The Death of “Death Panels”: Reforming End-of-Life Decision Making

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Quotable quotes

- When choosing between two evils, choose the one you have not tried before.
- If you cannot be a good role model, at least be a bad example.
- “I’ve made up my mind but I’ve made it up both ways.” — Mae West
- “Here’s a rule I recommend. Never practice two vices at once.” —Tallulah Bankhead

“Until we are sick, we understand not.” *Keats*

Riffs on Keats

“Until we are dying, we understand not.” *Me*

“Until we are deciding, we understand not.” *Me*

End-of-Life decision making in the current American context

- value individualism and self determination
  - autonomy and duty not to interfere
- pluralistic society
  - autonomy challenged by collective cultures
- technology rush
- lack of universal health care access
- increasing political polarization
- decreasing civility in public discourse
  - public square or boxing ring?
- paper bag approach to death

How we think about death

- Simple—we don’t!
- More complex:
  - enemy
  - friend
  - “that good night”
  - “the dying light”
  - loss
  - eternal rest
  - the end
  - the beginning

Assumptions

- Ethics is a process, a method, for making good decisions personally, professionally, and in the public square.
- Theologically informed voices should be heard in the public square.
  - Shared values and concerns, e.g., dignity
- Reform is not there-and-then or here-and-now but an on-going, transformative process of discernment and change.

Assumptions

- Health care is a right, a social good needed to participate in community.
  - Health care is not only about me and mine but also about us and ours.
  - Society has a serious ethical obligation to fulfill this right.
- Each of us approaches thinking about health, illness, and the end-of-life with our own life experiences and values.
  - Both are rich resources for ethics.

Assumptions

- End-of-life decisions must be fully informed
  - – Requires knowledge and understanding of options and the possible consequences of acting or not acting on a particular option
  - – Requires the ability to consent (autonomy)
- “Nobody knows me better than me.”
  - – Decide for yourself.
  - – Appoint someone to decide if you cannot.

Context of EOL decision making

- Technological advances, changes in social and family systems, and “the tyranny of choice” steadily increase the complexity of end-of-life care and decision making.
  - Technology has not created the EOL ethical landscape but forces us frequently to confront ethical questions about sustaining life medically.
- High-profile, game-changing court cases and legislation influence public opinion, regulation, law, and ethical approaches to dying and end-of-life decision making.

Ethics is . . .

- the study and identification of standards of human behavior that seek to achieve “the good.”
  - Asks us to justify *who we are* and *how we behave*.
- *thinking carefully* and *speaking helpfully* about things that really matter.
- rarely blue or red; but, usually shades of purple.

Ethics is not . . .

- primarily about answering difficult questions; but, about providing perspectives from which those questions can be asked and deliberated.
- Ethics is about questions—about who asks (and who does not), what they ask for and why.

Two key ethics questions

- Who should I be?
  - What character traits should I display by habit? E.g., honesty, consistency, compassion, justice
  - What type of person should I be and become?
- How should I act?
  - How do I make the “right” decision about what to do?
  - What standards (should) guide my decision?

Fundamental concept

Ethics

- is about *choices*
- is about giving *reasons* for those choices
- and about how those choices affect the quality of our relationships with others.

At the heart,

Ethics

is

about

relationships.

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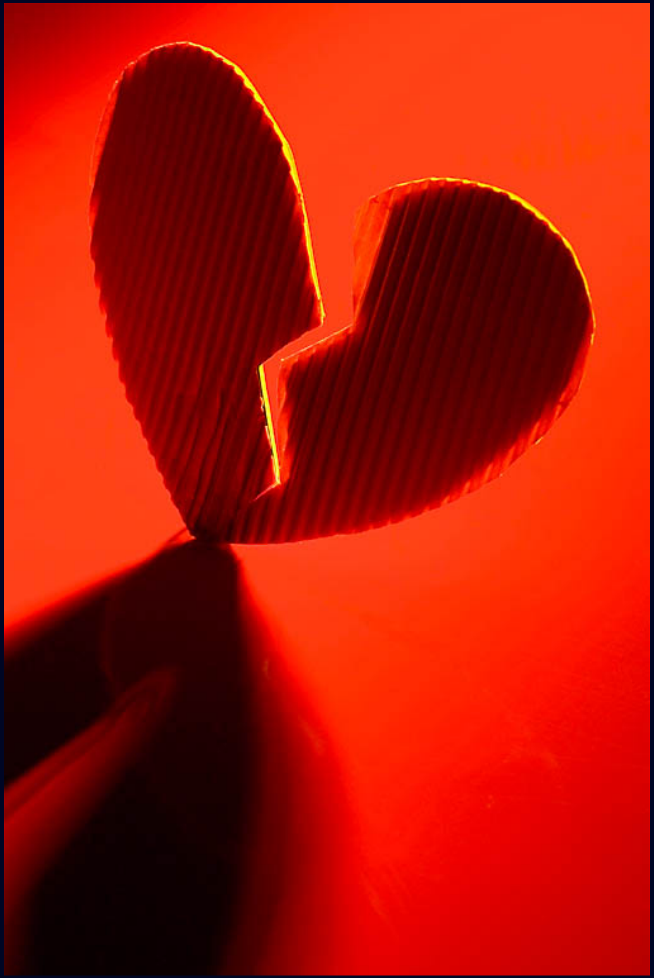
At the heart,

End-of-life decisions are about relationships—relationships that are changing, in need of review, and perhaps in need of reconciliation and restoration.

End-of-life decisions complicated by

- changing relationships
- the loss of memory *and*
- the memory of loss



A motto for mortality

“Medical technology has brought us many miracles, from babies conceived in Petri dishes to children reborn with someone else’s heart. But it has become fearsome to us, too. ‘I wouldn’t want to be kept alive that way’ has become a motto for American society.”

Anna Quidlen

New York Times, 8/14/91

Life and death

- “Traditional model” => life and death as distinct states with a relatively clear line between them.
  - – Medicine and technology smudge the “line” between life and death,
  - – moving us from “tame death” to “wild death.”

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“Tame Death” & “Wild Death”

- “Tame death” = premodern death mediated by the comforts offered by family and community
- “Wild death” = modern death in which dying is out of (our) control because the means of dying have been given to technology and institutions

(Dan Callahan, *The Troubled Dream of Life*, 1991)

The drift from “Tame” to “Wild”

- Public sanitation, clean water, and antibiotics eliminated many diseases which destroyed whole populations.
- Increase in life span makes us vulnerable to diseases that did not afflict our ancestors.
- Increase in our technical capacity to intervene in and to prolong the dying process

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Fear of “Wild Death”

- becoming dependent
- loss of control (autonomy)
- loss of dignity
- unrelenting pain
- unbearable suffering

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Dying is a process.

- Not death as an unwanted goal => life results in death; living produces dying;
- but, dying as process => living and dying are the same thing—a single process we call "life."
  - "Be busy about living or be busy about dying. Prefer the first until it is time for the second." (bumper sticker)

Proposed ethical standard

- . . . that recognizes the value of life throughout the process of its loss and affirms that different moral obligations are appropriate at different stages.
- Proposed ethical standard:

Dying like living is a process and paying attention to the dying process is an intrinsic good.

Human living

- Two “intuitions” that inform our view of human life:
  - Life is a fundamental good and of value.
  - Life is neither the only nor the absolute good.
- These “intuitions” tell us that life must not needlessly be destroyed, but it need not always be preserved.

Life cannot always be preserved.

- We are being asked to make increasingly difficult decisions about increasingly complicated options for medical intervention.
  - For ourselves
  - For loved ones
  - For strangers

Ethics seeks decisions that are:

- Authentic
- Compassionate
- Caring
- Courageous

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Authenticity . . .

- respects autonomy.
- recognizes the importance of who we are and how we live.
- claims that we should die as we have lived—true to ourselves.

Compassion

- "*Compassion* is the heartfelt capacity whereby the weakness, suffering, and vulnerability of another draws us in and impels us to act." Stephen Privett, SJ
  - "Com-passion" = with passion on behalf of
  - "Com-passion" = with **action** on behalf of
  - What would it mean to be com-passionate in our end-of-life decision making?
    - Proactive
    - Think it forward

Compassion recognizes that:

- dying is a natural transition, not a personal or medical failure.
- a medically prolonged dying process may be worse than death itself.
- the transition from living to dying includes:
  - time to prepare
  - managing the final stages of a terminal condition

Caring . . .

- demands that we treat those who are ill and those who are dying with dignity.
- recognizes that a dying person is a person in relationship and that those relationships are changing.
- claims that living and dying ought to occur within a caring community.
- asks us to listen to those on the “underside.”
  - listen and respond to the stories of those who are vulnerable and often unseen—people who are sick, suffering, dying

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Response demands courage

“Of all the virtues, courage is the most important--it allows us to exercise the other virtues with consistency.”

Maya Angelou