

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

Session 5

**Physician Aid in Dying: Continuing the Discussion
and**

Euthanasia, Brain Death, Persistent Vegetative State, Minimally Conscious State

Prayer

O Holy Spirit, enter into our midst as we return to this group to discuss, in mutual love and respect, what we have been considering prayerfully over the past week. Help us listen for your still, small voice amid the voices of others—the authors of the position papers and those in this circle with us. Open the ears of our hearts to what each person is saying, even if their opinion is different from our own. And keep us ever mindful that we travel through the wilderness of dying and death with you, both today and whenever these issues impact our lives. We ask these prayers in the name of Jesus, whose peace is always with us. Amen.

Reading – Ps 139:1-18, 23-24

Physician Aid in Dying: Continuing the Discussion

Now that people have had a chance to read through the two position papers on PAD, let's discuss them. Below are some questions to help focus the discussion.

Has your outlook on PAD changed in any way?

What issues that were raised in the paper outlining concerns of disability rights activists had you not considered before?

Did it make you think any differently about “loss of dignity” or “loss of autonomy?”

Did it make you wonder if any safeguards can effectively protect people with impaired judgment due to depression from ending their lives?

Did it make you wonder if the availability of PAD might encourage people to believe they have “a duty to die,” especially if they are worried about the cost of their care or the burden they are placing on family members or if they are being abused or coerced?

Did it make you wonder about the impact of PAD on long-term care for people with disabilities and terminal illness?

Can you understand why disability rights activists who are part of the UCC feel that passing a resolution in support of PAD at a General Synod would “would fuel so strong a sense of rejection and abandonment among activists in the disability community”?

What issues that were raised in the paper submitted in response had you not considered before?

Did it cause you to reconsider your ideas about PAD?

Would you like to know more about the multiple safeguards built into the Oregon law?
(See Resources section for further information)

Does the fact that some persons with disabilities and some disability rights activists are supportive of PAD in strictly safeguarded circumstances affect your thinking about these issues?

Have you been able to come to any conclusions for yourself as to whether or not PAD should be allowed with the stipulations outlined in the Resolutions presented at General Synod?

This is one of those issues that we will be coming back to for your opinion in the survey that we will be taking in the spring. Please do continue to consider it and pray about it so that when the time comes, you will be able to say whether or not you would support the resolutions that have been put forward about PAD.

Information

Since there has been confusion as to what the difference is between PAD and euthanasia, we wanted to give you the definition of euthanasia so that you will be informed as to what it is and know that euthanasia is NOT allowed in the U.S., nor is it supported by those who are proponents of PAD within the UCC.

Euthanasia

As noted in the Introduction, 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.” [1] 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, Persistent Vegetative State, Minimally Conscious State

As we approach the end of this study series, we want to mention some terms that are used to describe the level of brain activity and consciousness in persons with severe brain damage that you may want to better understand.

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.”[2] 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).

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.”[3] 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.

“The persistent vegetative state was first described in 1972 in a landmark article in the British journal *The Lancet*. They 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.” [4]

“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. Brain death is recognized as the equivalent of cardiopulmonary death in all states, although a couple of states allow for a religious or moral objection to this neurological definition of death.”[5]

There have been cases where people say that someone who was in a PVS for many years, all of a sudden recovered. Recent studies have shown that these individuals were actually inappropriately diagnosed. They were actually in what is known as a minimally conscious state.

Minimally Conscious State

Minimally Conscious State (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.[6]

“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.”[7]

Closing Prayer

Mother and Father of us all, help us hold each person in this circle like a sister or brother as we close our discussion today. Help us reflect on what we have heard: things we agree with, things we cannot accept for ourselves, and things that seem “strange” or “different” to us. Help us continue to ponder all that we have considered over the past five weeks, as we move towards Holy Week and recall Jesus' betrayal, suffering and death. We ask these things in the name of Jesus, your Son and our brother, whose path to heaven passed through Calvary. Amen.

Footnotes:

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

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

[3] Tubbs, 124.

[4] 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>.

[5] Ibid.

[6] Ibid.

[7] Ibid.