Christian Decision Making at Life's End

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A workshop for thinking through how to make decisions concerning end-of-life. This workshop will not give specific answers to specific questions. These are constantly changing. The goal is to provide a framework and resources to help with the decisions that need to be made.

The Challenge

M. Luther "We should familiarize ourselves with death during our lifetime, inviting death into our presence when it is still at a distance and not on the move. At the time of dying, however, this is hazardous and useless, for then death looms large of its own accord. In that hour we must put the thought of death out of mind and refuse to see it, as we shall hear. The power and might of death are rooted in the fearfulness of our nature and in our untimely and undue viewing and contemplating of it."

1. Death in Luther's Day: Plague, Childbirth, Price on his head

2. Death today:

"Today most people do not die of war, famine or plague as in the past. Now because of chronic illness they slowly fade away from sight, from others, from life."

Complexity of medical system, lack of understanding

Distance: physical, emotional. Distance from known medical providers

Medical Assistance in Dying

3. Goal: Be prepared

"It is my eager expectation and hope that I will not be at all ashamed, but that with full courage now as always Christ will be honored in my body, whether by life or by death. For to me to live is Christ, and to die is gain... Only let your manner of life be worthy of the gospel of Christ, so that whether I come and see you or am absent, I may hear of you that you are standing firm in one spirit, with one mind stiving side by side for the sake of the faith of the gospel" (Philippians 1:20-21, 27).

Questions for discussion

How is death handled in your family and church?

Is it discussed or not talked about?

When, if ever, is the appropriate time to talk about life and death?

With whom should we have the conversation?

Having the Conversation

5 W Questions—Who, What, When, Where, Why, How

Who: family, friends, especially the agent(s)

What: Kinds of treatment, Best Interest Standard, Community, Heaven

When: Now. Day after Thanksgiving. Sooner.

Where: Documents—Last Will and Testament, Durable Power of Attorney for

Health Care Issues

Why: Better Care, Better Decisions, Cut down guilt, Gift to your family

How: Blame me! Blame your pastor! Just git-r-done!

¹ Martin Luther. "A Sermon on Preparing to Die" Am Ed. VI 42 p.101-102.

Case 1: Oscar, a 75-year-old man, who had been deeply involved in the vegan movement for many years, fell ill with Alzheimer's disease and was placed in a residential home, where in accordance with his previous habits he was served vegan meals. One day, by mistake, he happened to eat a portion of meatballs, potatoes, brown sauce and lingon berries that was intended for another resident. He enjoyed it very much and at the next meal noticed for the first time that different food was served to all the others. The case workers persuaded him to eat his vegan meal, but the next day he refused point-blank to eat 'any special muck that's only for me'.

His key worker discussed the situation with his wife, who in no uncertain terms expressly forbade the staff to give him anything but vegan food. She insisted that it was against his (and her) conviction to eat meat or 'warmed-over dead body parts', as she put it. The staff tried to comply, but encountered vociferous protest at each meal from the man, who sometimes, with triumph and great delight, managed to appropriate food left over by someone else at the table.

The head of the unit and the staff were not sure to handle this. Should they allow him to eat meat? What should they tell his wife?

What Ethical Issues are involved in this case?

Ethics:

- a. Consequentialism Egoism, Utilitarianism
- b. Deontology (Greek: Deon, "It is necessary") Where do you get your principles? A. Religion, B. Intuition, C. Reason
- c. Virtue Ethics

Bioethics

- 1. Principlism (Beauchamp and Childress):
 Autonomy, Beneficence, Non-maleficence, Justice
- 2. Quality of Life
- 3. Medicine/Legal: Advance Directives
 - a. Durable power of attorney for health care issues, (Health Care Agent)
 - b. Living Will
- 4. Issues:
 - a. Do Not Resuscitate (DNR)
 - b. Artificial nutrition and hydration
 - c. Allow Natural Death
 - d. Voluntary Stopping of Eating and Drinking (VSED)
 - e. Medical Assistance in Dying

What are the strengths and weaknesses of these ways of dealing with death?

The church's solution

- 1. Not autonomy but community.
- 2. Quality of Life
- 3. Seek God's way always: 3rd and 7th Petitions
- 4. Best Interest Standard
- 5. Two statements:
 - (1) God is present and heals through the hands of doctors and nurses (medicine is God's gift).
 - (2) "I'm but a stranger here, heaven is my home."

Decision Making: Pray, Pray, and when all else fails pray

Questions to consider at End of Life.

- a. How soon do we need to make a decision?
- b. What things need to be decided and in what order?
- c. Who do we need to talk with in order to make the decision?
- d. What information do we need in order to decide?
- e. What does God's Word say about the situation?
- f. What do others in the church think about the situation?

After prayer, conversation with the medical people, prayer, discussion with others in the church, prayer, discussion within the family, prayer, go forward with the decision knowing that we aren't really making a decision because God is in charge and he always will do what is best in his eyes for his people and knowing that if later we think we made a wrong decision God forgives and loves us always.

Updated Guided Principles

In 1979 the CTCR released a document entitled: "Report on Euthanasia With Guiding Principles. These principles were intended "to help individual Christians and groups of the faithful in their response to the issues which confront us in this area." Below is a simplified and updated version of these principles.

- 1. Every person is valuable in the sight of God and his people for God created and saved all through his Son, Jesus Christ. Therefore, everyone deserves the best possible care throughout their lives and in the hour of their death.
- 2. God will heal all disease when he chooses either here or in his presence eternally.
- 3. God alone knows the number of a person's days. He has the sole power to create and end life. Therefore, euthanasia is against God's will. This includes any form of Medical Assistance in Dying.
- 4. Christians are called on to "bear one another's burdens" including at the end of life.

We are here to encourage, support and care for one another as we await the day of the Lord.

- 5. Death is not a part of life but its opposite brought into the world because of man's sin.
 - We are not to seek death nor to seek continued life as if it is the highest good. A Christian is free to die in the confidence of the resurrection. Therefore, one can reject or stop treatments that are no longer beneficial for the person.
- 6. We make decisions based on the best information that can be gathered, in consultation with other members of the Body of Christ, praying that God's will be done. We always depend on the strength and forgiveness of our Lord.

An End-of-Life Statement of Faith (Creed)

Throughout my life and especially at the hour of my death I want my family to know that I believe the following:

- (1) We are not our own. We belong to Christ (1 Corinthians 6).
- (2) We've been through death and resurrection once before in baptism (Romans 6).
- (3) We are never alone. God is always with us (Matthew 1:23, 28:20).
- (4) He is greater than all things. His Son has destroyed the power of darkness (John 1).
- (5) In him we have life because he died for us (1 John 5).
- (6) Nothing can separate us from him not even death (Romans 8).

Finally, (7) "'Death is swallowed up in victory.' O death, where is your victory? O death, where is your sting? The sting of death is sin, and the power of sin is the law. But thanks be to God, who gives us the victory through our Lord Jesus Christ" (1 Corinthians 15:54b-57).

Resources

"Christian Decision Making at Life's End." T. Rynearson available by email. peacelut@brookings.net

Part 1: Having the Conversation, Terminology (with Commentary),

Part 2: Diminished Decision-Making Capacity

Part 3: Information Overload

Part 4: Substituted Judgement

Part 5: Medical Assistance in Dying

"Christian Care at Life's End," 1993) A Report of the Commission on Theology & Church Relations, LCMS. www.lcms.org

Gilbert Meilaender, "I Want to be a Burden to my Family", *First Things*, October 1991 https://www.firstthings.com/article/2010/03/i-want-to-burden-my-loved-ones

To live or to die? When the time comes, Gilbert Meilaender wants his fate in his family's hands, not his own.

Recently I was a speaker and panel member at a small educational workshop on "advance directives" sponsored by the ethics committee of our local hospital. The workshop was an opportunity to provide information about, and discuss the relative merits of, living wills and durable powers of attorney as different ways of trying to deal in advance with medical decisions that might have to be made for us after we have become incompetent. This is not the first such workshop for me, and I suppose it may not be the last. And I was struck, as I have been before, with the recurrence of a certain theme.

Many people come to such a workshop already quite knowledgeable about the topic to be discussed. They come less for information than for the opportunity to talk. Some earnestly desire the chance to converse about a troubling issue; a few just want to express themselves. In either case, however, it is remarkable how often they may say something like the following: "I'm afraid that if my children have to make decisions about my care, they won't be able to handle the pressure. They'll just argue with each other, and they'll feel guilty, wondering whether they're really doing what I would want. I don't want to be a burden to them, and I will do whatever I can in advance to see that I'm not."

And after someone has spoken words to this effect, there will be a chorus of assent from the people who, evidently, share the speaker's view.

Now, of course, we can in many ways understand and appreciate such a perspective. None of us wishes to imagine his children arguing together about who really knows best how he should be treated (or not treated). We hate to think that our children's last thoughts of us would be interwoven with anger at each other, guilt for their uncertainty about how best to care for us, or even (perhaps) a secret wish that we'd get on with the dying and relieve them of this burden.

Nonetheless, as the workshop wore on, I found myself giving it only a part of my attention, because I couldn't help musing on this recurring theme. Understandable as it surely is in many respects, there is, I am convinced, something wrong with it. I don't know how to make the point other than a little too crassly—other than by saying that I want to be a burden to my loved ones. But, rightly understood, I think I do.

The first thought that occurred to me in my musings was not, I admit, the noblest: I have sweated in the hot sun teaching four children to catch and hit a ball, to swing a tennis racket and shoot a free throw. I have built blocks and played games I detest with and for my children. I have watched countless basketball games made up largely of bad passes, traveling violations, and shots that missed both rim and backboard. I have sat through years of piano recitals, band concerts, school programs—often on very busy nights or very hot, humid evenings in late spring. I have stood in a steamy bathroom in the middle of the night with the hot shower running, trying to help a child with croup breathe more easily. I have run beside a bicycle, ready to catch a child who might fall while learning to ride. (This is, by the way, very hard!) I have spent hours finding perfectly decent (cheap) clothing in stores, only to have these choices rejected as somehow not exactly what we had in mind. I have used evenings to type in final form long stories—longer by far than necessary—that my children have written in response to school assignments. I have had to fight for the right to eat at Burger King rather than McDonald's. Why should I not be a bit of a burden to these children in my dying?

This was not, I have already granted, the noblest thought, but it was the first. And, of course, it overlooks a great deal—above all, that I have taken great joy in these children and have not really resented much in the litany of burdens recited above. But still, there is here a serious point to be considered. Is this not in large measure what it means to belong to a family: to burden each other—and to find, almost miraculously, that others are willing, even happy, to carry such burdens? Families would not have the significance they do for us if they did not, in fact, give us a claim upon each other. At least in this sphere of life we do not come together as autonomous individuals freely contracting with each other. We simply find ourselves thrown together and asked to share the burdens of life while learning to care for each other. We may often resent such claims on our time and energies. We did not, after all, consent to them. (Or, at least, if we want to speak of consent, it will have to be something like that old staple of social-contract theorists, tacit consent.)

It is, therefore, understandable that we sometimes chafe under these burdens. If, however, we also go on to reject them, we cease to live in the kind of moral community that deserves to be called a family. Here more than in any other sphere of life we are presented with unwanted and unexpected interruptions to our plans and projects. I do not like such interruptions any more than the next person; indeed, a little less, I rather suspect. But it is still true that morality consists in large part in learning to deal with the unwanted and unexpected interruptions to our plans. I have tried, subject to my limits and weaknesses, to teach that lesson to my children. Perhaps I will teach it best when I am a burden to them in my dying.

This was my first thought. It led to a second. Perhaps it is a good thing, lest we be tempted to injustice, that the dying burden the living. Some years ago Robert Burt wrote a book about medical decision-making for incompetent patients. The book's title was *Taking Care of Strangers*. Burt's point, which carried a *double entendre*, was essentially this: Patients who are unable to make decisions for themselves are often in a state (e.g., severely demented, comatose) in which they become strangers to us. They make us uneasy, and we react with ambivalence. And to say, "I'll take care of

him" about such a patient may be a statement freighted with ambivalence. Burt worries that, no matter how devoted our care, our uneasiness with a loved one who has become a stranger to us may prompt us to do less than we ought to sustain his life. (Nor, should we note, are physicians immune to such uneasiness.) It is, therefore, essential that we structure the medical decision-making situation in such a way that conversation is forced among the doctor, the medical caregivers, the patient's family, and perhaps still others, such as pastor, priest, or rabbi. Advance directives, designed to eliminate the need for such extended conversation—lest it should burden loved ones—are, from this perspective, somewhat problematic. They may not force us to deal with our own ambivalence in "taking care of" a loved one who is now a burdensome stranger.

This does not mean that advance directives are entirely a bad idea. It does suggest, however, that a durable power of attorney for medical care—in which we simply name a proxy to make decisions in the event of our incompetence—is better than a living will in which we attempt to state the kinds of treatment we would or would not desire under a variety of medical circumstances. At this point in my life, for example, I would surely turn over to my wife my power of attorney. In doing so I simply announce to medical caregivers: "Here is the person with whom you must converse when the day comes that you cannot talk with me about my medical care." I myself do not particularly like the recently fashionable attempts to combine the two forms of advance directives by naming a proxy and giving that proxy as much detail as possible about what we would want done. That move—though, again, it will be seen as an attempt to avoid burdening the loved one who must make such decisions—may not, in any case, accomplish our aim. What it commits us to is an endless, futile search to determine what a now-incompetent person would wish. Still more important, it is one last-ditch attempt to bypass the interdependence of human life, by which we simply do and should constitute a burden to those who love us.

I hope, therefore, that I will have the good sense to empower my wife, while she is able, to make such decisions for me—though I know full well that we do not always agree about what is the best care in end-of-life circumstances. That disagreement doesn't bother me at all. As long as she avoids the futile question, "What would he have wanted?" and contents herself with the (difficult enough) question, "What is best for him now?" I will have no quarrel with her. Moreover, this approach is, I think, less likely to encourage her to make the moral mistake of asking, "Is his life a benefit to him (i.e., a life worth living)?" and more likely to encourage her to ask, "What can we do to benefit the life he still has?" No doubt this will be a burden to her. No doubt she will bear the burden better than I would. No doubt it will be only the last in a long history of burdens she has borne for me. But then, mystery and continuous miracle that it is, she loves me. And because she does, I must of course be a burden to her.