Haiku on Dying

a yellow leaf
touching the green ones
on its way down

--K. Ramesh
Session 6
Recapitulations, Poems, Nagging Doubts and Responses

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7 Elements of Dying Well--Recapitulation

1. Seeing my death as “natural” and necessary--in personal, social, and cosmic terms
2. Accepting/Embracing some of the blessings of finitude
3. Distinguishing problems of dying from the mystery of death
4. Opening myself to some of the spiritual possibilities of dying
5. Relinquishing some of my ego needs for “the death of my desires” or “the death that honors my life”
6. Practicing virtues: courage, love, gratitude, forgiveness, hope, and . . .
7. Preparing myself and those who love me through ADs, proxy designations, and discussions
More on virtues

- Dispositions, demeanors toward the world, habits of practice...

- Virtues require routine practice, e.g., giving three compliments every day, or keeping a gratitude list

- Virtues shape decisions... so I can, hopefully, die in character
The Need for Ritual

- Transition through liminal states, changes that are threatening, movements into the unknown, must be undertaken with care.
- Rituals hold us together and alleviate fear and dread.
- Rituals require communities.
- Rituals reflect “the way it should be done”, i.e., connection between “rite” and “right”.
- Rituals as ways to get in touch with mysteries.
Dying Rituals of the Past

“death was a ritual organized by the dying person himself, who presided over it and knew its protocol…”

--Philippe Aries, *Western Attitudes Toward Death*, p. 11ff.
Rituals – Past and Present
Currently we have Rituals for Death; Not so much for Dying

- Death: funerals and memorial services; burials, spreading of ashes. eulogies, obituaries.

- Dying: Hospice, perhaps? In the effort to attend to the whole person and the caregivers
Rabindranath Tagore, 1861-1941
I'm lost in the middle of my birthday. I want my friends, their touch, with the earth's last love. I will take life's final offering, I will take the human's last blessing. Today my sack is empty. I have given completely whatever I had to give. In return if I receive anything—some love, some forgiveness—then I will take it with me when I step on the boat that crosses to the festival of the wordless end.
Raymond Carver, 1938-1988
Further Thoughts and Responses

- Further thoughts from previous sessions, conversations, or provided via email, from participants in our group...
A medical/legal/ethics system that only asks us what we want and gives us options based on our “preferences” fosters a perverse ethics.

The medical, legal and ethics systems needs to ask us what is most important to us, and what we want our deaths to mean, for ourselves and others.
When facing a terminal diagnosis, asking my doctor:

1. What are my options and what do you recommend, and why?
2. Please give your best estimate of how long I have.
3. What am I likely to experience from now until the end? What additional services can you help me mobilize to minimize suffering?
4. I trust you, but—if you were me—would you seek a second opinion?
Hardwig focuses on duties to others. Do I also have not just a wish but also a duty to myself, to try to honor that sense of self that I prize, through a dying that I help to time and orchestrate?

But...is trying to honor the self too self-centered, or a fantasy?
Is the Quest for a Death that Honors My Life Quixotic?
A typology of the range of values re: dying vis-à-vis medical interventions

- Fearful Minimalists
- Hopeful Vitalists
- Anxious Agnostics
“Loving Realists”

- They are realists because they understand and accept that our bodies are programmed to die, just as individual cells in our body are programmed to die.

- They are loving, because they would make many of the same choices as the fearful minimalists, but with very different motives--wanting to spare their loved ones unnecessary/unwelcomed stress, worry, anguish, exhaustion, guilt, disturbance, diversion, and financial burdens.
Two Kinds of Cellular Death

- Apoptosis (ἀπόπτωσις, "falling off") pre-determined biological cell death, which determines when a person dies, if there is no illness that accelerates the timing of death.

- Necrosis (νέκρωσις) is cell death caused by factors external to the cell or tissue, such as infection, toxins, or trauma.
To call VSED ‘suicide’—in a situation of advanced illness-- ignores context, causes and purpose. Refusing food and drink is more like refusing a respirator, a feeling tube, or a major surgery. It is “non-beneficial” in one of two senses.
1. Am I hungry/thirsty? If “NO,” then this lack of hunger and/or will can be seen as a sign that I am in a dying process. I have discerned that my time has come and that nutrition and fluids are “non-beneficial.”

2. Am I hungry/thirsty? If “YES,” and I want to avoid a death I find unacceptable, then I will see food and drink as “non-beneficial” in the sense of thwarting my pursuit of the death I want.
An elderly man with widely metastatic cancer was seen in palliative care consultation. He was referred for hospice care, and a commitment was made to maximize his quality of life. He asked about potential access to physician-assisted death in the future (not legal in his state of residence). He also inquired about other potential legally available options to end his life should his suffering become unacceptable, and he was made aware of the possibility of voluntarily stopping eating and drinking (VSED). He initially perceived this prospect to be “barbaric,” but, given his limited options, he learned more about it.
Several months later he developed multiple, painful fractures in both legs such that he could no longer walk. He was admitted to the palliative care unit, and wanted to discuss current options for hastening his death. He had full decision-making capacity. His pain was controlled when he was still but became severe with any movement. Although his clear preference was physician-assisted death, after a thorough assessment, including ethics and psychiatric consultations, he began VSED. --from Timothy Quill et al.
A few days later the patient becomes delirious and makes repeated requests for liquids.

What should the physician do?

If there is a proxy decision-maker, what should he/she do?
Can VSED include a “Ulysses Contract”

Odysseus and the Sirens, J. W. Waterhouse
Recommendations from Quill, et al.

- Discuss in advance with professionals and proxy and plan for the possibly of loss of capacity, requests for fluids, and changes in patient’s desires.
- Aggressively manage the delirium
- Use medications to help alleviate thirst
- Some patients do not succeed on the first try at VSED
“Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects”

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--Timothy E. Quill, MD; Linda Ganzini, MD, MPH; Robert D. Truog, MD; Thaddeus Mason Pope, JD, PhD
What is Your “Take Away”?
“Every person thinks the limits of his own field of vision are the limits of the world.”
--Arthur Schopenhauer, 1788-1860
Humility means:

- Being open to future learning
- Remembering that we are moving targets (mutable lives)
- Noting our sketchy record on predicting what we will want
- Heeding our Socratic ignorance of some deep values
- Remaining open to truths we do not now understand, and cannot even imagine

“We live our lives forward but understand them backwards”

-- Soren Kierkegaard
Thank you!