

# 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 30<sup>th</sup> 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 not 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

# 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

# What's it like & what is “success”??



- 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 under-lying 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
- Its often the spouse who calls first....
- ^ Number of New Yorkers diagnosed w AD
- In 2016 New Yorkers w AD age 65-75 = 51,000  
- age 75-84 = 160,000; > **85 yrs = 180,000**

# 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

# Hannah, continued



- 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

# Brian & Judith



- 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

# Brian continued



- The plan was for Brian to come home to fast w hospice support – arranged by pri 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 & eol 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

# Thank you for your attention & questions



- We provide support to all New Yorkers
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