**SESSION 4:**  
**Physician Aid in Dying//Physician-Assisted Suicide**

**Prayer**  
God of mercy and justice, during this session, as we consider some issues about which we do not all agree, we ask that you give us all ears to hear different points of view and hearts that are open to one another and to you as all of us seek to speak our own truth in love. Be with us as we discuss our fears and concerns about dying. Be with us as we confront controversy with full respect for each one in our group. Help our differences as well as our agreements to enhance our expanded understanding of your will for our lives. We ask these things in Jesus’ name, knowing that you are with us always. Amen.

**Reading** – Ps 139:1-18, 23-24

**Introduction**

This Lenten study has been looking at a variety of issues important to persons facing the end of their earthly lives. Earlier sessions have focused on making one’s own wishes known through advance healthcare directives; providing information on pain, palliative care and hospice; and exploring the healthcare choices one has as the end of life approaches. This session goes beyond information about various legal options one may consider to a controversial proposal – physician aid in dying, also described as physician-assisted suicide (from here on designated as PAD). Following a resolution passed at the General Synod in 2007 calling for study of PAD, Justice and Witness Ministries convened a committee to study both PAD and other end-of-life issues. This study series is a part of that process.

Here is the Resolution on Physician Aid in Dying enacted by General Synod 26 in 2007:

(As a mini-Bible reading, let us ground ourselves by reading together the words in bold type in the first five parts of this resolution:) (read in unison)

**LEGALIZATION OF PHYSICIAN AID IN DYING**  
(Resolution of Witness)

**RESOLUTION**

WHEREAS, life is both a sacred and a perishable gift from God (Psalm 90:1, 3-4)  
WHEREAS, God intends that created life be more than simply the existence of a human organism (John 10:10)  
WHEREAS, faith sees death as a door into another room in God’s house (John 14: 1-3)  
WHEREAS, compassion - love acted out - flows from the heart of God and through God’s children (Luke 10: 25-37)  
WHEREAS, from the beginning of our lives to life everlasting, God leads us, sustains us, and is always with us (Psalm 139: 7-12)

(The next seven “Whereas” statements are informational and factual in the view of the resolution’s presenters, although some question the accuracy of the tenth WHEREAS which states that there have been “no abuses” of the Oregon law, as we will discuss later. Take a few moments to read these statements for yourselves.)  
(Pause)
WHEREAS, medical technology, pain management and palliative care have made great advances, yet some persons still face intolerable suffering during a terminal illness.

WHEREAS, the Ninth General Synod and the Eighteenth General Synod both passed end-of-life choice resolutions entitled "Rights and Responsibilities of Christians Regarding Human Death," which did not address the issue of physician aid in dying.

WHEREAS, other faith communities have addressed end-of-life issues over the past years.

WHEREAS, Oregon in 1997 passed a "Death with Dignity Act" permitting a mentally capable, dying adult to request and receive from a physician a prescription to hasten death if the patient finds his or her suffering to be unbearable, but only if strict and specific safeguards are followed.

WHEREAS, in Oregon since 1997 there have been no incidents of abuse of this law, and its use has been a rare choice, since the will to live is the greatest safeguard there is, yet thousands who will never use the law to hasten their own death are comforted to know that this choice is legally available if they should be among the few who need it and choose it.

WHEREAS, The United States Supreme Court has affirmed Oregon's right to have such a law; WHEREAS, many physicians, religious leaders, dying patients and family members strongly support physician aid in dying with strong safeguards to prevent abuse.

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.

These four lines contain the basic proposal, which is being widely debated in our states. It needs to be prayerfully considered within our faith communities. Looked at, phrase by phrase, are six definitions and grounds for the proposal. These definitions and rationales, or similar ones, are incorporated in most proposed “aid in dying” legislation that has been discussed in a number of states. To date, such proposals have become law only in Oregon (1997), Washington (2008) and (subject to court challenge) Montana (2008).

Please note these key elements of the General Synod study resolution:

+ Grounds of compassion and choice
+ Strict, consistently followed safeguards to prevent abuse
+ A terminally ill and mentally competent adult
+ A legal right to request and receive medication to hasten death
+ A willing physician
+ A patient who finds his or her suffering unbearable.

Discussion
Which of these phrases, if any, do you feel uncomfortable with?

What is your overall initial response to these six phrases?

How do you think the law should define “unbearable suffering”?

The Central Atlantic Conference also submitted a resolution, which the Executive Council sent to this Task Force to include in our deliberations. Here is part of that resolution:

**IN SUPPORT OF PHYSICIAN ASSISTANCE IN DYING**
(Resolution of Witness)

**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

(Both resolutions are available in their entirety in the Resources section)

**Discussion**

Which of these phrases, if any, do you feel uncomfortable with?

Do you prefer the phrase "periods of severe, unrelenting and intolerable physical discomfort or pain" to the first Resolution's phrase "unbearable suffering"?

(These next three Discussion questions are in reference to both Resolutions)

How do you react to these statements as a whole?

Are you willing to listen to persons whose present views are different from your own?

What questions do you have which you would like hear addressed?

**Scenario**
Richard died at 62. He had been diagnosed with colon cancer. He presumed that his lower back pain was temporary, the result of too much golf or lifting something too heavy. By the time the true cause was known, the cancer had spread to his liver. At each turn in his treatment, he imagined that the next round of chemotherapy would end the disease. When the oncologist told him that more treatment would not be beneficial, he began, in earnest, to contemplate the end of his life. He had learned to live with pain and he wondered whether the pain to come might be difficult, even impossible, to bear. He asked himself whether medication sufficient to relieve the pain would leave him unable to communicate with his wife of 41 years or cause him to become dependent, even addicted. He feared that his care would burden his family, depleting limited resources and imposing on loved ones. He agonized over his impending dependence. He dreaded the idea that he would more than likely die in an unfamiliar place. He wondered whether the doctor who seemed so certain of how to treat his illness knew how to respond now that no cure seemed possible.

The scenario above is based on the dying experience of a real person. Each year, millions of Americans die. The quality of the care they receive, the support they are offered, and the understanding that they and loved ones have concerning end of life issues vary widely.

In survey after survey, when asked how they would hope to spend the last days of their life, an overwhelming majority of people say that they want to die at home, free of pain, and surrounded by loved ones. Often, as mentioned in the session on hospice, we tend to die in institutions, away from home. Enrolling in hospice care, which is available throughout the U.S., can help us remain in our own homes or in a home-like setting with medical and spiritual support to meet our needs and also counsel our families. Even so, some would argue that there will be terminally ill individuals who wish to die before their illness progresses further.

**Questions for discussion**

If you were in Richard’s position, which of his questions and concerns would be yours?

What concerns of Richard’s do you believe could have been addressed by Hospice care and counseling?

What other questions would you find yourself facing?

Would you want to know about how long the doctor thinks you will live?

What new realities and questions would face you at learning this news?

- The likelihood that you will soon die?
- Wondering whether you may become a heavy burden for your family?
- Apprehension that you may suffer in ways that will be unbearable?
Deciding what is most important to you in the time you have left?

Giving up the assumption that you were going to live a much longer life?

Exploring ways you can have some control over your dying process?

Who could you talk honestly and openly with about any of these concerns?

Would you turn to your faith and your faith community for support at this time?

What are other questions that are important to you?

Have you known people who died “good” deaths? If so, think a moment about their and their families’ experiences. Do you see anything of value that going through the dying process might offer?

Do you think going through the dying process might be part of what God intends as our preparation for eternal life?

Here are brief excerpts from two contrasting essays to help you explore further the diverse views on this important issue: (To download entire essays see Resources)

In 2002 the California State Assembly’s Select Committee on Palliative Care convened a citizen committee composed of physicians, ethicists, nurses, church leaders, a disability rights activist, a hospice director, a social worker and others to engage in a public policy dialogue on Physician Aid in Dying (PAD) and other end-of-life issues. On many issues the group reached consensus; on the subject of PAD or Physician-Assisted Suicide (PAS) (the group could not even come to consensus on what to call it), two separate reports were prepared. What follows are a few contrasting excerpts from these reports, which are representative of the ongoing discussion points we need to continue to address.

 Concerning the very language of the debate:

From the essay opposing PAS:
Despite attempts by advocates to change the language from "assisted suicide" to "aid in dying," what is being described is the same: the act of self-killing with outside assistance. Mental health experts have long held that the desire for suicide is an illness, with the same root causes in all circumstances. It is contradictory to the standards of medical practice to carve out a special class of suicidal patients, i.e., the terminally ill, and suspend the rules.

From the essay supporting PAD:
This is not "suicide" as this pejorative word is generally construed. Suicide is usually a tragic, isolated, often violent act of a depressed person whose life could go on with new hope. Physician aid-in-dying is the choice for a carefully safeguarded, peaceful end of a life which is already in the process of ending.

**Autonomy and the Common Good**

From the essay supporting PAD:
Respect for autonomy and promotion of the common good are two key values in American culture and law. Sometimes, however, these are in potential conflict, and need to be balanced with each other. Autonomy must necessarily be constrained when its exercise would be hurtful to other persons. But our liberal democratic principles stand for the proposition that the only legitimate constraints upon the liberty of the individual are those that are necessary to protect others from demonstrable harm. Physician aid-in-dying legislation, as proposed in a number of states and enacted in 1997 in Oregon, seeks a careful balance between individual autonomy and the common good.

From the essay opposing PAS:
"Physician-assisted suicide" by its very definition is not an autonomous act. While individuals are free to end their own lives, the state has a strong interest in preserving life and preventing exploitation and harm in conduct between individuals. Autonomy does not trump state interests in protecting vulnerable members of society from their own decisions.

**Compassion**

From essay supporting PAD:
People of all faith communities (or none) agree with the affirmation of the sanctity of human life. Many also believe that at the end of life when intractable suffering can no longer be assuaged, a competent, dying adult should have a legal right to choose a hastened death with the assistance of a willing physician. In religious terms, this is an issue of free will and compassion.

From essay opposing PAS:
Compassion literally means, 'to bear another's suffering.' Assisted suicide is not an appropriate response to dealing with these emotions as it eliminates suffering, not through treating the illness or emotions, but only by eliminating the sufferer. It does not get to the real issues. Understanding and dealing with the underlying suffering, while more demanding of the caretaker, has always been the hallmark of a compassionate society. Suffering is often a consequence of poor medical and social services and of societal attitudes towards people with disabilities and people who are dying. Legalizing PAS will do nothing to address these problems and might well distract attention from them. Compassion should never encompass ending suffering of others by ending their lives.

**The Role of Law**

From the essay opposing PAS:
Legalizing assisted suicide will have profound public policy implications. Changing the traditional parameters of medical practice will damage the common good by removing a protective boundary from a vital profession and exposing vulnerable populations to an expectation that they avail themselves of PAS rather than become a burden on society or their families.

From the essay supporting PAD:
Some say that it is not the role of the government to be involved in the issue of physician aid-in-dying. But the government is already involved via laws in many states prohibiting assisted suicide, and in one state, Oregon, in permitting it in very limited circumstances. When the Supreme Court ruled on this issue in 1997, the Court strongly affirmed the proposition that it was and should be within the discretion of each sovereign state to determine its position on this important issue.

**Suffering and the Role of Physicians**

From the essay supporting PAD:
A physician who has been a hospice doctor, who supports PAD said, “If the very best end-of-life care does not deal with the patient's suffering, do I need to say 'You have to suffer; I can't help'? That doesn't meet the highest medical standards. It is a violation of the Hippocratic dictum, 'Do no harm.' If you leave a patient in that situation, you are doing harm to that patient as she or he defines it. It is abandonment of the patient when the patient's suffering can no longer be addressed. Therefore, physician aid-in-dying at a patient's request is viewed by many physicians as a rare action at the far end of a continuum of care. It becomes the willing physician's compassionate role to assist because the physician is the gatekeeper to the medication which can allow the patient to die peacefully when the burdens of continued existence, even with the best palliative medicine has to offer, significantly outweigh the benefits.”

From the essay opposing PAS:
A physician opposed to PAS said: “Since the time of Hippocrates medicine has stopped short of causing intentional harm. Medicine, defined by common understanding of the principles of beneficence and benevolence, is separated by a bright line from harm done either for the perceived greater good, the State, or for personal gain. These principles protect both the public and the profession. Physicians must not be put in the position of making judgments outside the domain of their professional expertise. Determining who ought to be candidates for death and who ought not to be is one such judgment.... Physicians should go to the bedside of the dying with compassion and understanding, including an acceptance of their own limitations. The prescription of lethal drugs is outside of and not a part of a continuum of end-of-life care.”

**In conclusion:**

From essay opposing PAS:
Public policy requires us to consider the common good, the social welfare above individuals' personal desires. Because public policy is the expression of our common values and beliefs, it should only be changed when it benefits the common good, and never be changed for the wishes of a few.
From essay supporting PAD:
Enlightened public policy is inconsistent with a blanket prohibition of physician aid-in-dying when the medical profession and society as a whole are seriously divided. In such situations, the matter should remain one of personal and professional conscience, constrained only by legislation that provides reasonable protection against the abuse of vulnerable patients. Current law, by prohibiting physician aid-in-dying, favors those who believe it is immoral. Legalization would give equal (not preferential) treatment to those who believe physician aid-in-dying can be a principled moral choice.

Ask the groups to talk amongst themselves, discussing whether or not they agree with the supporting or opposing groups. Then bring the group back together and ask them to talk about their concerns, fears, doubts, and questions. Acknowledge that there will be people on both sides of this issue and that these discussions are to help people become better informed by the debate that has been going on in the U.S. for many years, and that no one side is yet being supported by the UCC. Remind then that there will be time allotted at the beginning of the next session to continue the discussion and that there will be two position papers given to them before they leave that will add to their ruminations.

In closing this session, let us hear from one of the wise ones of the last century, poet Carl Sandburg, who wrote a poem he called "Elephants are different to different people":

Wilson and Pilcer and Snack stood before the zoo elephant.

Wilson said, "What is its name? Is it from Asia or Africa? Who feeds it? Is it a he or a she? Hold old is it? Do they have twins? How much does it cost to feed? How much does it weigh? If it dies, how much will another one cost? If it dies, what will they use the bones, the fat, and the hide for? What use is it besides to look at?"

Pilcer didn't have any questions; he was murmuring to himself, "It's a house by itself, walls and windows, the ears came from tall cornfields, by God; the architect of those legs was a workman, by God; he stands like a bridge out across deep water; the face is sad and the eyes are kind; I know elephants are good to babies."

Snack looked up and down and at last said to himself, "He's a tough son-of-a-gun outside, and I'll bet he's got a strong heart. I'll bet he's strong as a copper-riveted boiler inside."

They didn't put up any arguments.

They didn't throw anything in each other's faces.

Three men saw the elephant three ways

And let it go at that.
They didn't spoil a sunny Sunday afternoon;

“Sunday comes only once a week,” they told each other.

Closing prayer: God of wisdom and grace, help us to ponder all that we have heard during the coming week so that we might return ready to continue this discussion in the hope that we can better understand this issue. Help us to truly hear opinions that differ from our own and to consider every side of every argument prayerfully, speaking our truth in love to one another as we go. Remind us that you are always present and available to us in each moment of our living, our dying, and our rising to new life. We ask these things in the name of Jesus, who called us to love one another.

Please distribute the two position papers that are on the following pages to all attendees and ask that they read through them and be prepared to continue to discussion about PAD, having been informed further by these two position papers.
A Plea on Behalf of Disability Rights Activists to Consider in the Discussion about PAD/PAS

As people of faith, there are many factors to consider in deciding whether or not to allow Physician Aid in Dying/Physician-Assisted Suicide (PAD/PAS). A few of these are discussed below.

People who are opposed to PAD/PAS do not want any one to suffer. Legalizing PAD/PAS may have serious unintended consequences which cannot be prevented no matter how carefully the legislation is crafted. These consequences make PAD/PAS fundamentally dangerous. People should have the right to die a natural, peaceful death in God’s own time surrounded by their loved ones, with appropriate healthcare—including long-term care and hospice care—in their own homes, free from physical or psychological pain, abuse, or neglect. We are concerned that the availability of PAD/PAS decreases the likelihood that this will happen. Adequate pain relief must be provided for all people by using pain medication, or sedation if necessary. Adequate pain control should be provided in terminal illness, even if medication used to achieve pain control contributes to a person’s death, as long as the medication is not intended to hasten death. Individuals throughout the U.S. have the right to use or refuse life-sustaining treatments such as dialysis and antibiotics.

Activists in the disability rights movement are strong opponents of assisted suicide. We believe it is largely based on fear and the erroneous premise that living with a disability—in this case a disabling terminal illness—that causes dependence on others, the loss of control over bodily functions, the loss of “dignity,” and the loss of autonomy is a fate worse than death. Marilyn Golden writes, “Assisted suicide seems, at first blush, like a good thing to have available. But on closer inspection, there are many reasons legalization is a very serious mistake…. We must separate our private wishes for what we each may hope to have available for ourselves some day and, rather, focus on the significant dangers of legalizing assisted suicide as public policy in this society as it operates today.”1 The NY State Task Force on Life and the Law argues that, among these dangers, “Clinical safeguards proposed to prevent abuse and errors are unlikely to be realized in everyday medical practice. Moreover, the private nature of these decisions would undermine efforts to monitor physicians’ behavior to prevent mistakes and abuse.” 2

More than 76% of the individuals who chose PAD/PAS in Oregon from 1998-2008 did not cite “inadequate pain control or concern about it” as a reason. The reasons they cited were “loss of dignity” (83.8%), “loss of autonomy” (89.9%), “loosing control of bodily functions” (58.7%), and “not wanting to be a burden” (38.3%). 3 Our culture imparts deeply ingrained social prejudices which say that wearing a diaper, using a catheter or a wheelchair, or needing the help of others is “undignified” and a “loss of autonomy,” and that these things make one “a burden.” People with disabilities know, from our lived experience, that this is absolutely, demonstrably false—something we call “ableism”—and we argue that legislating “death with dignity” for terminally ill persons for reasons like “loss of autonomy,” “dignity,” “loosing control of bodily functions,” and “not wanting to be a burden,” is morally and ethically wrong.

Many national disability rights organizations fervently oppose PAD/PAS. (Please see Appendix 1). A long list of medical professionals do as well, including the American Medical Association,
Disability rights activists are concerned that the availability of PAD/PAS may encourage people who are terminally ill to feel they have a “duty to die,” particularly if their health insurance (if they have it) does not cover the services they need; if they are poor; if they are concerned about the burden their illness places on others; or if they are suffering from abuse, neglect, or coercion. In the first eleven years of Oregon’s “Death with Dignity Act,” over 38% of those who chose PAD/PAS gave “burden on family, friends or caregivers” as a reason for their choice.

Many people with disabilities, including the author of this essay, have been asked by people who love us dearly why we just don’t kill ourselves. We believe that people who are terminally ill and have PAD/PAS available to them may receive similar encouragement. We are also concerned that people with terminal illness who do not choose PAD/PAS when it is available to them could be blamed, either subtly or overtly, by others for the deterioration of their health because they chose not to die.

Some researchers have raised concerns that one-quarter of terminally ill people in Oregon who request lethal prescriptions met the criteria for depression. Michael Freeland had terminal cancer and a 43-year history of acute depression and multiple suicide attempts. He was given a lethal prescription even though the Oregon law requires that individuals whose request may be influenced by a mental health disorder must receive a psychiatric evaluation. None of the forty-nine people who died under Oregon’s “Death with Dignity Act” in 2007 were referred for a psychiatric consultation. Furthermore, “only 6% of Oregon psychiatrists are ‘very confident’ they can determine in a single visit when depression may be affecting decisions to commit assisted suicide.” People with depression deserve counseling, not lethal drugs.

We are greatly concerned that the availability of PAD/PAS will decrease the emphasis on providing quality long-term care. Radiation oncologist Dr. Kenneth J. Stevens, MD notes in a 2005 report that “In 2003, the Oregon Health Plan stopped paying for medicines for 10,000 poor Oregonians; this included patients with AIDS, bone marrow transplants, mentally ill and seizure disorders. In 2004 and the first half of [2005], an additional 75,000 Oregonians were cut from the Health Plan, to keep the state budget balanced. Assisted suicide may become the ‘only choice’ for some vulnerable patients.” In 2008, the Health Plan sent a letter to cancer patients Barbara Wagoner and Randy Stroup denying their requests for life-prolonging drugs and telling them that the Health Plan would cover physician aid in dying. Premier PAD/PAS advocate and Hemlock Society founder Derek Humphry writes, “In the final analysis, economics, not the quest for broadened individual liberties or increased autonomy, will drive assisted suicide to the plateau of acceptable practice.” “30% of those surveyed said they would rather die than live permanently in a nursing home….Why do we, as a nation, not allow these people to die…? Their lives would conclude with dignity and self-respect, and one measure of cost containment would be in place.”

The 369 Centers for Independent Living—founded by people with disabilities—have helped tens of thousands of people with severe disabilities maintain control over their lives and care and remain in their own homes—a life-affirming, cost effective solution that avoids nursing home placement. The success of this effort demonstrates that, regardless of their disabilities or

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limitations, no one should feel that they have to die to have dignity, to maintain their autonomy, to be relieved of pain, because they are loosing control over their bodily functions, or because they do not want to be a burden on others.

I believe that if the UCC adopts a resolution in support of PAD/PAS, disability rights activists in the UCC and elsewhere will see it as reinforcing societal prejudices that living with a terminal illness that is disabling is a fate worse than death. Disability rights activists in the UCC can think of no other action the UCC could take that would fuel so strong a sense of rejection and abandonment among activists in the disability community. Jesus healed people with disabilities. As Christians, we are called to heal the deep wounds of isolation and discrimination that people with disabilities bear. The UCC has a centuries-long record of standing against oppression and for civil rights, and seeks to create an expansive welcome for all persons. Please do not cause us to forsake our calling or limit our welcome by rejecting the pleas of our brothers and sisters with disabilities and endorsing the legalization of PAD/PAS. Thank you.

Denise Karuth, M Ed, is a disability rights activist; UCC seminarian; immediate past Moderator of the Hampshire Association, Massachusetts Conference of the UCC; past chair of the Massachusetts Coalition of Citizens with Disabilities; and an advisor to the UCC Disabilities Ministries Board on end-of-life concerns. Denise is legally blind and relies on her live-in personal care assistant Fred Pelka, her dog guide Barry, and a power wheelchair. She lives with MS, severe neurological pain, retinopathy of prematurity, optic neuritis, osteoarthritis, and other disabilities. She can be reached at dkaruth@eds.edu.

Appendix 1: Medical Professionals on Record as Opposing PAD/PAS

- American Medical Association
- American College of Physicians/
  American Society of Internal Medicine
  (116,000 members)
- American Cancer Society
- National Hospice and Palliative Care Organization
- American Nurses Association
- Hospice Nurses Association
- Oncology Nurses Society
- American Psychiatric Association
- American Geriatrics Society
- American Osteopathic Association
- American Neurological Association
- American Academy of Neurology
- American Academy of Physical Medicine and Rehabilitation
- American Academy of Pain Medicine
- American Hospital Association
- American Academy of Pain Management
- American Society of Pain Management Nurses
- Society of Critical Care Medicine
- American Association of Critical Care Nurses
  and others. 4

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Appendix 2: National Disability Groups on Record Opposing Physician Aid in Dying

- **American Association of People with Disabilities (AAPD)** - AAPD is a national cross-disability membership organization promoting political and economic empowerment for the more than 56 million children and adults with disabilities in the United States.

- **American Disabled for Attendant Programs Today (ADAPT)** - ADAPT advocates for the civil rights of people with disabilities, old and young, to receive long term care services in the community instead of being warehoused in nursing homes and institutions.

- **Association of Programs for Rural Independent Living (APRIL)** - APRIL is the national association of centers for independent living, statewide independent living councils, and other organizations working with people with disabilities living in rural areas.

- **Disability Rights Education and Defense Fund (DREDF)** - DREDF is the leading force in education and legal enforcement of the ADA and other laws that prohibit discrimination based on disability.

- **Justice for All (JFA)** - Justice for All and its extensive email network were formed to defend and advance disability rights and programs in the U.S. Congress.

- **National Council on Disability (NCD)** - NCD is an independent federal agency making recommendations to the President and Congress on issues affecting 56 million Americans with Disabilities.

- **National Council on Independent Living (NCIL)** - NCIL is the national association of hundreds of consumer-controlled Centers for Independent Living: non-residential grassroots advocacy and service organizations operated by and for people with disabilities.

- **National Spinal Cord Injury Association (NSCIA)** - NSCIA is an international nonprofit organization for people living with spinal cord injury. Their mission is to enable people with spinal cord injuries to make choices and take actions so that they might achieve their highest level of independence and personal fulfillment.

- **Not Dead Yet (NDY)** - NDY is a grassroots disability rights group formed to oppose the movement to legalize assisted suicide and euthanasia after Dr. Jack Kevorkian was acquitted in the deaths of two women with non-terminal disabilities.

- **TASH** - TASH is a civil rights organization for, and of, people with mental retardation, autism, cerebral palsy, physical disabilities and other conditions that make full integration a challenge. (TASH once stood for “The Association for the Severely Handicapped.”)

- **World Association of Persons with Disabilities (WAPD)** - WAPD advances the interests of persons with disabilities at national, state, local and home levels.
• **World Institute on Disability (WID)** - WID is an international public policy center dedicated to carrying out cutting-edge research on disability issue and overcoming obstacles to independent living. It was founded by Ed Roberts, the “father” of the independent living movement.


**Notes**


10. “A Gift of Treatment – When the Oregon Health Plan fails to cover a cancer drug, the drug maker steps in” by Tim Christie; *The Register-Guard* newspaper, Eugene, Oregon; June 3, 2008.

A Statement in Favor of Legalization of Physician Aid in Dying (PAD) in Limited Circumstances – in Response to a Contrasting View from Some Members of the Disability Community

In 1995 in a case before the Supreme Court Justice O'Connor stated that decisions regarding the legality of physician aid in dying should be made in “the laboratory of the States.” Oregon voters in 1997 decided by a 60% to 40% margin to enact the nation's first law permitting physician aid in dying in certain restricted and carefully safeguarded situations. There are now eleven years of data since the Oregon law went into effect.

In Oregon (and now also in Washington and Montana) persons have the peace of mind of knowing that this legal choice is available: to request and receive help in hastening their impending death. Oregon’s experience has demonstrated that this is a rare choice.

In Oregon physician aid in dying is patient driven. No one else can make this request on behalf of a patient. Only a willing physician will write the prescription.

As stated in the Oregon Death with Dignity law, specific safeguards include:

To be qualified to receive physician aid in dying, a patient
- Must be an adult resident of the state;
- Must be diagnosed as terminally ill by two concurring physicians competent to make such a determination;
- Must be judged to have decisional capacity by two physicians, subject to a mental health consultation if clinical depression is suspected;
- Must request medication voluntarily;
- Must make two oral requests to the physician, with at least a two week waiting period between requests;
- Must submit a written request witnessed by two persons, one of whom shall not be entitled to any portion of the patient's estate upon death;
- May rescind the request at any time in any manner;
- Must be informed of any other possible treatment options, such as hospice care and pain medication.

In addition:
- Without a terminal diagnosis, no person with a chronic illness or a disability is qualified for physician aid in dying;
- Physicians assess for presence of issues which may be coercive. Inducement or coercion of any patient to ask for physician aid in dying is a felony.
- Finally, the primary safeguard against abuse is the will to live. Only when suffering has become unbearable will a rational person seek a hastened death.
- The Oregon Act defines "terminal disease" as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months."

Faithfully Facing Dying: A Lenten Study Guide on Critical Issues and Decisions for the Members of the United Church of Christ – Session 4
“The American Public Health Association (APHA) has long recognized patients’ rights to self-determination at the end of life and that for some terminally ill people, death can sometimes be preferable to any alternative.... A small fraction of dying people confront a dying process so prolonged and marked by such extreme suffering that they determine hastening impending death to be the best alternative.... There is no evidence that since its passage that the Oregon Death with Dignity Act has had a disproportionate impact on persons in vulnerable populations, including persons with disabilities.... The American Public Health Association supports allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place, and manner of his or her impending death, where safeguards equivalent to those in the Oregon Death with Dignity Act are in place.”

Proponents of PAD agree with disability rights advocates concerning the failure of the health care industry in the U.S. to provide adequate health care for millions of U.S. citizens, most notably poor, elderly and disabled persons. Finally our lawmakers are seeking to remedy this failure. (Thanks to Barbara Baylor and Justice and Witness Ministries, convener of the committee studying end-of-life issues, for being in the forefront of this effort!) There is no question that persons with disabilities are frequently underserved; unfortunately it is also true that some who do not presently suffer a major disability will on occasion say to a disabled friend in effect: “If I had to live like you do, I would probably kill myself.” Rev. Harold Wilke was the founder of the UCC Disabilities Ministries and one of the signers of the Americans with Disabilities Act – with his foot since he was born with no arms. He often called non-disabled persons TABS – temporarily able-bodied. The courageous lives lived by Rev. Wilke and millions of other persons with disabilities make up many of the most inspiring stories of the strength of the human spirit, empowered by the Holy Spirit, not just to survive but to prevail.

There is disagreement whether or not more persons with disabilities believe or do not believe that terminally ill, mentally competent patients, disabled or “temporarily able-bodied” should have a carefully safeguarded right to “request and receive from a willing physician medication to hasten death if their suffering becomes unbearable.” Proponents of PAD within the disability rights community argue that they should not be denied the right to physician aid in dying if they are terminally ill and that is their choice. Clearly many disability rights organizations are on record against such a right. But from personal experience in the PAD movement over the past 18 years, I have known scores of persons with disabilities who are part of the quest for limited legalization. Every court case on PAD that has gone to State courts or the U.S Supreme Court has included amicus briefs from disability rights advocates which argue in favor of PAD. In addition, in national and regional polls that have been taken on this subject over the years, when a sub-set persons with disabilities has been included, their responses have been similar.
to those of all other respondents, that is, in each case more have been in favor of a right to PAD than have been opposed.

I remember my friend John, who died of AIDS in 1996, speaking out in favor of physician aid in dying. He said in one conversation we had, “Picture a hospital room with two patients in it. In one bed is a man hooked up to several machines to keep him alive. He says to his doctor, “Please disconnect these machines; I am ready to die.” The doctor removes the machines. The patient dies, and this is legal. In the other bed is a patient dying of AIDS, suffering greatly. He is not connected to any machines. He asks the doctor to write him a prescription so he can die peacefully. The doctor cannot legally respond to his request. He must continue to suffer.” That is wrong.

Many persons will choose to draw the last possible breath no-matter-what. That choice will remain for every person who wants it. A few others, when end-of-life suffering becomes unbearable, will decide that continued existence on earth without hope or meaning is no longer tolerable. They may ask to have the choice of a peaceful release. Those arguing in favor of PAD believe that every adult in our nation, poor or privileged, old or young, a person with a disability or a temporarily-able-bodied person, should be able to exercise the same rights.

The following is the last paragraph of an article in the Montana Law Review, Summer 2007 by Kathryn Tucker, who has argued in favor of aid in dying in two Supreme Court cases:

“A fraction of dying patients, even with excellent pain and symptom management, confront a prolonged dying process marked by extreme suffering and deterioration. Some of these patients determine that hastening impending death is the better alternative. Recognition of such a right would harm no one, and would benefit both the relatively few patients in extremis who would make use of it, and a great many more who would draw comfort from knowing this option is available should their dying process become intolerable to them.”

Rev. John Brooke is a retired UCC minister. He served seven churches in the western states over 38 years. Following experiences with his mother and a close friend, since 1992 he has been engaged in studying and working politically and through the church to expand the choices available to persons at the end of life. He was the primary author and spokesperson for the resolution on Physician Aid in Dying which General Synod 26 voted to study. This study guide is a step in that process. John can be reached at: johnrbrooke@earthlink.net