Caring for Those with Life-Threatening Illness
Pre-Session, CHA Assembly  |  June 1, 2013

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Overview

• Those caring for seniors require a lived spirituality that
  – Recognizes the importance of narrative
  – Grounds and expresses itself in prayers and liturgy
  – Understands sacramental presence
  – Appreciates the reality of diminishment and death
Respecting the Importance of Narrative
Story

- Using an image or metaphor
- Recalling a life experience
- Acknowledging sense of loss and diminishment
- Celebrating a sense of hope
Use of Metaphor

- Asking
- What does this feel like?
- Have you ever felt like this before?
Definitions

• **Narrative**
  – a story or account of events or experiences
  – the representation in art of an event or story

• **Story**
  – an account of incidents or events
Definitions

• **History**
  – Aggregate of past events
  – a chronological telling of events
  – an established record

• **Hermeneutics**
  – The science of interpretation
History

- The actual **facts or events**
  - e.g., Pearl Harbor
- **Interpretation** of the facts or events
  - as told by Japanese pilot
  - as told by U.S. sailor
  - as told by Churchill, FDR
  - as told by Hawaiian child
History

• History is the **event** and the **interpretation** of the event
• Listen to different stories, different voices
• In order to allow light and clarity to shine through
Listening to a Story

- The story (or parable) as told carries its own meaning and significance
- But listen to the *way* that it is told
- And listen for the *story beneath the story*
  - to reveal the deepest meaning
  - to evoke the strongest commitment
Narrative Theology

Narratives function to sustain the particular moral identity of a religious (or secular) community by rehearsing its history and traditional meanings as these are portrayed in Scripture and other sources.

- James Gustafson
Narrative Theology

Through our participation in such a community, the narratives also function to give shape to our moral characters, which in turn, deeply affect the way we interpret or construe the world and events and thus affect what we determine to be appropriate action as members of the community.
Narrative and the Christian

• Each one of us has different narratives in our lives
  – Not inconsistent
  – Similar to a great symphony, playing simultaneously
    • The deep story
    • Our personal story
    • Our communal story
Learnings

• Stories reveal the moral character of individuals and communities
• Stories
  – describe who we are
  – shape who we are
  – provide us with guidance for the future
  – sustain us through the challenges we face
Spiritual Sense Grounds
One’s Life
Grounded in Spirituality

- Deeper, more fundamental than cognition
- Lived more deeply than theology
- Becomes one’s “default”, especially in times of crisis or stress
- Comforts one in times of sorrow, loss
Deeper than Cognition
One’s Religious Life Grounded in

• The faith of believing community
• Expressed in prayers
• Ritualized in Liturgy
  – Repeated throughout our lifetimes
  – Daily prayers
  – Weekly liturgy
  – Moments and times of remembrance
Theological Foundation

- *Prolixitas Mortis*
  - Gregory the Great
- *Ars Moriendi*
- Prayers for a happy death
- Christian practice to reflect on last things
Recognizes Sacramental Presence
Sacramental Foundation

- Human body, soul, spirit, therefore,
- Health care includes holistic understanding of human person
  - physiological
  - spiritual
  - psychological
  - social
Sacramental Foundation
Sacramental Foundation
Sacramental Foundation

• End-of-life needs extend far beyond physical reality and needs to include
  – forgiveness of sins
  – anointing of the sick
  – receiving the Eucharist
  – communal prayer
Expresses itself through:

- Bathing the patient/resident
- Dressing, grooming, the person
- Serving food (even something as basic as a cup of tea)
- Covering the person’s body (modesty)
- Greeting/acknowledging the person
Appreciates the **Reality** of Diminishment and Death
Stained Glass Window
Recognizing the Reality of Death

- Death is natural
- Nature brings balance
- Nature gives abundance
- Nature serves as guide

Reality of Loss and Nature

“When despair for the world grows in me and I wake in the night at the least sound in fear of what my life and my children's lives may be, I go and lie down where the wood drake rests in his beauty on the water, and the great heron feeds. I come into the peace of wild things who do not tax their lives with forethought of grief. I come into the presence of still water. And I feel above me the day-blind stars waiting with their light. For a time I rest in the grace of the world, and am free.”

➢ Wendell Berry, “Sex, Economy, Freedom and Community: Eight Essays”
Steve Jobs (Stanford, 2005)

"Remembering that I'll be dead soon is the most important tool I've ever encountered to help me make the big choices in life. Because almost everything -- all external expectations, all pride, all fear of embarrassment or failure -- these things just fall away in the face of death, leaving only what is truly important. Remembering that you are going to die is the best way I know to avoid the trap of thinking you have something to lose. You are already naked. There is no reason not to follow your heart."
The Comfort of Time!

We do not lose anything but are always gaining. It is true that ultimately this is known only to the believer....Life gathers itself together more and more, the more apparently the past lies behind us. The more it seems like that, the more we have in front of us. And when we arrive, we find our whole life and all its real possibilities and the meaning of all the possibilities which had been given to us. There is not only a resurrection of the body but also a resurrection of time in eternity.

➢ Karl Rahner, Theological Investigations, Vol. III
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THOMAS NAIRN, O.F.M.
SENIOR DIRECTOR, ETHICS
I am a Franciscan . . .

- St. Francis of Assisi
  - “Praised be to you, O Lord, through Sister Death . . .”
- St. Bernardine of Siena
  - Only the foolish person believes that death can be evaded.
  - Evidence of a “life sinfully loved.”
Witnesses to Hope

• “Too often, physicians misunderstand the ingredients of hope, thinking it refers only to cure or remission. . . . This is done with the best of intentions, but the hell whose access road is paved with good intentions becomes too often the hell through which a misled person must pass before he or she succumbs to inevitable death.”

  (Sherwin Nuland, How We Die)

• Francis embraced illness and approaching death as sisters.
  – “Praised be You, my Lord, through our Sister Bodily Death, from whom no one living can escape.”

• Religious can be truthful, speaking the truth about sickness (and even death) and not fearing to name them.
  – Enabling and empowering others.
  – We can show others that they need not fear sickness, diminishment and even dying.
Witness to Acceptance: Sickness and End of Life

• Technology
  – Use of technology is the ordinary way that action is carried out.

• “Technological Monism”
  – All meaningful actions are technological.
    ▪ Technological acts or omissions.
  – What nature does, its underlying causes and pathologies, is irrelevant.
    ▪ No death is natural.
    ▪ No natural cause is determinative unless failure to deploy technology makes it so.
The Catholic Tradition: A Limited Duty to Preserve Life

• Human life is sacred and a gift of God.
• Therefore, do have a duty to protect and preserve our lives.
• Duty, however, is not absolutely binding under all circumstances.
  – While sacred, human life is not absolute.
• Since the 16th century, widely accepted among Catholic moralists that one need only employ “ordinary” means of preserving life, but not means that are deemed “extraordinary.”
  – Limits on the duty to preserve life.
The Catholic Tradition: A Limited Duty to Preserve Life

• Stewardship of and duty to preserve life.
  – A limited duty. Why?
    ▪ Human life is sacred and of value, but not absolute.
    ▪ Because it is a limited good, duty to preserve it is limited to what is beneficial and reasonable.
  – “Life and physical health are precious gifts entrusted to us by God. We must take reasonable care of them, taking into account the needs of others and the common good.”

(CATECHISM OF THE CATHOLIC CHURCH, §2288)
Witness to Acceptance: Sickness and End of Life

- Decisions about use of technology made in light of …
  - Human dignity.
  - Christian meaning of life, suffering and death.

- **Avoid two extremes** (*Ethical and Religious Directives* – ERDs).
  - Withdrawing technology with intention to cause death (euthanasia).
  - Employing useless or burdensome means (vitalism).
Witness to Acceptance: Sickness and End of Life

• Ordinary (or proportionate) means.
  – Those means that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community (ERDs, Directive #56).

• Extraordinary (or disproportionate) means.
  – Those means that in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community (ERDs, Directive #57).
Benefit and Burden … in the Tradition

- Extraordinary Means According to St. Alphonsus Liguori (1696-1787)
  - Great effort
  - Enormous pain
  - Exquisite means and extraordinary expense
    - Not obliged to spend an exorbitant amount of money to conserve one’s life.
  - Severe dread (*Vehemens horror*)
    - A procedure or means can be so feared that it becomes a moral impossibility.
Nutrition and Hydration (ERDs #58)

- Presumption in favor of nutrition and hydration *as long as it is of sufficient benefit to outweigh burdens*

  - (Medically assisted) nutrition and hydration in principle are ordinary means for one who can reasonably be expected to live indefinitely if given such care.
  - (Medically assisted) nutrition and hydration are extraordinary means (and morally optional) when they cannot be reasonably expected to prolong life or when they would be excessively burdensome for the patient or cause significant physical discomfort.
Witness to Trust

- American culture places great value on individual choice and autonomy.
  - Can religious give witness to deciding *with* others.
  - Witness to human dignity may demand more than autonomy's “right to be left alone.”
  - Can emphasis on autonomy become abandoning a sick Sister or Brother?

- Sickness can become a valuable time to recognize one’s dependence and to *trust* others.
  - Importance of advance directives and having a health care surrogate.
Witness to Trust: Advance Directives

• Advance Directive understood by law as a means to preserve autonomy.
  – Not best interest judgment
  – Transmitted judgment

• How to determine surrogate (agent).

• Importance of discussing values and choices with the surrogate.

• Who should have advance directives?

• Five Wishes
  – **Wish 1:** The Person I Want to Make Health Care Decisions for Me When I Can't
  – **Wish 2:** The Kind of Medical Treatment I Want or Don’t Want
  – **Wish 3:** How Comfortable I Want to Be
  – **Wish 4:** How I Want People to Treat Me
  – **Wish 5:** What I Want My Loved Ones to Know
Witness to Trust: Pain vs. Suffering

• Pain
  – Physical sensation of a harmful stimulus

• Suffering
  – Impairment of the quality of life
    • “Serious, and certainly prolonged, illness brings with it social disruptions in the life of the patient, not to mention family crises, financial worries, premonitions of death, and the concerns that arise from the manifestation of new symptoms and their possible significance.”

  (Patrick Hill and David Shirley, A Good Death)
Witness to Trust: Catholic ERDs Directive #61

Patients should be kept as free of pain as possible so that they may die comfortably and with dignity, and in a place they wish to die. Since a person has the right to prepare for his or her death while fully conscious, he or she should not be deprived of consciousness without a compelling reason. Medicines capable of alleviating or suppressing pain may be given to a dying person even if this therapy may indirectly shorten the person’s life, so long as the intent is not to hasten death. Patients experiencing suffering that cannot be alleviated should be helped to appreciate the Christian understanding of redemptive suffering.
Living the Gospel with Hope . . .

• Sick and aging community members as prophetic witnesses to the reality of the human condition.
  – In a world that often denies death, a witness to hope.
  – In a world that often needs to control, a witness to acceptance.
  – In a world that often exaggerates autonomy, a witness to trust.

• Other community members as prophetic witnesses of faithfulness and care.
  – Community as source of care (hope).
  – Community as a healthy and supportive place to live and to die (acceptance).
  – Community as faithful and dependable (trust).