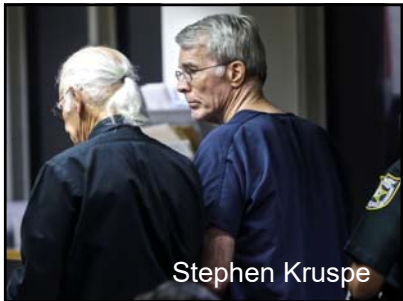


Disclosures
 I have **no conflicts** of interest or relevant financial interests.

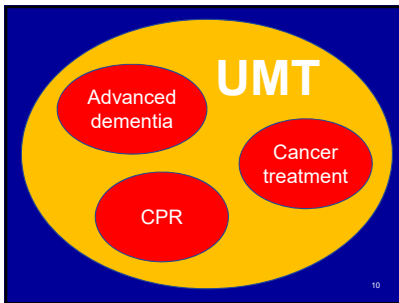


BUT

Many lives **prolonged** in advanced dementia

Unwanted Medical Treatment

UMT



The New York Times

Online – Friday, 4/7
Print – Tuesday, 4/11

Roadmap

12

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

**Advanced
Dementia**

14

> 40 million
> 80 million by 2040

Prince, Alz & Dem 2013

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

21

ANH
ONH

22

ANH = UMT
ONH = UMT

23

ANH
Burdens

24

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

Hand
73 min
Tube
25 min

Cheaper

Cost (staff + food)

Oral	Tube
\$4200	\$2400

Lucrative

Medicaid
reimbursement
higher



**NC right
to refuse
ANH**

Settled
law &
ethics

**Living
will**

STATE OF NORTH CAROLINA

ADVANCE DIRECTIVE FOR A
NATURAL DEATH ("LIVING WILL")

COUNTY OF _____

NOTE: YOU SHOULD USE THIS DOCUMENT TO GIVE YOUR HEALTH CARE PROVIDERS INSTRUCTIONS TO WITHHOLD OR WITHDRAW LIFE-PROLONGING MEASURES IN CERTAIN SITUATIONS. THERE IS NO LEGAL REQUIREMENT THAT ANYONE EXECUTE A LIVING WILL.

GENERAL INSTRUCTIONS: You can use this Advance Directive ("Living Will") form to give instructions for the future if you want your health care providers to withhold or withdraw life-prolonging measures in certain situations.

NOTE: YOU MAY INITIAL ANY OR ALL OF THESE CHOICES.

_____ (Initial)	I have an incurable or irreversible condition that will result in my death within a relatively short period of time.
_____ (Initial)	I become unconscious and my health care providers determine that, to a high degree of medical certainty, I will never regain my consciousness.
_____ (Initial)	I suffer from advanced dementia or any other condition which results in the substantial loss of my cognitive ability, and my health care providers determine that, to a high degree of medical certainty, this loss is not reversible.

2. These are My Directives about Prolonging My Life:

In those situations I have initialed in Section 1, I direct that my health care providers:

NOTE: INITIAL ONLY IN ONE PLACE.

_____ (Initial)	may withhold or withdraw life-prolonging measures.
_____ (Initial)	shall withhold or withdraw life-prolonging measures.

HCPOA

G. Authorizing the withholding or withdrawal of life-prolonging measures.

5. Special Provisions and Limitations.

(Notice: The authority granted in this document is intended to be as broad as possible so that your health care agent will have authority to make any decisions you could make to obtain or terminate any type of health care treatment or service. If you wish to limit the scope of your health care agent's powers, you may do so in this section. If none of the following are initialed, there will be no special limitations to your agent's authority.)

Right to refuse ANH through LW and/or agent

Many with adv. dementia **still get** ANH

Causes

1

No AD
completed



PewResearchCenter
NUMBERS, FACTS AND TRENDS SHAPING THE WORLD

NOV. 21, 2013

Views on End-of-Life Medical Treatments
Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive

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

2

Not
found

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

U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

Individuals fail to make & distribute copies

- Primary agent
- Alternate agents
- Family members
- PCP
- Attorney
- Clergy
- Online registry

3

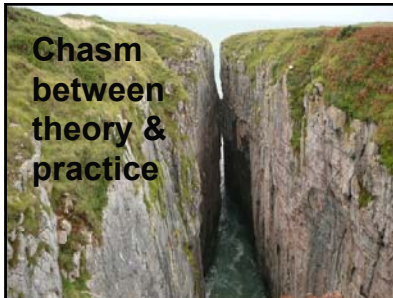
Ignored
Misplaced



Doctors
Hospital
Augusta
v.
Alicea
(Ga. 2016)

4

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

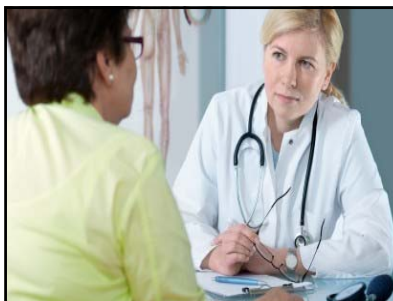
Bad

1972



“lengthy
polsyllabic
discourse”

2016



“lengthy
polsyllabic
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



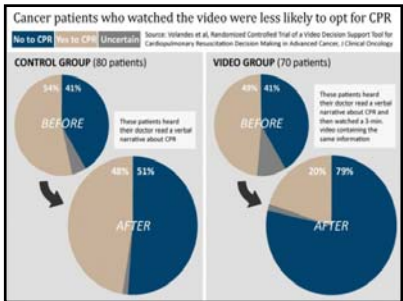
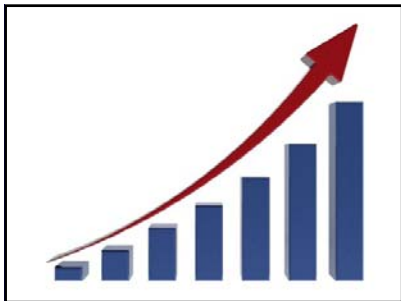
Evidence based educational tools



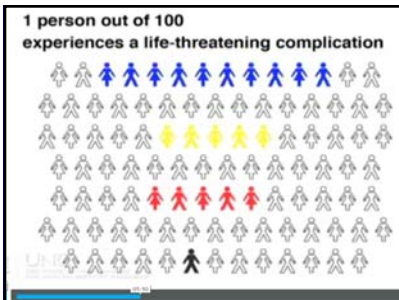
Accurate
Complete
Understandable

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

1

No PDA



Proposed Decision Memo for Screening for Lung Cancer with Low Dose Computed Tomography (LDCT) (CAG-00439N)

Shared decision making, including the use of one or more **decision aids**, include benefits, harms, follow-up, diagnostic testing, over-diagnosis, false positive rate, and total radiation exposure;

Proposed Decision Memo for Percutaneous Left Atrial Appendage (LAA) Closure Therapy (CAG-00445N)

A formal **shared decision-making** interaction between the patient and provider using an evidence-based **decision tool** in anticoagulation in patients with NVAF must occur prior to LAAC, must be documented in the medical records, must include a discussion of the benefits and harms, must

2

Assure PDA quality

Certification



Labor &
Delivery
(2016)

Next priority
area:
End of life care
(2018)



Reimbursement
& liability
incentives
to use PDAs

More PDA
↓
More informed

More informed
↓
Less ANH



ANH = UMT ✓
ONH = UMT

ONH = UMT

If reject ANH, **still** ONH

ONH also often **unwanted**

Some deplore living advanced dementia **at all**

2 solutions

Solution One

VSED

Voluntarily
Stopping
Eating &
Drinking

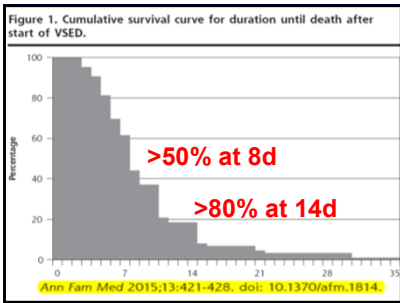
Definition
VSED

3

Physiologically
able to take food
& fluid by mouth

Voluntary,
deliberate
decision to stop

Intent: death
from dehydration



THE NEW ENGLAND JOURNAL OF MEDICINE

SPECIAL ARTICLE

Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death

Linda Ganzini, M.D., M.P.H., Elizabeth R. Goy, Ph.D., Lois L. Miller, Ph.D., R.N., Theresa A. Harvath, R.N., Ph.D., Ann Jackson, M.B.A., and Molly A. Delorit, B.A.

Most deaths:
“peaceful, with
little suffering”

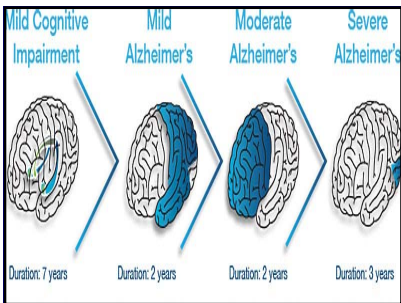
Even though
MAID available,
“almost twice”
chose VSED

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”

The New York Times **News**

WORLD, U.S., S.I., BUSINESS, TECHNOLOGY, MARKETS, HEALTH, SPORTS, OPINION

Doctor Cleared of Murdering Woman With Suicide Machine

By [unreadable] and [unreadable]

Published: 10/18/2006

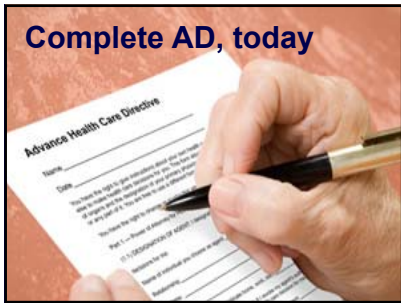
Intolerable life comes **after** lose capacity

VSED with capacity, then **too early**

Solution Two

Advance VSED

1



2

Direct VSED
in **future**

3

When reach
point you define
as intolerable

Legality
in NC

Living will
HCPOA

Living
will

STATE OF NORTH CAROLINA

ADVANCE DIRECTIVE FOR A
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INSTRUCTIONS TO WITHHOLD OR WITHDRAW LIFE-PROLONGING MEASURES IN CERTAIN
SITUATIONS. THERE IS NO LEGAL REQUIREMENT THAT ANYONE EXECUTE A LIVING WILL.

GENERAL INSTRUCTIONS: You can use this Advance Directive ("Living Will") form to give instructions for the
future if you want your health care providers to withhold or withdraw life-prolonging measures in certain situations.
You should talk to your doctor about what these terms mean. The Living Will states what choices you would have
made for yourself if you were able to communicate. Talk to your family members, friends, and others you trust about
your choices. Also, this form allows you to work with professionals, such as your doctor, pharmacist, and lawyer.

NOTE: YOU MAY INITIAL ANY OR ALL OF THESE CHOICES.

(initial)	I have an incurable or irreversible condition that will result in my death within a relatively short period of time.
(initial)	I become unconscious and my health care providers determine that, to a high degree of medical certainty, I will never regain my consciousness.
(initial)	I suffer from advanced dementia or any other condition which results in the substantial loss of my cognitive ability and my health care providers determine that, to a high degree of medical certainty, this loss is permanent.

2. These are My Directives about Prolonging My Life:

In those situations I have intiated in Section 1, I direct that my health care providers:

NOTE: INITIAL ONLY IN ONE PLACE.

(initial)	may withhold or withdraw life-prolonging measures.
(initial)	shall withhold or withdraw life-prolonging measures.

HCPOA

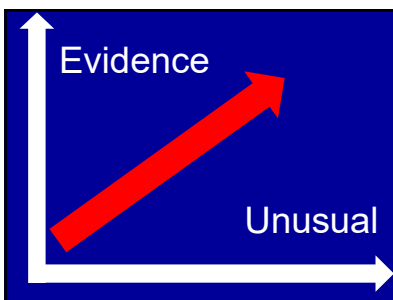
F. Giving consent for, withdrawing consent for, or withholding consent for, X-rays, anesthesia, medication, surgery, and all other diagnostic and treatment procedures or used by or under the authorization of a licensed physician, dentist, podiatrist, or other health care provider. This authorization specifically includes the power to consent to measures for relief of pain.

G. Authorizing the withholding or withdrawal of life-prolonging measures.

No legal obstacle to
NC agent authorizing
VSED

Still “soft” obstacles

Practical tips



Be very
specific on
the when

Be very
specific on
the what

Lessons
from 2
recent cases

PART 1: POWER OF ATTORNEY FOR HEALTH CARE

I revoke all prior advance health care directives and durable powers of attorney for health care signed by me. This document shall not be affected by my subsequent incapacity. I am not a patient in a skilled nursing facility, and I am not a conservatee.

1.1 NAME AND ADDRESS OF PRINCIPAL. My name and address are:

 Nora R. Harris, 83 Arnold Drive, Novato, CA 94949

PART 2: INSTRUCTIONS FOR HEALTH CARE

2.1 END-OF-LIFE DECISIONS. I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

Initial a. I Choose **NOT To Prolong Life**. If I initial this line, I do not want my life to be prolonged and I do not want life-sustaining treatment to be provided or continued if any of the following conditions apply:

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?

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. 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. 207

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212