes for yourself as to the sense of your congregation, association and/or conference when they discuss each question.

There are many resources that you will find at the end of each section and in the footnotes as well as a listing of resources on the UCC-JWM webpage. However, here are a few that we want to highlight for you:

- ◆ *Our Own Terms - Moyers on Dying*, based on the PBS special. <http://www.pbs.org/wnet/onourown/terms/index.html>. This is a set of 4 video tapes and/or DVDs that you can purchase for use with your congregants. The first one of the series gives an excellent overview and can easily begin the conversations about dying and death. It is an

unbiased report – as only Bill Moyers can do. (You can purchase it at: <http://www.shoppbs.org/product/index.jsp?productId=2407930>.)

◆ The report from Congressional Research Service/Congressional Research Reports for the People, *End-of-Life Care: Services, Costs, Ethics and Quality of Care*, published in February 2009. The report can be downloaded from http://assets.opencrs.com/rpts/R40235_20090223.pdf.

◆ The Hastings Center *Bioethics Briefing Book*, which you will find online at <http://www.thehastingscenter.org/Publications/BriefingBook/Default.aspx>. The Hastings Center is a non-partisan research institution dedicated to bioethics and the public interest since 1969. We have cited this briefing book in several areas of our study guide and we believe you will find them of help as you prepare to lead these sessions.

◆ A new book entitled, *A Clergy Guide to End-of-Life Care*, which was written by the editor of this study guide, The Rev. Dr. Martha R. Jacobs, a UCC clergyperson and professional chaplain. This book, which is published by The Pilgrim Press will be available for purchase in late January. It is specifically written for clergy to help them look at their own issues around dying and death and provides tools for clergy to use with their congregation to talk about end-of-life issues. You will also find resources on her website: www.deathisnotthenemy.com. Segments of many of the sections in this study guide were adapted from her book.

Suggested Guidelines for Leading Groups

Try to create a safe space where people can voice their feelings and opinions without criticism or rebuke.

Ask people to speak using “I” and not “we” or “us,” but to claim only for themselves what they are saying. (You may need to remind people several times to do that. We are a society that likes to include everyone in our opinion, even if the reality is that most others would disagree. So, gently remind them to use “I” when they start talking in generalizations.)

Remind people that we need to respect opinions that are different from ours, and that what is important is that they listen to each other and can agree to disagree.

Try not to let people get into one-on-one discussions. Seek to include the whole group so that the conversation is not dominated by one or two outspoken individuals.

Invite those who have not contributed to the conversation to do so, if they choose.

Please do your best to keep your own opinions out of the conversations. You are there to facilitate; if you appear to be “favoring” one opinion over another, the group may not be able to process the information because they will be thinking more about your bias than the topic at hand. While we know it is hard not to voice one’s opinion, we strongly urge that you try to avoid doing so.

Please give the following ground rules to your group at the beginning of each session:

Turn off cell phones or mute them.

Respect each other’s opinions – people are entitled to their opinions and their feelings.

Each person is entitled to his or her opinion, but it is to be expressed in a respectful way – remembering that we are all God’s creations.

Feelings are feelings – they don’t always make “rational” sense. That is why they are feelings. Try not to judge yourself or others because of how you feel about something.

Allow everyone the chance to speak. Try not to dominate the conversation.

Do not interrupt someone who is speaking.

No answer is “right” or “wrong.”

People are also entitled to believe what they believe. Again, remember, we are all God’s creations.

Be aware of the difference between intent and impact. Our intentions in what we say or do are not always the same as the impact that our speech or action has on another person. At times our behaviors can have unintended consequences. This can lead to misunderstanding. If this happens, please slow down and talk through what has taken place. Please do know that what we say does not always have the impact that we intend, and please remember that we are all brothers and sisters in Christ.

This forum is not a chance to convince someone of something or to “convert them.” This forum is a chance to learn about different aspects of dying and death. This is an opportunity to receive information, explore your own feelings and desires and, if the

information is new to you, to begin to figure out for yourself what you do and do not want done to you or for you as you move towards death.

And, most importantly, this is a conversation where God is also very present.

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 require 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.

What better time to talk about these issues than during Lent, a time when we go within to soul search, reflect, take stock of our lives as Christians, and consider what our relationship with Jesus is all about and why Jesus died for us. These forty days are a reminder of Jesus' time in the wilderness. Looking at dying and death can be a wilderness experience because wilderness can be the unknown, which reflects the uncertainty of life and where life is leading us. Further, not knowing when we will die requires of us to be prepared, knowing that God will be with us, both in our living and in our dying. As Paul writes in his letter to the Romans (14:8), "If we live, we live to the Lord; and if we die, we die to the Lord. So, whether we live or die, we belong to the Lord."

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 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; support 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 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 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 and was supported both times by the Council for Health and Human Service Ministries.[1]

Recent Resolutions Presented at General Synod

This study guide came from a Working Group that was formed following GS 26 (2007), where a resolution was presented from the Northern California/Nevada Conference titled, “Legalization of Physician Aid in Dying.” The Committee charged at General Synod to work on this resolution could not reach a consensus on whether to recommend its adoption as presented. The presenter of the original resolution suggested changing the resolution to one calling for study rather than immediate action on the proposal “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.” The resolution as modified was passed by the Synod, asking Justice and Witness Ministries (JWM) to coordinate a study during the coming biennium with input from interested parties, reporting back to General Synod 27. JWM convened a Working Group that held several meetings which were useful in exploring a variety of issues but did not yield consensus on the issue of physician aid in dying.[2]

Because the Working Group was unable to reach consensus, we 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. We proposed that a follow-up survey be taken so that we could determine where the members of our denomination stand on various end-of-life issues. We would use this information to formulate resolutions on the issues for presentation to GS 28 (2011). If one or more resolutions were approved at GS, another Guidebook would be prepared and made available to all UCCers. Then any congregant facing the often complex and difficult decisions at the end-of-Life would have the assistance of our denomination. This recommendation was accepted by the Executive Council and agreed to by the Justice and Witness Ministries Board. A smaller Task Force was charged with creating this study guide and the survey that will follow.

Meanwhile, 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. (See Session 4 for part of the content of that resolution. The entire resolution can be found in the Resources section.)

The Format We Are Recommending

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. Therefore, these conversations are not about convincing each other of what is the “right” position or the “wrong” position. Our society allows us choices, and that is what these conversations 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.

In addition, we want to help you reflect on the vital social question of “physician aid in dying” – what it means, why many people call for its availability and many others oppose it, and what you think about making it a legally recognized option. Later we will ask you to help us think through this issue, by completing the survey mentioned earlier.

The topics that we are asking you to cover should be appropriate for six ninety-minute sessions. Clearly most of these topics could take several hours each, but we are very aware of the time limits that exist for most of us, so we have tried to make these sessions succinct and to the point. You can choose to offer them differently, or spend more time in certain areas and less in others. Resources for each session will be noted at the end of that session, and an overall Resource section will be on the web site. Hopefully, people will want to investigate further those areas that are of greater interest or more difficult to understand, so they can find a way to grasp each area of discussion so that it will have meaning for them. Our hope is that each of these topics will be covered at some point, because they will be addressed in the survey that we will be sending out in late spring.

As with any discussion that occurs in church, God should also be at the table or in the circle or in the classroom, sanctuary or wherever these sessions occur. We ask that you consciously make sure that God is included in these discussions. There is a prayer at the beginning of each session as well as a prayer at the end that we hope you will find useful.

Each session will have the topics that are to be discussed outlined at the beginning, and there will be suggested questions for use to get the conversations going. We tried to use scenarios as much as possible. They are potential “real-life” examples as most people can identify more easily with stories than abstract presentations of “fact.” The facts will follow, but the scenarios are good places to start.

At the end of each section there will be suggested resources that can be either purchased (books) or downloaded from the internet. We have tried to include correct URL’s but sometimes these change, so if you can’t find the resource, try to Google it. We have also tried to be even-handed and give as many viewpoints as we can, and have also tried to find resources that are “fact” and not “opinion.” You will find a section in the JWM webpage that will also have resources that you can download. If you do not have access to the internet, please let JWM know and they will send you some of the materials, being conscious of the costs involved in printing and mailing.

What Will Happen Next

An online post-Easter survey of all UCC congregations (addressed to clergy or lay leaders), and key leaders and/or constituencies in associations and conferences, will be sent out. Provisions will be made for churches without internet connectivity. The results of this survey will be evaluated and the responses used to help the Work Group not only respond to the current Resolutions, but to consider the possibility of other resolutions being sent to GS 28 that reflect the various end-of-life stances that are raised through the survey. Following GS 28, a guidebook will be prepared reflecting the denomination’s stances on these issues, as informed by the survey responses.

Definitions

Below are definitions that we are using for various terms. These are not necessarily the only definitions of these terms but they are the most common.[3] Additionally, there is no “standard” within the United States. Each State has its own set of “rules” that apply to end-of-life issues, particularly Health Care Proxies, Do Not Resuscitate Orders, Living Wills and, mental health treatment directives. So be sure to check your own State Health Department website or local hospital for the particulars within your State.

Advance Directives

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.

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 or 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.

“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 when 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. Brain death is therefore distinct from a Persistent Vegetative State (see below).”

Capacity and Competence

“Competence” is a legal term. Whether or not someone is “competent” is determined by a judge. The judge determines 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.

Clear and Convincing Evidence Standard[5]

“Clear and convincing evidence” is a legal standard that must be met in some states (e.g., New York, Missouri and Florida) and is required when there is no written proxy or living will. Clear and convincing evidence could be repeated oral expression, but must be specific to time and place with exact words used.

Do Not Resuscitate (DNR) Orders/Do Not Intubate (DNI) Orders

A DNR Order is a directive in the medical record that precludes the use of resuscitative measures such as chest compressions, artificial respiration, defibrillation, and/or 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. A DNI Order means that a breathing tube will not be inserted down the throat if a patient experiences breathing difficulties or respiratory arrest. However, a “code” is called and all other resuscitative measures such as chest compressions, defibrillation and/or cardioactive medications may still be administered.

Double Effect Principle

The principle of the 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.”[6] 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.[7] 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.[8, 9,10]

Euthanasia

(From the Greek for “good death”) Euthanasia 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.”[11] 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.

Health Care Proxy or Durable Power of Attorney for Health Care

This advance directive allows an individual to appoint another person called the Health Care Agent, to make health care decisions for the individual should that individual not be able to make decisions for him or herself. As the individual's 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 the health care needs of that individual. The Agent is expected to act in accordance with the wishes of the individual.

HIPAA (Health Information Portability and Accountability Act)

The HIPAA Privacy Rule creates national standards to protect individuals' medical records and other personal health information.

- It gives patients more control over their health information.
- It sets boundaries on the use and release of health records.
- It establishes appropriate safeguards that health care providers and others must achieve to protect the privacy of health information.
- It holds violators accountable, with civil and criminal penalties that can be imposed if they violate patients' privacy rights.
- It strikes a balance when public responsibility supports disclosure of some forms of data – for example, to protect public health.[12]

Hospice

Hospice provides patient-centered palliative care for individuals who are terminally ill. Hospice 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 and deals with the social, emotional and spiritual issues that may arise.

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.”[13]

Living Wills (LW)

A living will specifies what the individual wants or does not want done in the event he or she becomes incapacitated or unable to participate in the discussions about his or her medical treatment decisions. It can be as specific or general as an individual wishes. 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 statutory form. Because the LW may be interpreted or used differently in different states, it is important to check your state's particular laws.

Long-Term Care (LTC)

Long-term care is “a variety of services that includes medical and non-medical care to people who have a chronic illness or disability.”[14] 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.”[15]

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.[16,17]

Palliative Care

Palliative Care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”[18] All hospice care is palliative care. All palliative care is not hospice care. “The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity while remaining sensitive to personal, cultural and religious values, beliefs and practices.[19] Palliative care should be an applicable approach throughout a person's treatment, not just at the end-of-life.

Patient Self-Determination Act (PSDA)

This legislation, passed in 1991, 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. [20]

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.”[21] A patient in a PVS remains alive, unlike a patient who is determined to be “brain dead.” Patients in 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.

Physician Aid in Dying (PAD)

“Providing terminally ill patients with a potentially lethal prescription that they could ingest on their own to relieve otherwise intractable suffering.”[22] This lethal prescription, self-administered by the patient, directly hastens death. 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. Physician aid in dying is currently legal in only three states: Oregon, Washington and Montana.

Physician-Assisted Suicide (PAS)

See “Physician Aid in Dying.” There are many who consider these two terms to be interchangeable, but also many who do not, as the discussion above indicates.

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.’”[23] Health care quality of life assessments “focus on the physiological and mental conditions that limit or enhance the patient’s life experiences.”[24] 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 him or her self.

Slippery Slope Argument or Wedge Argument

“A claim that the moral acceptance of some type of (previously impermissible) actions will lead to other acts or practices that cannot be similarly justified and should not be accepted.”[25] If no clear evidence or argument is given as to the inevitability of the unwanted circumstances, the slippery slope argument is considered a fallacy. One form of this argument, “focuses on the psychological or sociological context in which the act or practice in question would be accepted and employed and questions whether

other social or cultural attitudes or forces might not lead to expansion of that act or practice in unacceptable ways.”[26] An example is the concern that permitting Physician Aid in Dying (PAD) for people who are terminally ill will lead to an increase in requests for PAD from people who are chronically ill. The concern is that (a) legalizing PAD would legitimize the belief that some lives are so unbearable that death is a reasonable option, and therefore (b) this legitimization could give people who are chronically ill, particularly those who suffer from depression, a justification for ending their lives.

Substituted Judgment and Best Interests Standards

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.”[27]

“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.[28] “Some prefer to call this process ‘palliative sedation,’ since it aims at relieving pain rather than bringing about death itself.”[29]

Ventilator/Respirator

“An automated machine used to deliver breathable air to and from the lungs of an individual who is unable to breath or whose breathing capacity is not sufficient to maintain adequate oxygen supply to the body.”[30]

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.”[31]

Resources:

You will find resources for these topics in the sessions where they are discussed and online in the Resources section.

Footnotes:

[1] A copy may be obtained at: www.deathisnottheenemy.com.

[2] See also, Epperly, B., & Mills, J. (2009). *A word to the Church on end of life care: Theological, spiritual, and ethical reflections*. Retrieved 4/13/2008, from <http://www.ucc.org/science/pdf/microsoft-word-end-of-life-care-with-theological-ethicsl-spiritual-resources.pdf>.

[3] Parts of many of these definitions are from Martha R. Jacobs. *A Clergy Guide to End-of-Life Issues*, Cleveland: Pilgrim Press, 2010.

[4] The Merck Manuals Online Medical Library, <http://www.merck.com/mmpe/sec16/ch212/ch212d.html>, accessed on 1/23/09.

[5] New York State Department of Health web site: http://www.health.state.ny.us/professionals/patients/patient_rights/molst/frequently_asked_questions.htm, Accessed 11/18/07.

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

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

[8] 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.

[9] 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.

[10] 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.

[11] Tubbs, 54-55.

[12] <http://www.hhs.gov/ocr/privacy/hipaa/faq/about/187.html>, accessed 10/5/09.

[13] Kleespies, 56-57.

[14] U.S. Government Health and Human Services Web site: <http://www.medicare.gov/LongTermCare/static/Home.asp>, accessed 2/9/09.

[15] Ibid.

[16] 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, 345-405.

[17] 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.

[18] World Health Organization. (2007) Programs and projects: Cancer and Palliative Care, Retrieved July 30, 2008, from <http://www.who.int/cancer/palliative/definitions/en/>.

[19] Task Force on Palliative Care, Last Acts, Precepts of Palliative Care, December 1997. <http://www.aacn.org/WD/Palliative/Docs/2001Precep.pdf>, accessed 2/9/09.

[20] 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.

[21] Tubbs, 124.

[22] Timothy E. Quill, "Physician-Assisted Death in the United States: Are the Existing 'Last Resorts' Enough?," *Hastings Center Report* 38, No. 5 (2008), 17.

[23] Tubbs, 137.

[24] Ibid., 138.

[25] Ibid., 156.

[26] Ibid., 156-7.

[27] Kleespies, 69.

[28] *End of Life Care: An Ethical Overview*, Center for Bioethics University of Minnesota, http://www.ahc.umn.edu/img/assets/26104/End_of_Life.pdf, accessed January 16, 2008, 33.

[29] 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, 19.

[30] Tubbs, 182.

[31] American Public Health Association, *Gerontological Health Section Newsletter*, Spring 2009.

Task Force members

(with contact information for those who are available to answer questions, etc.)

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Larry Schulz Served on staffs of Council for Christian Social Action, UCC and Committee for Racial Justice Now, UCC. Was Executive Director of the Anti-Poverty Task Force of the National Council of Churches. Elected Executive Director of the Council for Christian Social Action, UCC which, during his tenure, became the Office of Church and Society of the UCC. Co-author of Pronouncement presented to, and adopted, by the General Synod in 1973 titled "The Right to Die." Local church pastor for two decades, now retired at Pilgrim Place in Claremont, California. Strong advocate for choice and personally impacted by this issue as the quality of his health diminishes.

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