Disclosures

I have no conflicts of interest or relevant financial interests.

Stephen Kruspe

Want to avoid advanced dementia

Many lives prolonged in advanced dementia

Unwanted Medical Treatment

UMT
Advanced dementia
Avoiding artificial N&H
Avoiding oral N&H

> 40 million
> 80 million by 2040

5-7% of 60+
Double every 6 years
10-14% 66+
20-28% 72+

3 Stages
Early
Middle
Late
Symptoms
- Lose control bodily functions
- Lose speech
- Cannot recognize family
- Behavior changes
  Difficulty swallow & eat

Feed by tube
Feed by mouth

ANH
ONH

ANH = UMT
ONH = UMT

Burdens

Advanced dementia
Difficulty eating

Difficulty eating
ANH
Alleged benefits

Prolong survival
Reduce aspir pneumonia
Improve nutritional status
Improve function
Improve wound healing

Feeding tubes do none of this

Even worse

No benefit
But also creates harm

More aspiration
More pressure ulcers
More infections
+ Require restraints

Why administer

Provider driven

Faster
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<th>Cheaper</th>
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<tbody>
<tr>
<td>Hand</td>
<td>$4200</td>
</tr>
<tr>
<td>Tube</td>
<td>$2400</td>
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<tr>
<td>Time</td>
<td>73 min</td>
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<tr>
<td></td>
<td>25 min</td>
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<th>Medicaid reimbursement higher</th>
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<th>Settled</th>
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NC right to refuse ANH
Many with adv. dementia still get ANH

Right to refuse ANH through LW and/or agent

Causes

1
No AD completed

Completed

Not found

18-29 15%
30-49 33%
50-64 38%
65-74 61%
75+ 58%

65-76% of physicians whose patients have advance directives do not know they exist

Individuals fail to make & distribute copies

Primary agent
Alternate agents
Family members
PCP

Attorney
Clergy
Online registry

3
Ignored
Misplaced

Doctors Hospital Augusta v. Alicea (Ga. 2016)

Failed informed consent

Chasm between theory & practice

Theory
Appellate opinions autonomy self-determination

Practice
Not even close

Too much
Too fast
Too complex
Also in medicine

Bad 1972

Jerry Canterbury

Justice Mosk

“lengthy polysyllabic discourse”

2016

“lengthy polysyllabic discourse”
Still

Terrible outcomes

Just 2 examples

Only 5 in 100 understand cancer diagnosis

Only 3 in 100 understand PCI / stents

>90% fail rate

Solution

Patient decision aids
Evidence based educational tools

Accurate
Complete
Understandable

Robust evidence shows PDAs highly effective

> 130 RCT
Dementia

PDA

Accurate
Complete
Understandable

Mitigates bias, COI

Not used

Valuable proven tool

Very little clinical usage
“Promise remains elusive”

Move PDAs from lab to clinic

No PDA

Assure PDA quality

Certification
Labor & Delivery (2016)

Next priority area:
End of life care (2018)

§ 3056
Affordable Care Act

Reimbursement & liability incentives to use PDAs

More PDA
More informed

More informed
Less ANH
Some deplore living advanced dementia at all.
VSED

Voluntarily Stopping Eating & Drinking

Definition VSED

3

Physiologically able to take food & fluid by mouth

Voluntary, deliberate decision to stop

Intent: death from dehydration

>50% at 8d
>80% at 14d
Most deaths: “peaceful, with little suffering”

Even though MAID available, “almost twice” chose VSED

North Carolinian with capacity may VSED

North Carolina clinician may support VSED

BUT

If still have capacity, then have “good” time left
“Adkins could still recognize her husband, play tennis and carry on a conversation.”

Intolerable life comes *after* lose capacity

VSED with capacity, then too early

**Solution**

Two

Advance VSED

1

Complete AD, today

2
Direct VSED in future

When reach point you define as intolerable

Legality in NC

Living will

HCPOA

Living will

STATE OF NORTH CAROLINA

ADVANCE DIRECTIVE FOR A NATURAL DEATH (LIVING WILL)

COUNTY OF ____________________________

NOTE: You will use this document to give your healthcare providers instructions on whether or not to continue ongoing life-sustaining measures in certain situations. Please include the term “supervising physician” in the instructions.

GENERAL INSTRUCTIONS: As you review the Advance Directive “Living Will” (hereinafter referred to as this document), you are responsible for selecting the appropriate medical options that reflect your wishes.

When you have completed this document, please sign and date it.

This document is in effect until revoked in writing.

In case of a legal dispute, this document will be governed by the laws of North Carolina.

Living will

HCPOA

Living will

NOTE: You may initial ANY or ALL of these options.

Living will

HCPOA

Living will
HCPOA

No legal obstacle to NC agent authorizing VSED
Still “soft” obstacles

Practical tips

Evidence
Unusual

Be very specific on the when
Be very specific on the what
Lessons from 2 recent cases
Margot Bentley

Probably meant this

DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT
ALIVE BY ARTIFICIAL MEANS OR “HEROIC MEASURES”.

B. NO NOURISHMENT OR LIQUIDS.

Nora Harris
Unresolved Challenges

Do later requests for water **revoke** the AD?

Maybe

All patients **presumed** to have capacity

**Until** rebutted

Decision specific

Patient might have capacity to make **some** decisions but not others

Legal status of incapacitated objection?

Margot Bentley
NC may authorize **later** VSED when lack capacity

But may “unintentionally” revoke

**Conclusion**

**Right** to avoid ANH

But must be **implemented** with more and better ACP

**Right** to VSED when capacitated

But such deaths often **premature**

**Unclear right** to advance VSED

Selected References

Medical Futility Blog

Since 2007, I have been blogging, almost daily, to [medicalfutility.blogspot.com](http://medicalfutility.blogspot.com). This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received over **2.5 million** direct visits. Plus, it is redistributed through WestlawNext, Bioethics.net, and others.

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