Voluntarily Stopping Eating & Drinking: An End of Life Option

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DEATH WITH DIGNITY-ALBANY
Plan for today: Discuss

- Overview of End of Life Choices NY
- Mission & efforts to make physician-assisted dying legal in NY
- In the meantime...VSED
- What’s necessary for “successful outcome”
- Definition of “successful outcome”
- Newest callers & use of advanced directives to avoid final stages of dementia
End of Life Choices New York

- 15 years in NYS – previously ‘DBA’ Compassion & Choices of NY
- Mission is to improve care & expand choice at End of Life (EOL)
- Not-for-profit organization providing advocacy information & support to all New Yorkers seeking best EOL options for themselves
- Collaborate with palliative care colleagues for improved health care law
EOL Consultation Service

- Lots of calls for lots of reasons
- Some simply want advance directive forms & information re which is best
- Some folks are sick...
- If terminally ill – encourage timely access to home hospice (need MD referral)
- Those w incurable/progressive diseases – facilitate good symptom management & access to palliative care
Members of both groups

- Seek information about controlling circumstances & timing of death
- Most would prefer to receive ‘magic’ pill >> go to sleep & not wake up
- Sadly, that doesn’t exist
- In the meantime...
Efforts to legalize MD-assisted dying

- Perhaps you heard?
- ‘May 30th Court of Appeals heard arguments
- If we “win” > would return the case to lower court for trial & testimony
- Decision expected late June or early July
- Meanwhile…ongoing (& probably futile) efforts to pass an OR-like law legalizing PAD
- And mean while….
Voluntarily Stopping Eating & Drinking

- Definitely no one’s FIRST choice (more later)
- Include discussion other legal, ethical, & palliatively accepted means to hasten death:
  1. Stop (or don’t start) any/all life-prolonging measures
  2. Aggressive use of opioids to manage pain
     - including palliative sedation for intractable suffering can’t otherwise be relieved > coma & withhold nutrition & hydration

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And, VSED

- This option is not appropriate for everyone
- Requires a decisionally capable, well informed & very determined person whose suffering has become unbearable & no good alternatives to hasten dying exist
- Also requires for “successful” outcome:
  1. family or other psycho-social supporters
  2. care-giving help >> 24/7
  3. access to hospice or palliative med over-sight
  4. patience
The goal is a peaceful, gentle death without great pain that occurs within a predictable number of days or weeks (my definition of successful outcome).

The length of fast depends upon underlying disease & physical state + ability to forgo fluids.

Cause of death is dehydration (NOT starvation).
Challenges to peaceful VSED death

- For terminally ill – forgoing food usually not difficult as appetite generally poor
- Forgoing fluids can be challenging – but good oral care, rinsing & spitting, fine spray etc help
- Also – use of small doses of opioids & anti-anxiety meds >> sleepy state
- Usual length of fast 10 da – 2 wks
- Often slip into coma final days
Challenges when NOT terminally ill

- Those with incurable/progressive diseases have more challenges
- First is to obtain medical over-sight
  - sometimes long-time MD will order meds & provide palliative management or order hospice
- In absence of terminal illness – fasting can be more ‘challenging’ & may take longer - up to 3 wks
- To succeed – must be clear to all that person’s suffering is simply intolerable & that their decision to ‘escape’ is thoughtful & well considered
Now hear from NEW group of callers

- Hear from folks recently diagnosed with early stage of Alzheimer’s disease (AD)
- They tell me they are DESPERATE to avoid the final stages of dementia
- It’s often the spouse who calls first....

^ Number of New Yorkers diagnosed with AD

● In 2016 New Yorkers with AD age 65-75 = 51,000
  - age 75-84 = 160,000; > 85 yrs = 180,000

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For those with early stage of dementia

- While retain decision making capacity
- Can decide to fast [onto death] while capable of making informed decisions AND able to remember decision made
- VERY challenging option - need lots of support
timing is everything – it becomes too late once decision making window closes
- Alternative is to complete very comprehensive written directive while competent - stipulating that assisted or hand feeding be withheld once decision making capacity & ability to self-feed are lost
WHO would make such a choice???

- Self-selected group who care passionately about HOW they die & want desperately to avoid disease’s final stages
- Often have family history of dementia & have observed the lingering/undignified death of loved ones
- For some, the ‘terminal’ stage of dementia: bed-bound, unable to speak or recognize loved ones, incontinent of urine & stool = a fate worse than death
- Terminal stage of AD can last for more than a year – PROVIDED the patient is hand fed by another
Requires careful, thoughtful discussions

- Initial consultation is with patient + most significant family member &/or appointed health care agent
- Subsequent conversations include other family members & significant stake-holders
- Best to get legal & medical buy-in for written directive while patient retains decision making capacity
- Include statement: “Even though I may appear to cooperate in feeding – the reflexive opening of my mouth when spoon touches my mouth does NOT constitute a change in my prior refusal to be hand fed.” once advanced stage of dementia occurs
Cases to compare & consider

- Hannah 98 yrs diagnosed with AD 15 years ago
- In ‘terminal’ stage for more than a year; bed-bound, in diapers for past 7 years; no longer speaks or seems to recognize only child or long time care-givers
- Is carefully spoon-fed 3 meals each day by 24/7 aides
- Each meal takes more than an hour but, with verbal encouragement, Hannah opens her mouth & appears to enjoy the glop she swallows without signs of coughing, choking, or other distress

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After husband died, Hannah & Ann went to family attorney to complete a new advance directive.

They had careful discussion re Hannah’s EOL wishes & concerns & Ann was to be her agent.

Ann knew Hannah would never want life-prolonging measures like feeding tube or resuscitation.

But nobody advised them to consider whether she wanted to be hand fed if suffering advanced dementia.
Hannah continued

- Even though Ann knows her mom would be horrified if she could see herself now & would say “Just shoot me!”
- While Hannah continues to readily open her mouth she will be fed BECAUSE there is no previously completed directive indicating a decision/choice NOT to be fed
- Hospice confirms...until she starts coughing or choking or resisting being fed – in the absence of prior directives to the contrary, she will continue to be fed - indefinitely
- Ann hopes she doesn’t run out of money before that time
Judith requested a consultation for her & husband Brian to discuss EOL options for him.

Brian is a Pulitzer prize-winning author diagnosed with AD several years ago & is horrified at prospect of losing his mind.

During initial discussion of options that would permit him to control timing of death he asked “What if I just take a gun & kill myself ?”

Spent a long time discussing VSED &/or completing a written directive to SED once dementia ‘moderately severe’ & capacity is gone along with ability to self-feed.
Brian continued

- They completed a written directive stipulating that hand feeding be withheld if dementia progressed to moderate stage & he was unable to self feed
- They took copies of document to family attorney & primary care physician – an old friend & supportive
- He moved to a ‘high end’ assisted living facility
- Judith called & told me Brian recently said he would soon have to begin to fast as he could no longer complete thoughts
The plan was for Brian to come home to fast with hospice support – arranged by primary care physician.

Judith called late one night in tears...her sister-in-law had called her a murderer for ‘suggesting’ this plan to her brother.

I suggested sister speak NOW to Brian about HIS wishes & end-of-life concerns + view the written directive.

She called 2 wks later to say her daughter, a MD, wondered whether Brian might still experience some “joy” even if severely demented.

Suggested she also speak to her dad & view the directive.
Final thoughts

• None of this is ‘easy’
• Cases are quite labor intensive – require lots of discussion & reflection
• But some folks diagnosed with early stage of AD care enough about avoiding final stages of dementia they take the time & energy to complete a comprehensive directive saying how their ‘incompetent’ self should be treated....
• Those instructions should be honored – as any other carefully considered advance directives ought to be honored
We provide support to all New Yorkers
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