EXTENDING ADVANCE CARE DIRECTIVES: THE (NEW) DEMENTIA DIRECTIVE

Death With Dignity-Albany

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- I have been the Clinical Director, EOLCNY & predecessor group for more than 15 years
- Not-for-profit organization providing accurate clinical information, support & counseling re EOL options & choices
- Respond to all who contact consultation service seeking help (212-252-2015)
- Also seek to pass physician-assisted dying legislation

Plan for today: Present/discuss

- A ground-breaking written advance directive
- Permits persons with early dementia to limit future assisted oral feedings when dementia becomes 'advanced'
- Background to development & landmark cases
- Where this directive fits with other NYS advance directive laws
- Challenges ahead

Dementia Data…

- 6 million Americans have Alzheimer's - that number is expected to ^ 14 million by 2050
- Advanced dementia (including Alzheimer's) is 6th leading cause of death in US & is the 5th leading cause for those > 65 yrs & third for those > 85 yrs
- Lifetime risk of dementia for cohort born in 1940 = 31% for men & 37% for women
- Although people can live well for several yrs w dementia – most want to avoid the final terminal stages that include inability to speak, ambulate, recognize loved ones or be continent

Background to development

- Two West coast landmark cases focused attention on issue of assisted oral feeding
- Legal & philosophical scholars have been thinking/writing about advance directives to limit oral intake e.g. – what's necessary for successful documentation
- First steps taken by sister group - EOLWA
- AND, we had our own difficult case + growing number of callers with concerns about dementia

1st West Coast Landmark Case

- Margo Bentley of Vancouver BC, Canada
- 1991 - retired RN completed/revised her final living will
- Wrote refused "..nourishment & liquids if suffering from extreme mental disability"
- Then suffered from Alzheimer's > 17 years
- Spoon fed in nursing home for years despite family' efforts & multiple unsuccessful court cases
- One judge ruled she had 'changed her mind'
- Finally died 2015 @ age 83

2nd Case, from Oregon

- Nora Harris, a research librarian
- 2009 'early onset' Alzheimer's at age 56
- Completed advance directive "to prevent her life from being prolonged when disease got worse"
- But - no mention of wishes re hand feeding
- Spoon fed for years in nursing home
- Husband went to court twice to stop feedings
- Judge said directive **not** specific enough
- Finally died 2017 age 64

Nora Harris

Meanwhile in NY, in 2016

- Patients & families began calling EOLCNY for new & different reasons
- Rather than diagnosis of terminal cancer NOW calling b/c Alzheimer's or other dementia
- Some had searing memories of slow & de-humanizing dementia death of loved one
- For others, the call was already too late

Hannah's daughter called

- Standing at foot of her bed, her daughter asked me "What did I do wrong?"
- Hannah now 99 was diagnosed 16 yrs earlier with Alzheimer's or some other dementia
- Before diagnosis they met w family attorney to complete adv dir – no consideration of future dementia or hand feeding then
- She has been in diapers for 9 yrs, in hospital bed in her living room
- She no longer speaks, or moves purposefully; she does not recognize her only child or long-time care givers

Nobody knew to ask about hand feeding – many still don't

- Hannah is spoon fed 3 x day by very patient aides – takes > than an hour
- She reflexively opens her mouth when spoon brought to its side…like a baby bird
- She had been deemed 'terminal' for > 2 yrs
- Hospice says she must continue to be spoon fed until she 'forgets' how to swallow
- They can't predict when that will occur

Further West coast developments

- 2017 EOLWA developed "Instructions for Oral Feeding & Drinking"
- Instructions for when dementia is 'advanced' - oral feeding to be limited to 'comfort-focused'
- Assisted feedings provided only while person seems to enjoy or willingly participates
- Received with much enthusiasm in WA…

In NYS - we thought we should go further

- Based on needs/requests EOLCNY clients newly diagnosed with dementia & their families
- Greatest fear was having to endure final stages advanced dementia…for months or years
- Some wanted more options than limiting oral intake to 'comfort feeding'
- While decisionally capable COULD chose stop all oral intake = **V**oluntarily **S**topping **E**ating & **D**rinking (we talked about that option last yr)
- VERY challenging absent terminal illness

Other NYS Advance Directive Laws

- 1991 Health Care Proxy Law: appoints person as decision maker once patient loses capacity
- Agent's decisions to be based on patient's wishes
- Only limitation on decisions: agent must know patient's wishes re med provided food & fluids
- **Proxy law silent** on question of hand feeding
- **Only 30%** of Americans completed some form of advance directive

For 70% without advance dir

- 2010 Family Health Care Decisions Act
- Legal mechanism for family or close friend to be "surrogate decision maker" for pt without capacity and no completed advance directive
- Surrogate chosen from list…highest person available & willing to serve
- Likely NO prior conversation re pt's EOL wishes
- Surrogate can NOT decide about oral feeding because not included in definition of 'health care'

Final NYS Adv Dir Legislation

- 2012 **M**edical **O**rders for **L**ife **S**ustaining **T**reatment (MOLST)
- For those with prognosis 1 - 2 years
- Completed by pt or health care agent [if capacity lost] and primary physician
- Combines all EOL wishes re CPR, level medical intervention, future hospitalization & tube feeds
- Patient CAN include additional instructions [e.g. should include wishes re hand feeding]
- Becomes medical orders

EOLCNY Dementia Directive

- Two Purposes:
- 1st to document wishes about limiting assisted oral feedings when dementia becomes advanced
- 2nd to ensure appointed health care agent is empowered to implement those choices when patient suffers from advanced dementia
- Does not replace but *augments* other completed directives or instructions

When do instructions become operational ?

- Triggering clinical criteria for dementia directive
- Health care agent consults w primary care provider & agree patient **now in 'advanced' stage of dementia &** symptoms include: inability to speak comprehensively, ambulate, recognize family or be continent (stage 6-7 on Functional Assessment Staging Test - FAST)
  And
- Patient unable to make health care decisions
  And
- Unable to feed self

Two options to limit assisted feeding

- **Option A:** forgoes all life-prolonging measures including CPR & **all nutrition & hydration** (N&H) whether provided medically **or** by assisted oral feeding **+**
- Specifically refuses oral feeding **even if** pt opens mouth when spoon brought to corner **and**
- Requests provision of excellent comfort care & symptom management with oversight by palliative/hospice care

2nd option limiting assisted feeding

- **Option B**: forgoes all life-prolonging measures including CPR & **medically provided N&H** & **limits oral feeding** to **comfort-focused as below**
- Feedings provided only while pt demonstrates enjoyment or positive anticipation re eating
- Only given foods & fluids seems to enjoy
- Feedings stopped once pt no longer appears interested or begins to cough or choke
- Pt not to be coerced or cajoled into eating
- Once stopped – access to comfort measures & medications with palliative/hospice oversight

Further instructions

- Once dementia directive completed, discuss with: pcp, health care agent, family attorney & all other 'stakeholders' who care about patient
- Give copies of directive to all of above
- Patient should make videotape of personal values & reasons why directive was completed
- Remind all you are trusting them to NOT disregard your wishes because you 'appear' comfortable or to have 'adequate' quality of life

Long term care considerations

- As dementia becomes advanced, long term care placement often becomes necessary
- In anticipation of transfer: patients & families should explore whether LTC administrators will honor dementia directive BEFORE entering facility
- In-service education with in LTC facilities will be necessary – particular among CNAs who provide most care & may not "know" patients & their values (importance of video)
- We anticipate judicial review

Determining Success of Directive?

- May be a some time before we learn if effective – one current case in Ithaca….
- EOLCNY has counseled ^^ numbers of persons with early dementia who have completed directive (almost all chose "A")
- Many have said they don't want to have to wait until dementia becomes 'advanced'
- **VSED** always an option for those who still have capacity & a DETERMINED will to avoid final dementia stages – hard choice

In Summary….

- Directive was created in response to pleas from New Yorkers newly diagnosed with dementia & their families
- **And** guided by demands for specificity in written directives by judges ruling in previous ‘landmark’ cases
- Goal: to have it widely distributed & used by those wishing control over length dementia-related dying
- Now believe there ought to be ongoing counseling for those considering completing

Final thoughts

- One MUST have an appointed health care agent to advocate for limiting oral feedings!!
- Re need for counseling? Limiting oral feedings from an incompetent loved one may be a hard choice for family to implement & should be discussed regularly
- We welcome your feedback, stories & experiences using this directive
- Thank you for your attention & questions
- Contact me with additional questions: judy@endoflifechoicesny.org
- or Call - 212-252-2015