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
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
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
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
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
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
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
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 = Voluntarily Stopping Eating & Drinking (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’
2012 Medical Orders for Life Sustaining Treatment (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:
  - 1\textsuperscript{st} to document wishes about limiting assisted oral feedings when dementia becomes advanced
  - 2\textsuperscript{nd} to ensure appointed health care agent is empowered to implement those choices when patient suffers from advanced dementia
  - Does not replace but \textit{augments} other completed directives or instructions
When do instructions become operational?

- Triggering clinical criteria for dementia directive
- Health care agent consults with 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
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
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.
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