# Session 6 Haiku on Dying

a yellow leaf touching the green ones on its way down --K. Ramesh

## Life & Death: Sides of the same coin --Thich Nhat Hanh



### Things to Pursue, Recapitulations, Need for Ritual, VSED, Take Aways

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### Leftovers from past sessions

- Permission to die https://www.pbs.org/newshour/health/letting-gohonoring-choices-end-life
- Caregivers and partners, experiences and needs Parting: A handbook for Spiritual Care Near the End of Life
- Having enjoyed a full life, why continue only to face the problems of aging?
- Feelings around a close relative with dementia
- Natural burial, cremation...

### Larkspurconservation.org

- Carbon costs of traditional burial and cremation
- Survivors visiting a place of natural beauty
- Preserving the land
- Honoring mother earth as our origins

### Recapitulation of major themes

- Seeing my death as my life's aim, and necessary-- in personal, social, and cosmic terms
- 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

### Major Themes, CONT'D

- 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, forgiveness, hope, and gratitude. . .
- 7. Preparing myself and those who love me through ADs, proxy designations, and especially, discussions

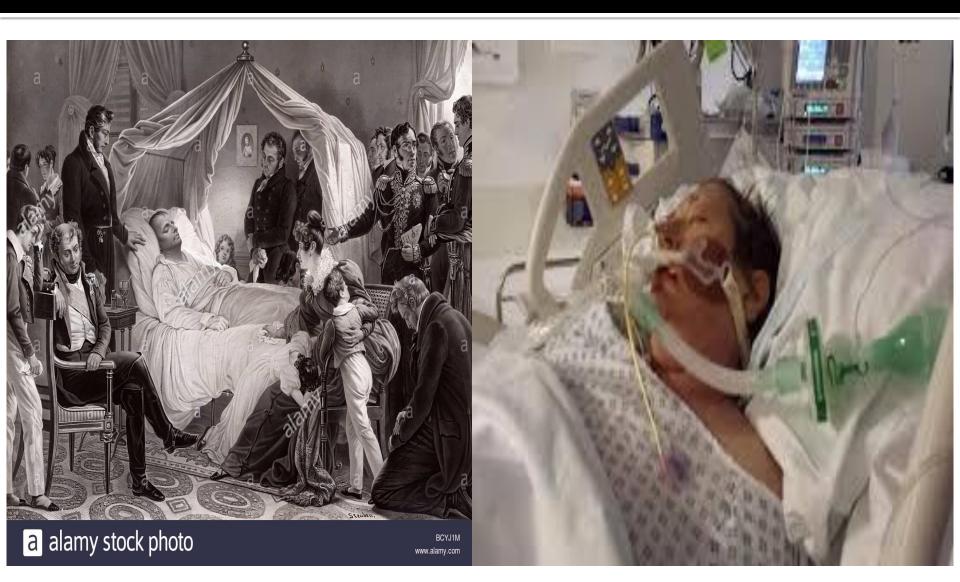
#### The Need for Ritual

- Function: ease 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., consonance 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.
- "dying had a solemn importance"
  --Willa Cather, Death Comes for the
  Archbishop, pp. 169-70

### Rituals –Past and Present

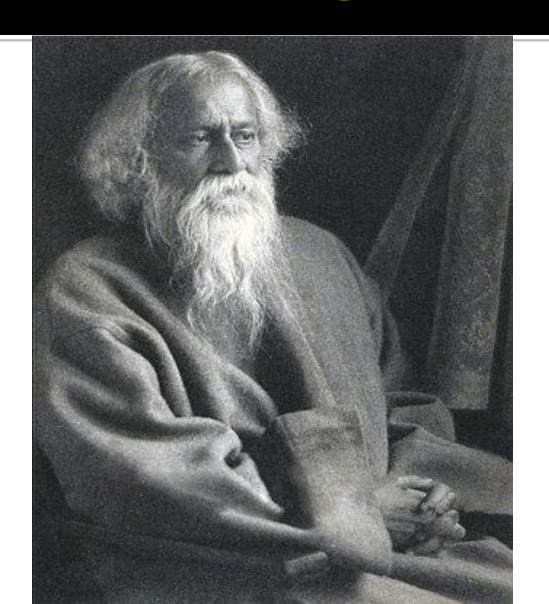


## Currently we have Rituals for Death; Not so much for Dying

 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, create community

### Rabindranath Tagore, 1861-1941



### Tagore's last words

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.

## Can We Welcome Death? Walt Whitman



### "When Lilacs Last in the Dooryard Bloom'd", Walt Whitman

Come lovely and soothing death,

Undulate round the world, serenely arriving, arriving,

In the day, in the night, to all, to each,

Sooner or later delicate death.

• • •

Over the tree-tops I float thee a song,

Over the rising and sinking waves, over the myriad fields and the prairies wide,

Over the dense-pack'd cities all and the teeming wharves and ways,

I float this carol with joy, with joy to thee O death.





### Further Thoughts and Responses

 Further thoughts from previous sessions, conversations, or provided via email, from participants in our group and past groups. . .

### Asking the wrong questions?

- A medical/legal/ethical system that only asks us what we want and gives us options based on our "preferences" fosters a perverse ethics.
- The medical, legal and ethical systems needs to ask us what is most important to us, and what we want our deaths to mean, for ourselves and others.

### What about a duty to oneself to die?

Hardwig focuses on duties to others. Do I also have not just a desire but also a <u>duty</u> 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 selfcentered, 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 fear a long, & undignified, dying, so accepting of an early death
- Hopeful Vitalists holding out for the last possible cure; accepting a greatly diminished life
- Anxious Agnostics want a death that is welltimed, but anxious about reading the signals for when.

### "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 could 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.

I hope to arrive at my death late, in love, and a little drunk.

XX

Atticus



## VSED: Voluntarily Stopping Eating and Drinking

- Usual context: a fatal or severely debilitating illness
- Combined with medical assistance or at least non-interference, and avoiding hospitalization
- Support of family or primary caregivers essential

## Is Voluntarily Stopping Eating & Drinking (VSED) Suicide?

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.

#### VSED: Two senses of Non-Beneficial

- 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.

#### VSED--a case, Time 1

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.

### VSED--a case, Time 2

 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.

#### VSED--a case, Time 3

- 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

#### Reference

"Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness— Clinical, Ethical, and Legal Aspects"

> JAMA Intern Med. jamainternmed.2017.6307 Published online November 6, 2017.

--Timothy E. Quill, MD; Linda Ganzini, MD, MPH; Robert D. Truog, MD; Thaddeus Mason Pope, JD, PhD

## A Dementia Advance Directive (including directions re: VSED)

- "If my dementia has produced inability or unwillingness to feed myself. . .my caregivers should refrain from hand feeding. If I appear receptive to handfeeding, agitated or upset by non-feeding, I authorize sedation to relieve that upset. . ."
- Norman L. Cantor, "On Avoiding Deep Dementia," Hastings Center Report, July-August, 2018

#### **Alternative Advance Directives**

finalexitnetwork.org



Final Exit Options For Hastening Death.pdf



Final Exit\_Supplemental Advance Directive For Dementia Care (1).pdf

### What is Your "Take Away"?

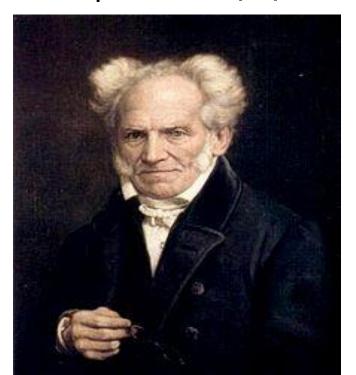


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### My "Take Away" --Humility

 "Every person thinks the limits of his own field of vision are the limits of the world."
 --Arthur Schopenhauer, 1788-1860



#### The Best We Can Do, for Now

#### **Humility means:**

- Remembering that we are moving targets (mutable lives)
- 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

### Selected Bibliography

- A Death in the Family, James Agee
- Being Mortal, Atul Gawande
- On Death and Dying, Elizabeth Kubler-Ross
- Final Exit, Derek Humphrey
- Living Up to Death, Paul Ricoeur
- Gilgamesh, Stephen Mitchell translation
- When Breath Becomes Air, Paul Kalanithi
- Dying in the 21<sup>st</sup> Century, Lydia Dugdale
- Modern Death: How Medicine Changed the End of Life, Haider Warraich

### Bibliography, cont'd

- A Noble Death: Suicide and Martyrdom among Christians and Jews in Antiquity,
   Arthur Droge & James Tabor
- The Hour of Our Death, Philippe Aries
- The Emperor's Handbook, Marcus Aurelius, Scot & David Hicks translation
- Intoxicated by My Illness, Anatole Broyard
- Parting: A Handbook for Spiritual Care Near the End of Life, Jennifer Holder & Jann
   Aldredge-Clanton
- As I Lay Dying, William Faulkner
- The Death of Ivan Ilych, Leo Tolstoy
- Dying Well, Ira Byock
- How We Die, Sherwin Nuland
- Handbook for Mortals, Joanne Lynn & Janice Schuster

### Thank you!

