Voluntary Stopping Eating and Drinking

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Looking where we are going

• In life we usually do best by looking where we are going, and making choices and course corrections.

• In death we may not do this, out of denial, fear, anger, social disapproval, or failing to intuit when to change direction: this can lead to unplanned physical and spiritual discomfort.

• Dying optimally is usually associated with at least some degree of intentionality.
-of course, we always knew this day would come...
...any time now.

we're just thankful we could all be here.

I better let you go—I see a bright light.

looks like I'll be home for dinner after all.
“Course Corrections” at the End of Life

• Foregoing potentially curative or life prolonging therapies
• Aggressive pain management
• Palliative sedation
• Voluntarily Curtailing or Stopping Eating and Drinking
• Medical Aid in Dying
VSED

• Choosing to shorten ones life by stopping all intake of food and fluid

• Fasting alone while continuing fluid can work too but is compatible with life for several weeks

• The physiologic process in VSED is dehydration
The “Ick” Factor

• Isn’t it uncomfortable?
• Neglectful?
• Unloving?
• Difficult?
Difficult Vocabulary

• Planned Death vs Suicide

• Suicide is a premature end, planned death is a way to manage an already inevitable death.

• Looking where you are going = planning death

• Planned death: Open, attended, respected, has resolution.

• Suicide: unsettling, clandestine, leaves unfinished business.
Difficult Vocabulary

- Starvation/Dying of Thirst vs VSED
- Forced vs voluntary
- Hunger and Thirst partially predicated on wanting to live
Social Considerations

• Politically complex for everyone

• Hard to advocate for VSED and also PAD; PAD looks better if VSED is unattractive

• Value of choosing a legal option
My Personal Connection

- #1 Patient DM 1998
- #2 SLC mother of teenagers ALS
- #3 My revered and heroic mother in law
- #4 64 years SP leukemia and stroke, aphasic X 7 years
Lessons from These People

• Typical course: One week normal consciousness, few days of increasing somnolence. Unresponsive for hours to a day. (Key is MINIMAL FLUID)

• Quicker than PAD qualifying process

• All remained upbeat

• Demented, aphasic patient can do it

• Their symptoms required minimal management
Lessons from These People

• Value of open and legal

• Value of patient directed process

• Hunger and Thirst partly driven by a desire to live

• Many Symptomatic Benefits

• Quicker than full PAD process

• Can be explored part way
Symptomatic Benefits

- Decreased dyspnea
- No death rattle
- Decreased edema
- Euphoria?
- Decreased need for toiletting
- Decreased Weight
Insight of the Day:
Downside, cf. PAD

• Death Can’t be scheduled
• May take more motivation
• Some risk of agitation
Care Issues

- Permission from Family and Caregivers: this is complex and may be surprisingly challenging
- Resolution of doubts and guilt
- Enough help at home
- “Failure” vs “Exploration”
Care Issues

- Consider initial diuretic
- Mouth Care
- role of intermittent sedation; benzodiazepine or opiate
Advantages

• Legal and relatively quick
• Patient driven
• Reversible: can be explored
• Has a natural feel, less startling
• Less dyspnea, edema, urine output
• Necessary Plan B if PAD unavailable
End of Life Choices NY: Patients’ VSED Experiences

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New York State = Land of “NO”

- In addition to no legal access to PAD
- Conservative legislators > cautious legislation
- Took 15 yrs pass surrogate decision-making law - “natural feeding” was NOT included in its definition of health care - thus
- NYS surrogates legally precluded from deciding to withhold hand feeding from incapacitated pts - regardless of patient’s prior statements or wishes
VSED: Only legal means for patient-controlled dying in NYS

- Four pre-conditions necessary for “success”
  - defined as peaceful, gentle death within days to 2 weeks after start of fast
  - A well-informed, capacitated patient with a determined will to hasten death
  - Access to hospice or palliative oversight
  - Supportive care-givers – ultimately 24/7
  - Ongoing family or other social support

EOLCNY provides information, support & advocacy

- Two groups of patients >> different VSED experiences
  - 1st group = terminally ill, receiving hospice care when choose VSED
  - Often diminished appetite for food or fluids
  - VSED process generally uncomplicated; few associated symptoms to palliate [dry mouth?]
  - Hospice supportive; death generally peaceful
  - On average, death occurs 10 days after start of fast
2nd group = NON-terminally ill

- Decisionally capable, suffering incurable & progressive disease, or permanent & intolerable condition (i.e., post stroke)
- Can be difficult to obtain palliative over-sight
- Challenging & unpredictable clinical course
- Hard to predict duration of fast
- Feelings of dry mouth &/or thirst often problematic
- Issues of cognitive disability add to challenges

This is Elliot
Non-terminally ill patients’ stories

- 86 yrs, married x 31 yrs, accomplished artist & great cook who loved food
- History of multiple spinal surgeries, ^ BP, heart disease, insulin-dependent diabetic
- Primary complaint: severe cervical stenosis > pain, muscle weakness & numbness/tingling fingers
- No longer able to paint, cook, walk, or manage ADLs – bed-bound
- “Unacceptable” quality of life; told PCP wanted to stop LST with hospice support*

Request to stop LST ‘heard’

- As request for assistance in suicide
- Ordered 3 wk trial anti-depressants + PT & OT
- No change in desire to stop all LTS >> hospice
- Although ‘accepted’ into hospice program... possible ‘ambivalence’ within team
- No previous experience with non-terminally ill patient who chose to VSED
- During 19 days of his fast, only analgesic ordered was tylenol
Elliot struggled...

- Easily stopped eating
- Going without fluids very difficult
- By day 9 – small dose of ativan was ordered
- By end of 2\textsuperscript{nd} wk – haldol was added b/c of episodes of agitation & hallucinations
- Complained of head aches [ice packs helped] & very dry mouth [was a mouth breather]
- Wife requested stronger pain meds...to no avail
- During 3\textsuperscript{rd} wk he would wake his wife shouting “I’m DYING of thirst!”

Struggle ended...

- By day 18 Elliot was non-responsive; he grimaced & appeared restless & uncomfortable
- That night, an LPN was sent by hospice
- She recognized that he was in pain...hospice agreed to morphine
- Elliot died the next morning
- His wife blames herself for not advocating more strenuously for earlier use of opiates.....
A different challenge

• Donald is 78 yrs – diagnosed w MCI & early stage Alzheimer's disease a year ago
• He disagrees with MD’s diagnosis – claims he has always been ‘forgetful’
• His wife contacted EOLCNY for assistance in helping him complete an advance directive
• He had completed ‘5 Wishes’ & wrote “If I ever have dementia, I want something done to end my life”
• Family unsure what their role should be

Initial meeting

• Had many prior conversations with his wife - suggested they look at descriptions of AD stages to determine when he would want to forgo oral feeding (Menzel & Chandler-Cramer 2014)
• At 1st meeting Donald was adamant that: he didn't have AD, never wanted to be in nursing home & wanted oral feeding withheld by wife/family – REGARDLESS
• Also stated he had low tolerance for any physical discomfort
Tremendous challenges

- Short term memory loss & difficulty planning
- May be too late to create useful adv dir that reflects his personal values re ‘future’ dementia & realistic instructions about withholding oral feedings
- He seemed unable to appreciate family’s (emotional, moral & ? legal) difficulties re withholding food/fluids from someone who seems to enjoy & cooperate in feeding
- Ongoing case...

Final thoughts

- Providing support for non-terminally ill pts & families who choose VSED is very time consuming
- Families need a great deal of emotional support throughout the process...and after death
- There will be increasing interest in VSED from future patients diagnosed with Alzheimer's
- Creative solutions must be found to challenges faced by such pts/families who wish to control timing of death