Dan Callahan (1995) writes that at the heart of bioethics lie three paramount human questions:

- What kind of person ought I to be in order to live a moral life and make good ethical decisions?
- What are my duties and obligations to other individuals whose life and well-being may be affected by my actions?
- What do I owe the common good or the public interest, in my life as a member of society?

What is Ethics?

- Ethics is the formal study of who we ought to be and how we should make decisions and behave in light of our identity

Million Dollar Question

- How does our Catholic faith and teaching inform our decisions and behavior in our Catholic ministries?
We speak and act as the Church

Understanding of our prophetic voice

- Prophetic (to the world, as well as inwardly to our Church and healing ministries)
- Condemnatory versus "Aspirational"
  "Prophetic" can be used by those on both the "right and left" of the theological and political spectrum
- Is being Prophetic saying "no" to things or being prophetic in terms of calling people to the good?

We speak and act as the Church

Pope Francis’ Field Hospital

- From this point of view, we need a Church capable of walking at people’s side, of doing more than simply listening to them; a Church which accompanies them on their journey; a Church able to make sense of the "night" contained in the flight of so many of our brothers and sisters from Jerusalem...We need a Church unafraid of going forth into their night. We need a Church capable of meeting them on their way. We need a Church capable of entering into their conversation...
• “The Church needs to be a field hospital and we need to set out to heal wounds, just as the good Samaritan did. Some people’s wounds result from neglect, others are wounded because they have been forsaken by the church itself; some people are suffering terribly (p. 16).” [Pique, Elisabetta. (January 6-12, 2015). “We must reach out.” America, 17-23.

The importance of integrity

• My personal integrity
• That of the patient and families with whom I work
• That of the health care professionals with whom I work—moral distress
• That of the systems and organizations with whom I work (Health Care, University, Church)

Integrity and Wholeness of Character

• Cradle Catholic immensely grateful for the gift of my faith but sometimes at odds with some of Church’s teachings on medical matters.
• Nurse passionate about accompanying seriously ill individuals and their families and all struggling to make health decisions to advance their interests
• Health care ethicist: clinical and organizational
• Ethics Educator for health care professionals and the public

• What are the promises we each make consciously or unconsciously by virtue of the commitments we each assume?
• How do we navigate conflicts of commitment?
Fractured Integrity

Grounding for the ethical obligations of health care professionals

- Fact of Illness (vulnerability)
- Promise we make (profess) as professionals
- Right and Good Healing Act

Shared Purpose Statement

Catholic Health Australia

- A Samaritan came near the man who was beaten, and when he saw him, he was moved with compassion. Lk 10:33

Like the Good Samaritan...

- We commit to show love and respect for those we serve and all who work with us, regardless of faith, culture, ability or status.
- We commit to be attentive to the whole person—body, mind and spirit.
- We commit to serve all with the best wisdom, resources and attention we can offer.
- We commit to hear and have heard the voices of all, especially those who are weakest, most vulnerable, neglected and stigmatised in our society.
- We commit to reach out with compassion so every encounter is an opportunity for healing, companionship, comfort and hope.
**Double-edged sword**
- If our faith is strong God will heal us and our loved ones...
- Paschal mystery entails recognizing human finitude. The only path to eternal life is through death.

**If you are willing you can heal me...**
- In one of the villages, Jesus met a man with an advanced case of leprosy. When the man saw Jesus, he bowed with his face to the ground, begging to be healed. “Lord,” he said, “if you are willing, you can heal me and make me clean.” Jesus reached out and touched the man. “I am willing,” he said. “Be clean.” And immediately the leprosy left him.” Luke 5:12-13

**Recognizing When It Is Time to Let Go...**

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- Self-actualization
- Self Esteem
- Love and belonging
- Safety
- Physiological

**Pope Francis’ Challenge**
- Pope Francis called on the world’s priests [all of us?] to bring the healing power of God’s grace to everyone in need, to stay close to the marginalized and to be “shepherds living with the smell of the sheep.”
What do I smell of?

Coming Attractions
- Moving Beyond LGBT Negativity
  - Case Study: Bill and the ‘Art of Accompaniment’
- Health Care Decision Making for the Seriously Ill and Dying
  - Case Study: Elton
- Voluntary Assisted Dying—Working within the Victorian legislation
  - Practicalities
  - The Church and Accompaniment
Rethinking Our Roles in Good Dying

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Ira Byock, MD, recently asked two important questions:
• Why are so many still dying badly?
• How can we provide the best care possible to seriously ill and dying people and their families?

Death and Dying: Four Paradigms

• Death as a natural part of life
• The "medicalization" of dying
  – Most Americans die in hospitals (63 percent), and another 17 percent die in institutional settings such as long-term care facilities
• Hospice/Palliative Care
• Death on Demand
Reflection Questions

1. What does it mean to be finite—to be creature? Are there ways in which our efforts to control and master nature work against our innate dignity as humans?

2. What does good care at the end-of-life "look like?"
   - pain and symptom management,
   - clear decision making,
   - preparation for death,
   - completion,
   - contributing to others, and
   - affirmation of the whole person

3. How can family and professional caregivers respond to the holistic needs of dying persons? What does it mean to be a healing presence for the dying and their families?

Assumptions Underlying Approaches to Death & Dying

➤ Life: No longer a "mystery" to be contemplated but a "problem" to be solved
➤ Importance of control/mastery
➤ Absolutization of autonomy

4. Do persons have the right to choose the time and manner of their dying? If you grant this right, are health care professionals and institutions obligated to meet all the requests patients make, so long as they are requests for legal interventions? Does the public (taxpayers) have an obligation to fund the services you desire?

5. Is reasonable to assume that once we grant the right to die this may evolve into a duty for some to die so that the resources they are consuming may be better allocated? Should government or some other body be granted the authority to determine who lives and who dies?

6. In what concrete ways do individual beliefs, values and faith commitments influence our response to the above questions?
Shifting care models:

Disease-modifying Therapy
(curative, restorative, palliative intent)

Supportive/Palliative Care

Presentation
Suffering-Relieving Therapy
6m
Death
Bereavement Care

State of the Science
How People Die

TENO STUDY-2004

- One in four people who died did not receive enough pain medication and sometimes received none at all. Inadequate pain management was 1.5 times more likely to be a concern in a nursing home than with home hospice care.
- One in two patients did not receive enough emotional support. This was 1.3 times more likely to be the case in an institution.
- One in four respondents expressed concern over physician communication and treatment options.

- Twenty-one percent complained that the dying person was not always treated with respect. Compared with a home setting this was 2.6 times higher in a nursing home and 3 times higher in a hospital.
- One in three respondents said family members did not receive enough emotional support. This was about 1.5 times more likely to be the case in a nursing home or hospital than at home.
What is our role in helping people die well?

- Address suffering, suffering, suffering...the neglected symptom
- Support the seriously ill and dying and their families and surrogates as they make treatment decisions that truly advance their interests
- Preserve our moral integrity

"Last Resort" Palliative Interventions

Ranked From Least to Most Controversial Ethically

- Standard pain management
- Forgoing life-sustaining therapy
- Voluntarily stopping eating and drinking
- Terminal sedation: heavy sedation to escape pain, shortness of breath, other severe symptoms (newer terminology, proportionate palliative sedation [PPS] and palliative sedation to unconsciousness [PSU])
- Assisted suicide/"Death with Dignity"
- Non-voluntarily stopping eating and drinking
- Voluntary active euthanasia

What was absent from that list?

- Standard pain management
- Forgoing life-sustaining therapy
- Voluntarily stopping eating and drinking
- Terminal sedation: heavy sedation to escape pain, shortness of breath, other severe symptoms (newer terminology, proportionate palliative sedation [PPS] and palliative sedation to unconsciousness [PSU])
- Assisted suicide/"Death with Dignity"
- Non-voluntarily stopping eating and drinking
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Pain, Discomfort, and Humanitarian Care, 1979

- "The chronic pain experienced by many persons afflicted with long-term or terminal illness is a multidimensional, hierarchical phenomenon that is influenced by somatopsychic, affective, cognitive, social and behavioral factors. The treatment of this suffering requires an integrated approach exemplified by the hospice model which addresses the patient's physical, mental, social, and spiritual needs."
- NIH, Consensus Development Conference Statement
Suffering: Starting Assumptions

- Being human necessarily entails suffering, dying and death.
- We can’t be truly human, perfected, REAL, unless we suffer.
- Suffering can “make” or “break” people—which is what makes responding to human suffering so critically important.
- The virtue hope, not merely sunny optimism, is the path through suffering, dying and death to healing and transcendence. But cultivating the virtue hope isn’t for the fainthearted.
- A little care goes a long way...the importance of cultivating the art of being a healing presence. Intimacy is the only antidote for suffering.

Suffering: What is it?

- “Suffering has been defined as a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted.
- The meanings and the fear are personal and individual, so that even if two patients have the same symptoms, their suffering would be different.” —Eric Cassell

Questions for Reflection and Discourse

- What priority do you assign to recognizing and responding to human suffering? What percentage of your clinical time do you devote to this?
- What is your capacity for “bearing witness” to human suffering: negligent, proficient, expert?
- Share a recent story when you identified and responded helpfully to a patient’s or family’s suffering.
- What strategies for both identifying and responding to human suffering have you found to be most helpful?
- Do you have a magic question that elicits patient fears, anxieties, concerns? How often do you use it?

Roman Catholic Teaching...

- Standard pain management
- Forgoing life-sustaining therapy
- Voluntarily stopping eating and drinking
- Terminal sedation: heavy sedation to escape pain, shortness of breath, other severe symptoms (newer terminology, pronounce palliative sedation [PPS] and palliative sedation to unconsciousness [PSU])
- Assisted suicide/"Death with Dignity"
- Non-voluntarily stopping eating and drinking
- Voluntary active euthanasia
4 Natural Law Principles that Apply to Health Care Decision Making for the Seriously Ill and Dying

- The dignity of the human person
- The duty to preserve life
- The fact of finitude
- The diversity of the human (Sulmasy)

Catholic Health Australia
Code of Ethical Standards

- 5.3 The use of life-sustaining technologies needs to be evaluated in the light of Christian beliefs about life, suffering, death and resurrection. In so doing two extremes should be avoided: on the one hand, an insistence on futile and overly-burdensome treatments which merely obstruct death, on the other hand, the deliberate withdrawal of treatment in order to bring about death. Since good medicine treats a person rather than a condition, respect for persons requires that they neither be under-treated nor over-treated; rather, when people are dying they should have access to the care that is appropriate to their condition.

- 5.9 Decisions about life-sustaining treatments for patients who are terminally ill raise two sorts of challenge: which treatments should be recommended and who should be involved in the decision making process. The fundamental ethical principle in this regard is that treatments may legitimately be forgone (withheld or withdrawn) if they are therapeutically futile, overly burdensome to the patient or not reasonably available without disproportionate hardship to the patient, carers or others. (See also 1.12-1.14)

- 5.20 It is never permissible to end a person’s life (whether that decision is made to relieve a patient’s suffering by euthanasia, to comply with the wishes of the family, to assist suicide, or to vacate a bed). By euthanasia is meant any action or omission which of itself and by intention causes death with the purpose of eliminating all suffering. Examples of euthanasia include administering deliberate overdoses of otherwise appropriate medications, and the unjustified withholding or withdrawing of life sustaining forms of care. Euthanasia must be distinguished from other care decisions which sometimes risk or have the effect of shortening life but which are not intended to hasten death (e.g. the giving of appropriate pain relief, the withdrawal of burdensome treatments). Advances in palliative care are now such that the control of pain should not normally lead to side effects such as loss of lucidity or consciousness or to the shortening of life.
Double-edged sword

- If our faith is strong God will heal us and our loved ones...
- Paschal mystery entails recognizing human finitude. The only path to eternal life is through death.

If you are willing you can heal me...

- In one of the villages, Jesus met a man with an advanced case of leprosy. When the man saw Jesus, he bowed with his face to the ground, begging to be healed. "Lord," he said, "if you are willing, you can heal me and make me clean. Jesus reached out and touched the man. I am willing, be clean. And immediately the leprosy left him." Lk 5:12-13

Recognizing When It Is Time to Let Go...

God Calls us Home

Vitalism  Death on Demand

- Self-actualization
- Self esteem
- Love and belonging
- Safety
- Physiological

A word about accompaniment
Distinction between being a companion and becoming an accomplice

- Then it raises the question, how do we place our selves in companionship with people who make the choice for PAS? How do we walk with people when we’ve laid out options and they make the choice we cannot agree with? How do we walk with them in a nonjudgmental way. Is there a role for us. I think some in the Church would say no. Where is it we continue to place ourselves—not just in the front end as people make decisions but as they continue on their paths.
- If we go back to the Gospel, Jesus walked with all these people, he didn’t just turn his back on them.
- In that sense you are witnessing and modeling the prophetic to be there even in the hard times when you might disagree. It is the prophetic and the pastoral together.

- We are fighting strong cultural currents, the focus on autonomy, messaging promoted by compassionate choices... It will be increasingly necessary for us to be able to articulate the Catholic teaching and vision on end of life care in a compelling and clear way... part of the goal of this project... bring something to broader Church that would be articulated.
- With regard to Brittany Maynard. People throughout the country really connected with her. She had an enormous effect on our society. Unfortunately some within the Church judged her and condemned her and as soon as they did that, what they had to say became irrelevant.

Canadian Bishops on Assisted Dying

- Two documents from Canada are interesting on the question of appropriate accomplishment in cases of assisted suicide. They take different approaches and clearly illustrate convergence on the moral teaching but great divergence on the pastoral approach. Here they are in order of their publication.

- Addresses death by assisted suicide and euthanasia as "grievous affronts to the dignity of human life from beginning to natural end" and states they are never morally justified. Offers guidance to pastors who are approached for the Sacraments of Healing (Penance and the Anointing of the Sick) and requests for the celebration of ecclesiastical funerals.
Atlantic Episcopal Assembly. (2016). A Pastoral Reflection on Medical Assistance in Dying

- Canada's legalization of medical assistance in dying "challenges us as a church and as individual Catholics to grow in our understanding of the church's moral teaching on this issue, and it calls us to discern how best to accompany those who find themselves struggling with illness, pain and difficulty in medical circumstances.

- In our efforts as Christians to understand and respond pastorally to this issue, the example of Jesus' own ministry is an important starting point. He ministered to those who were marginalized as he cared for their physical needs. In Luke 16:19-31, Jesus taught about the rich man and Lazarus. He listened attentively to the stories of those afflicted, and his profound attention allowed him to show the things that troubled them deeply. He eventually led them through a reflection on the scriptures, to a new awareness and encounter of his presence as they recognized him in the breaking of the bread. The example of Jesus shows that pastoral care takes place in the midst of difficult situations, and it involves listening closely to those who are suffering and accompanying them on the journey of their life situation.


Video Clip: Ellen

First set of questions

- If Ellen was a patient in your facility how do you think your staff would respond to her decision to stop eating and drinking?
- What is the position of the Catholic church on causing death this way? Should health care professionals have tried to change her mind?
- When Ellen said, "I wasn't worth living—so I wanted to take my life," what would a good response have sounded like?
- If you knew that Ellen had a gun in her house, how would you have responded?
- Is there any more difference among ending you life with a gun, taking an overdose of morphine, or stopping eating and drinking?

Second Set of Questions

- What if Ellen thought that stopping drinking would "take too long" and asked you if you couldn't just give her some medication so that she would fall asleep and never wake up. You know that there are drugs that would do this, and if you didn't feed her or provide fluids she would die within 7-21 days. Can you use the doctrine of double effect, "this is a foreseen but unintended consequence" to make this an ethical action in Catholic health care? How would you respond to this request?
Third set of questions

- Suppose Ellen is in Melbourne and wants to take advantage of the Voluntary Assisted Dying legislation. How would you respond to her request?
- What if some of the nurses who have been caring for Ellen for the last three years want to be present when she takes the lethal prescription? Ellen has told them how much this would mean to her and her family.