

Dementia, Withholding Food & Water, and Overcoming Barriers to VSED by Advance Directive

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Lansing, MI • Oct. 11, 2018

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Disclosures

I have **no** conflict of interest
to report.

I will **not** discuss any off-label
use of any product.

I have received **no** commercial
support for this presentation.

Objectives

Describe VSED.

Identify the limitations of traditional
advance directives for dementia.

Describe how patients can authorize
VSED when they reach advanced
dementia.

Assess the most effective advance
care planning for dementia.

Time

11:00 - 11:50

11:50 - 12:50

Lunch - Royale Atrium/Alcove

**2 Core
questions**

May a Michigander
leave instructions,
“**dehydrate me to
death**” when I reach
advanced dementia?

May / must
clinicians **honor**
such instructions?

Introduction

More & more
jurisdictions
expanding
EOL liberty

Most VISIBLE exit option

Medical
aid in dying

Adults

> 18 years old

Decisional
capacity

Terminally ill

6-mo prognosis

What

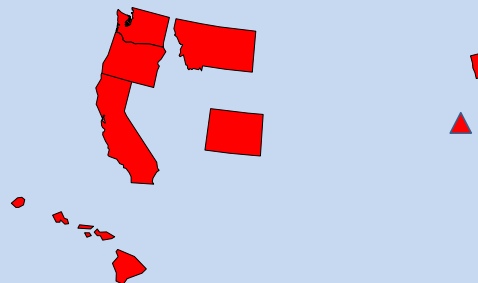
Ask & receive
prescription

drug

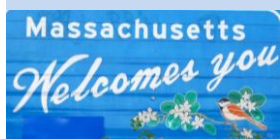
Self-administer

To hasten death

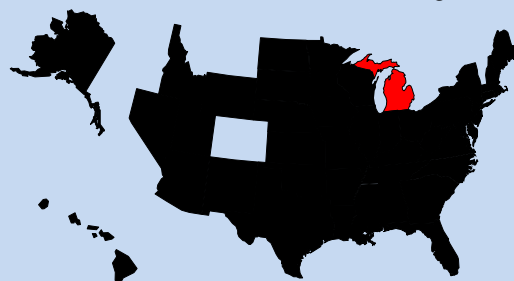
MAID legal in **8** US states



Maybe soon **11**



MAID illegal in **48**
including MI



SO

Focus on

Other exit
options

Dementia challenge

raised **repeatedly**

The New York Times

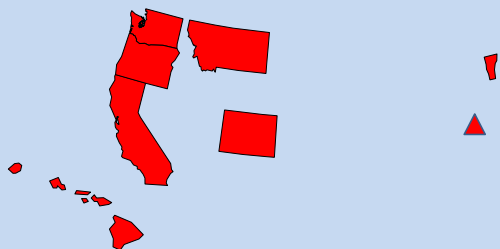
THE NEW OLD AGE

One Day Your Mind May Fade. At Least You'll Have a Plan.

By Paula Span

Jan. 19, 2018

Challenge even in these states



Cannot satisfy
2 conditions
at same time

Eligibility requirements in **all** MAID states

1

Terminal illness

“incurable and
irreversible . . .
condition . . .
death within
six months.”

2

Capacity

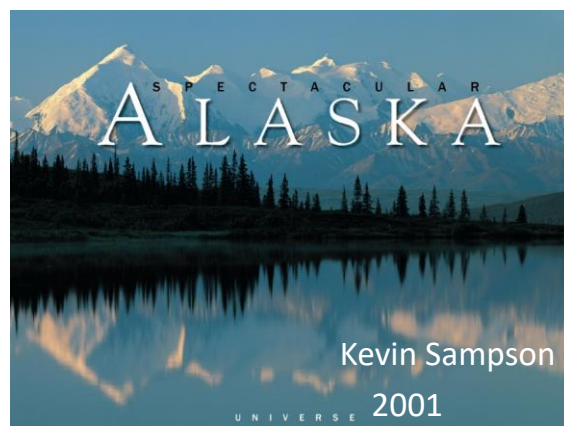
“solely and directly
by the individual . . .
**not . . . advance
directive**”

BUT

Capacity →
not terminal

Terminal →
no capacity

May change
someday

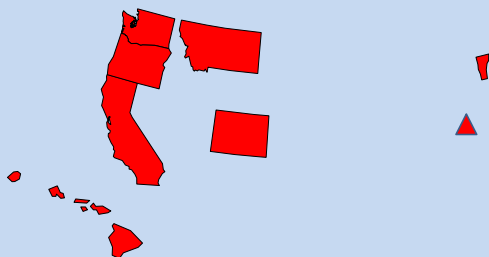




**But
today**

No “advance”
MAID in the
Americas

No help for dementia
even here



RESEARCH PAPER

Lifetime risk of common neurological diseases in the elderly population

Silvan Licher,¹ Sirwan K L Darweesh,¹ Frank J Wolters,^{1,2} Lana Fani,^{1,2} Alis Heshmatollah,^{1,2} Unal Mutlu,^{1,3} Peter J Koudstaal,² Jan Heeringa,¹ Maarten J G Leening,^{1,4,5} M Kamran Ikram,^{1,2} M Arfan Ikram¹

Women 45+
26% lifetime risk

SO

again

Other exit
options

VSED

Voluntarily
Stopping
Eating &
Drinking

MAID gets
massive
attention



Define VSED

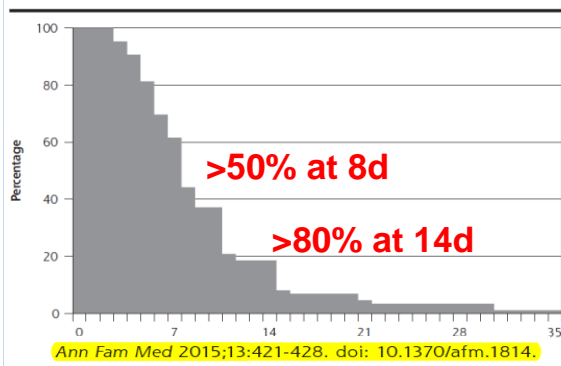
3

Physiologically
able to take food
& fluid by mouth

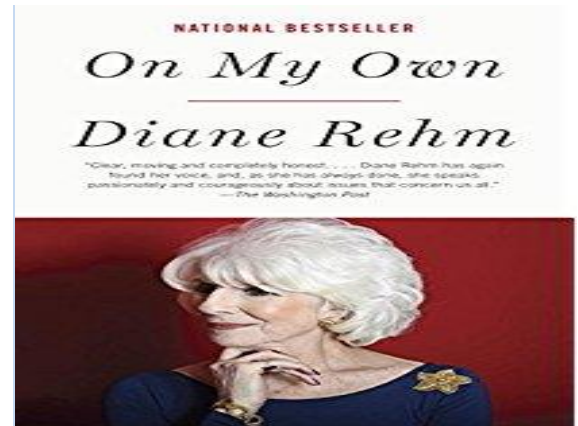
Voluntary,
deliberate
decision to stop

Intent: death
from dehydration

Figure 1. Cumulative survival curve for duration until death after start of VSED.



**Bad
rap**



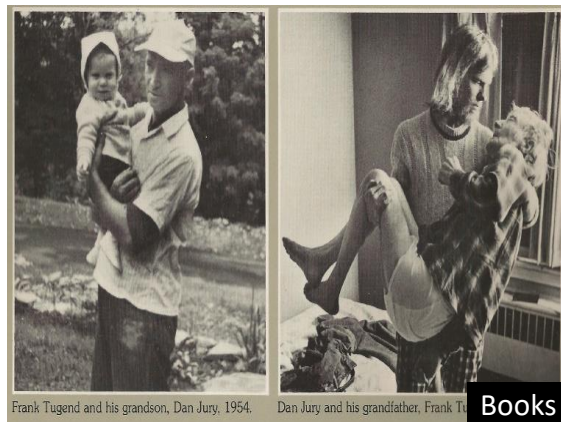
“Must legalize
MAID . . . or
else . . . VSED”

Actually

**Peaceful
Comfortable**

1

1st person narratives



Books

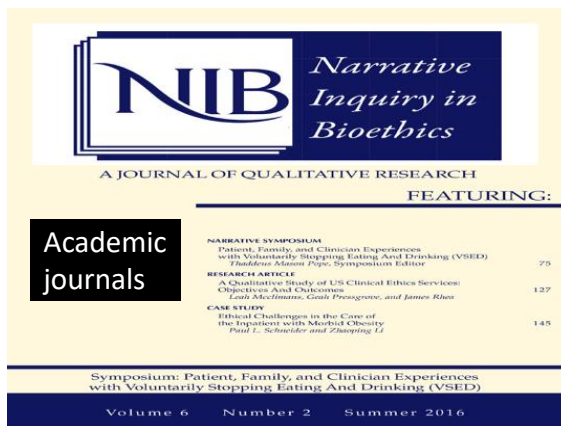


Films - Dying Wish



Phyllis Schacter

TED talks



2

Medical journals

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.

>100 Oregon nurses cared for VSED patients

Most deaths:
 “**peaceful**, with little suffering”

“opportunity for reflection, family interaction, and mourning”

Not for
everyone

Preferred
by many



Even though MAID
available, **“almost
twice”** chose VSED

3

**Clinical
guidance**

Good option

JAMA Internal Medicine | Special Communication | HEALTH CARE POLICY AND LAW

Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects

Timothy E. Quill, MD; Linda Ganzini, MD, MPH; Robert D. Truog, MD; Thaddeus Mason Pope, JD, PhD

JAMA Internal Medicine January 2018 Volume 178, Number 1 123

Journal of the
American Geriatrics Society



SPECIAL ARTICLE:
PALLIATIVE PRACTICE POINTERS

Voluntary Stopping Eating and Drinking

John W. Wax, MD, Amy W. An, MD, Nicole Kosier, MD, and Timothy E. Quill, MD

4

CPGs

v&vni knmg

Caring for people who consciously choose not to eat and drink so as to hasten the end of life



KNMG Royal Dutch Medical Association and V&VNI Dutch Nurses' Association Guide

2018
C&E - print & family edition



COLLÈGE DES MÉDECINS
DU QUÉBEC



Growing
professional
society
endorsements

POSITION STATEMENT



Nutrition and Hydration at the End of Life

Effective Date: 2017
Status: Revised Position Statement
Written by: ANA Center for Ethics and Human Rights
Adopted by: ANA Board of Directors

JOURNAL OF PALLIATIVE MEDICINE
Volume 20, Number 1, 2017
Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2016.0290

Position Statement

International Association for Hospice
and Palliative Care Position Statement:
Euthanasia and Physician-Assisted Suicide

Austrian Palliative Society (OPG)

themenschwerpunkt

Wien Med Wochenschr
<https://doi.org/10.1007/s10354-018-0829-z>



Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen

Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)

Angelika Feichtner · Dietmar Weidner · Alois Birkbauer

Eingegangen: 6. September 2017 / Angenommen: 7. Februar 2018
© Springer-Verlag GmbH Austria, ein Teil von Springer Nature 2018

Recap

Evidence
based EOL
exit option

**Legal
concerns**



BUT

Uncertainty,
reluctance

Prevalence of Formal Accusations of Murder and Euthanasia against Physicians

> 600 palliative
care physicians
perception of
legal risk

Action that might be misperceived	Mean rating of risk	SD	Actual number of physicians who were accused based on this action
Total sedation (the application of pharmacotherapy to induce a state of decreased or absent awareness [unconsciousness] in order to reduce the burden of otherwise intractable suffering)	4.1	1.1	2
Stopping artificially delivered nutrition/hydration	3.6	1.1	0
Stopping oral nutrition/hydration in a patient who can eat/drink when requested by the patient	3.3	1.2	0
Use of palliative and sedative medications in the process of discontinuing mechanical ventilation	3.2	1.3	6
Stopping dialysis	3.1	1.2	0
Use of barbiturates for symptom treatment	2.9	1.1	2
Use of opiates for symptom treatment	2.8	1.2	13
Use of benzodiazepines for symptom treatment	2.3	1.0	1
Other	N/A	N/A	6

Providers
ask

Is VSED
legal?

Is VSED
illegal?

Wrong
questions



Law is rarely binary

Risk
assessment

Measure
Mitigate

VSED
Legality



Prohibited

Unsure

Permitted



No U.S.
jurisdiction
expressly
prohibits VSED

BUT

Absence of a red light
not good enough



No **statutory**
permission

No **judicial**
precedent

Almost no
judicial
precedent



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Vancouver BC V6C 0B4 Toll Free: 1-800-461-3008 (in BC)
www.cpsbc.ca Fax: 604-733-3503

FINAL DISPOSITION REPORT OF THE INQUIRY COMMITTEE

February 13, 2018

CPS File No: IC 2017-0836

Complainant: Internal (referral from BC Coroners Service)

Subject Physician(s): Dr. Ellen Wiebe

No red lights
No green lights

Lack of clarity &
guidance



neglected in academic & policy circles



2

case
types

1

VSED **now**
by patient
with capacity

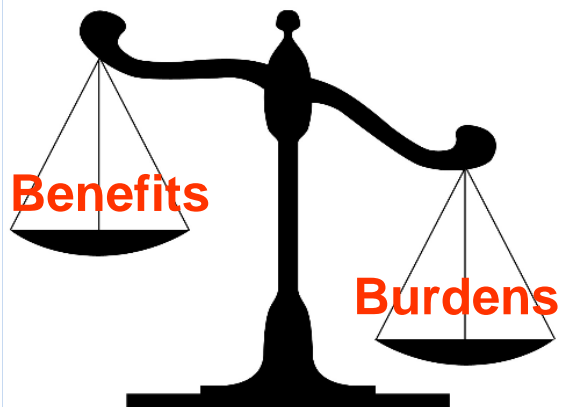
2

Advance
directive for
VSED **later**
(when Pt lacks capacity)

**VSED now,
patient with
capacity**

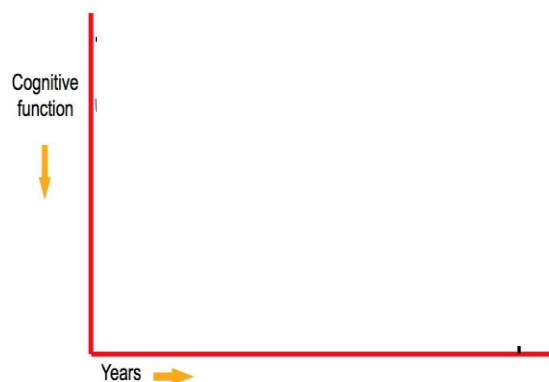
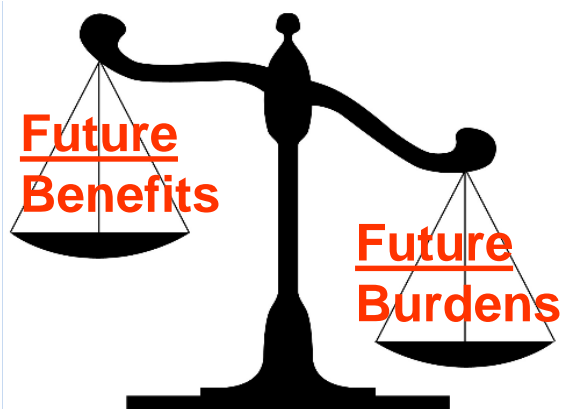
Why
do it

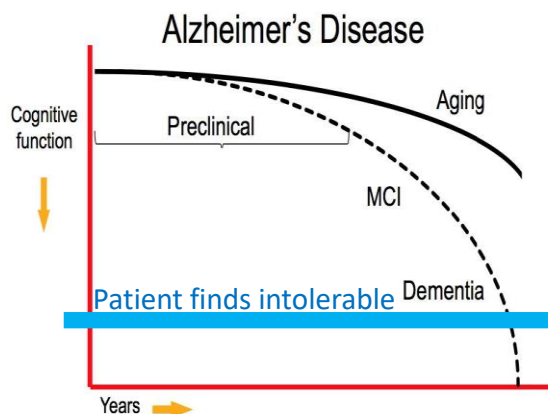
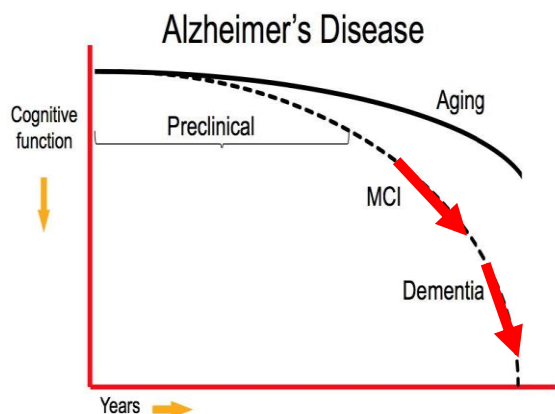
Cancer
ALS



Dementia

Progressive illness





What's that **line**?

Different for each of us

When I see people in my close family or see my best friends, I do not know who they are.

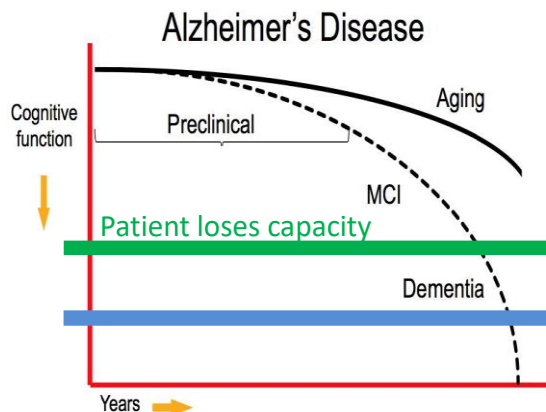
[3.1]



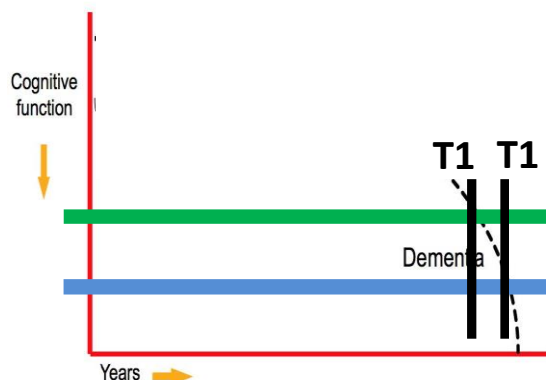
(This patient is both incontinent and dependent on others to change his diapers.)

I do not use bathrooms. I let my clothes get wet and dirty. Others must change my diapers (nappies). [4.5]





Hasten death
before losing
capacity



Life **not** intolerable

But act **now**,
because still
have capacity

BUT

Too
soon

Hasten death
while life still
worthwhile

Premature
dying

VSED
Legality

3

Criminal sanctions
Civil liability
Licensing discipline

Extremely
low risk

4 Arguments

1 Right to
refuse
medical
measures

Well established

> 4 decades

**Right to
refuse
treatment**

Vent
Dialysis
CPR
Antibiotics
Feed tube

Vent
Dialysis
CPR
Antibiotics
Feed tube

VSED

Unclear



Vent
Dialysis
CPR
Antibiotics
Feed tube

ICD

Vent
Dialysis
CPR
Antibiotics
Feed tube

VSED

A red arrow points from the 'VSED' label to the list of medical interventions.

Not DIY

Part of a broader
treatment plan

Supervised by
licensed healthcare
professionals



PAVSED

Palliated & Assisted
Voluntarily Stopping
Eating and Drinking

PAVSED

Highlights **medical role** in
palliating symptoms

Highlights the **direct care staff**
role in providing assistance

Recognized as
healthcare by
medical
profession

More position
statements
(e.g. ANA,
IAHPC)

More clinical
practice
guidelines

Recap

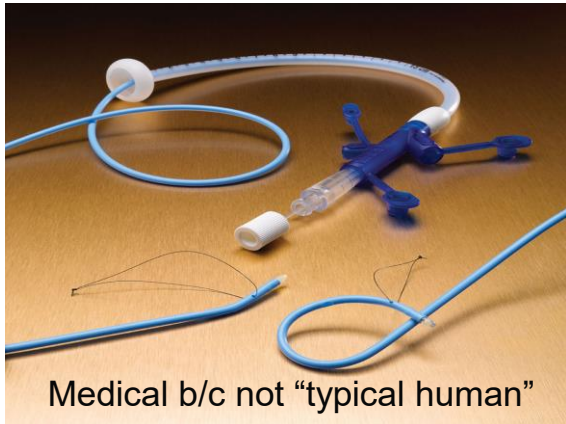
ONH =
“treatment”

Right to
refuse
treatment

VSED

BUT





ONH \neq
"treatment"

**Right to
refuse
medical**

VSED

**That's
okay**

2

Right to
refuse
unwanted
measures

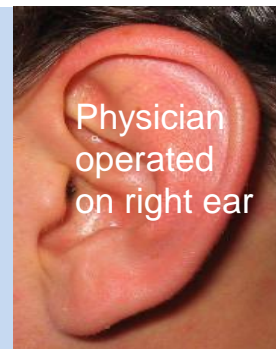
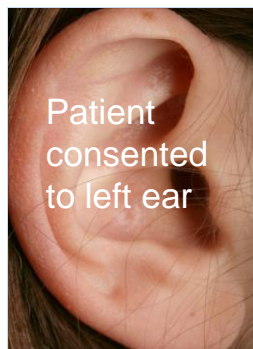
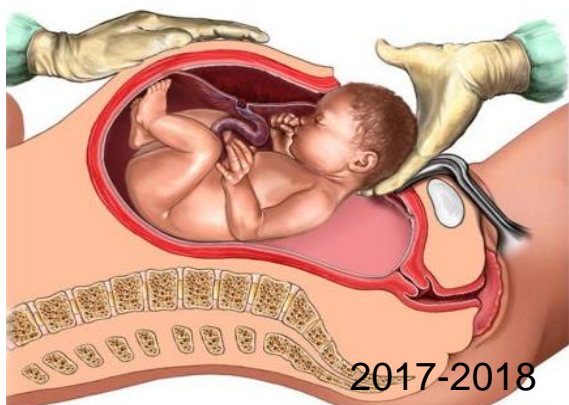
Does **not** matter
whether food &
fluid is “medical
treatment”

Right to refuse
any intervention
(medical **or not**)

Right to refuse
unwanted contact

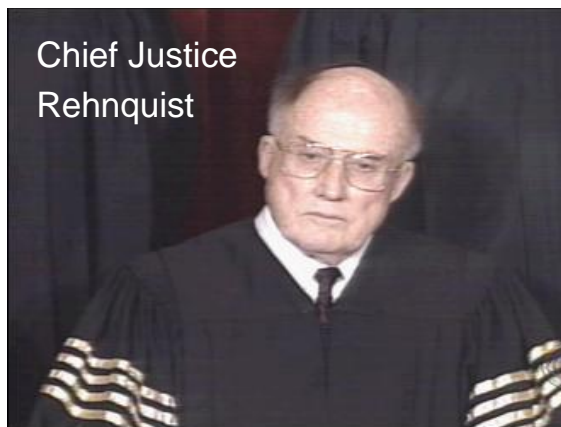
Even if it would
be clinically
beneficial

Battery



Mohr v. Williams (Minn. 1905)

Force feeding is a battery



“bodily integrity is violated . . . by sticking a **spoon in your mouth** . . . sticking a needle in your arm”

Move from legal bases, grounds for right

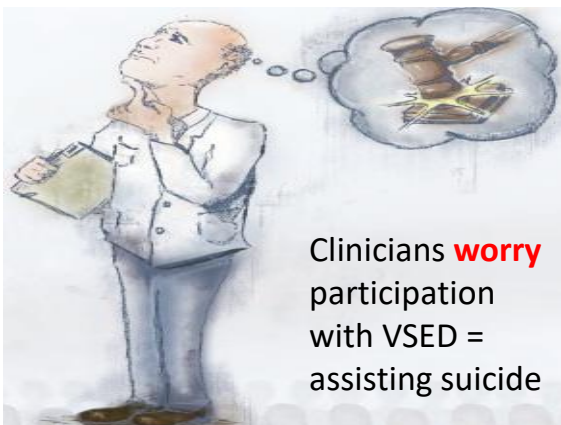
Respond to
2 main legal
concerns

3 VSED
is not
assisted
suicide

56 US jurisdictions

“Every person . . . aids, or advises, or encourages another to commit suicide, is guilty of a **felony**.”

Mich. Penal Code
750.329a



BUT

VSED ~~=~~
AS

Active

Passive

AS statutes
target **active**
conduct



Normally:

“Providing the **physical means** by which the other person commits . . . suicide”

VSED entails
only **passive**
conduct

No “active”
introduction of
any lethal agent

Plus

Even if otherwise
within scope

Exception

“Nothing . . . prohibit or
preclude . . . prescribing . .
. administering, . . .
purpose of diminishing . . .
pain or discomfort”

Everything
clinician does in
VSED expressly
exempted from
AS statute

Many physicians
& hospices
support VSED

0 cases

4 VSED is not abuse / neglect

Alleged risk

“The facility must provide each resident with **sufficient fluid intake** to maintain proper hydration and health.”
42 C.F.R. 483.25(j)
Tag F0327

557 results
(773 Deficiencies)

--- Previous 1 2 3 4 5 6 7 8 9 ... 15 16 Next ---

The number and severity of deficiencies shown below relate only to the search terms, not necessarily all deficiencies against the home.
Important: If you searched for a city or home name, results for that home may be spread over several pages. To improve results, select a state and sort by city.

Date	Nursing Home	City	State	Def.	Severity Range
Sept. 22, 2015	THE BROADMOOR AT CREEKSIDE PARK (REPORT)	The Woodlands	Tex.	2	K to L
April 28, 2015	BRIARCLIFF HEALTH CENTER (REPORT)	Tyler	Tex.	2	L
Aug. 7, 2013	KINDRED TRANSITIONAL CARE AND REHABILITATION-RIDGEM (REPORT)	Fort Worth	Tex.	4	L
Mar. '10	DAI MA DEAI / DSD/DPY	Merida	Tex.	1	-

Deficiencies With "Dehydrate"

By Severity

- B | 2
- D | 326
- E | 115
- F | 36
- G | 190
- H | 12
- I | 1
- J | 43
- K | 47
- L | 10

BUT



Tag 242

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-12-25
Baltimore, Maryland 21244-1850

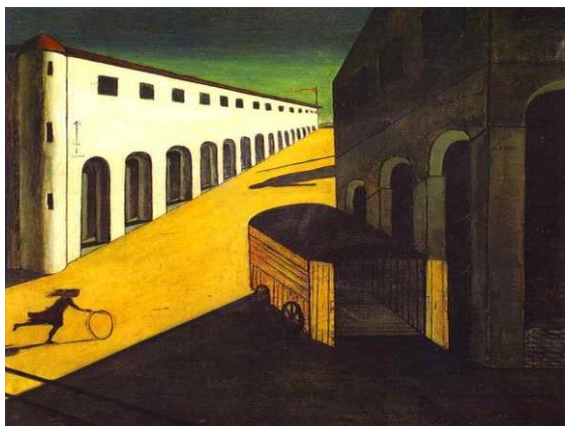


Center for Medicaid and State Operations/Survey and Certification Group

Recap

~~Risk = 0~~

226



Risk ~ 0

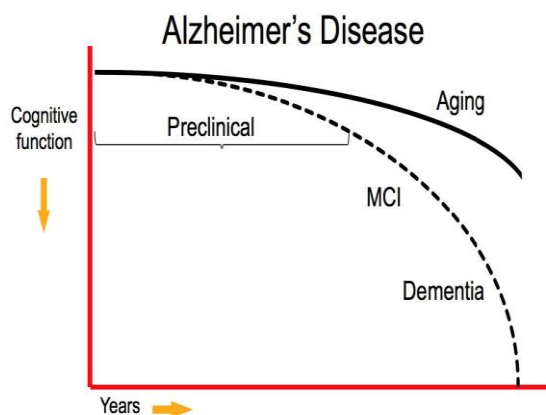
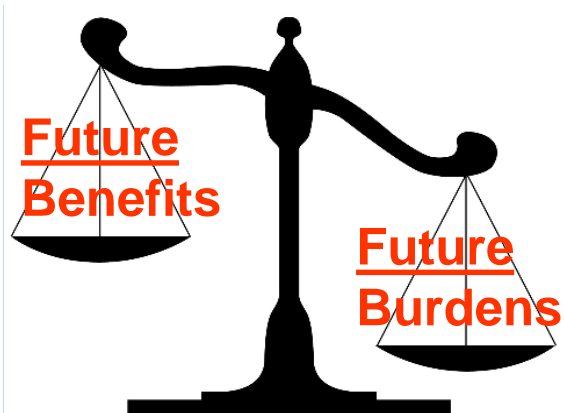
229

VSED now,
patient with
capacity

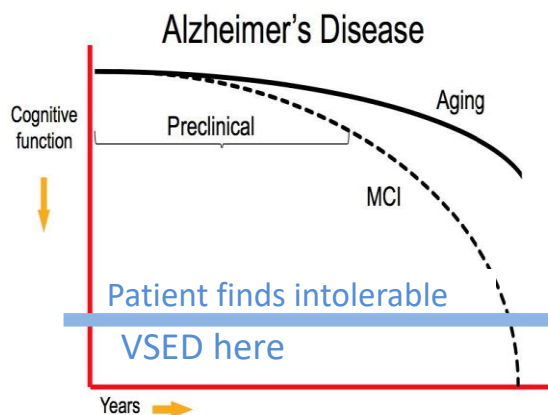
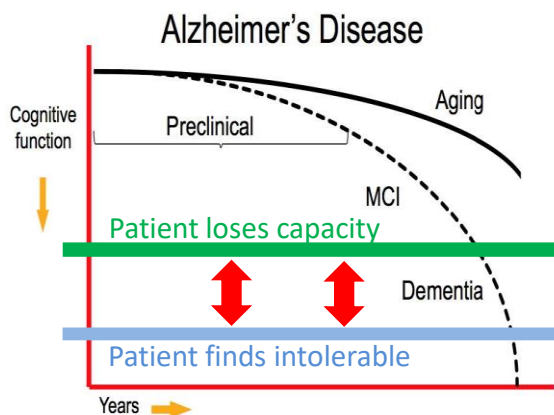
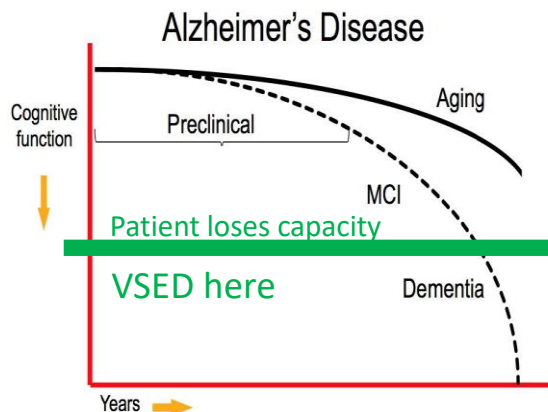
Advance
directive for
VSED later

(when Pt lacks capacity)

Why
do it



Contemporaneous VSED



What is
“advance
VSED”

1

Complete AD, today



2

Direct VSED
in **future**

3

When reach point
that **you** define
as intolerable

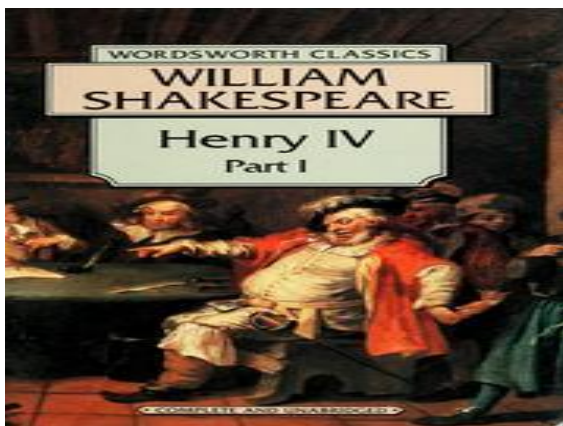
4

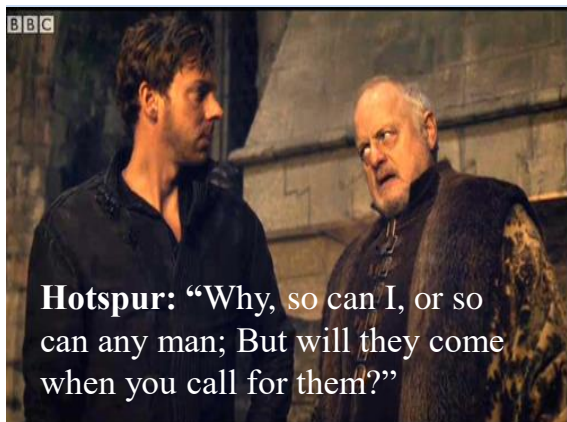
You **lack**
capacity at
that time

That is
“advance
VSED”

**Viable
option?**

Can you leave
VSED
instructions
in an AD?





You can **write** anything you want in an AD

But . . . will it be **honored**

**VSED
Legality**



Prohibited

Unsure

Permitted



No specific permission for VSED



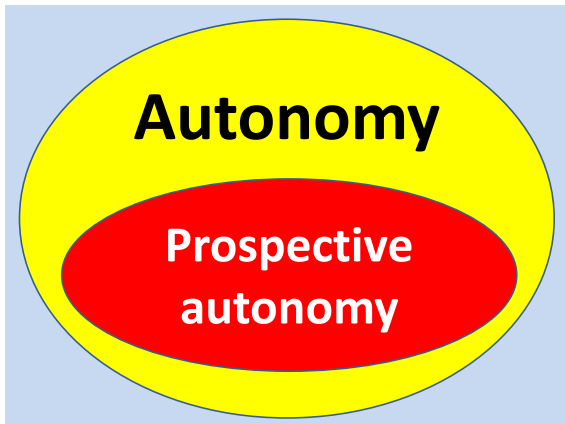
Sometimes,
advance VSED is
prohibited

Wis. Stat. 155.20

“A health care agent **may not consent** to the withholding or withdrawal of **orally** ingested nutrition or hydration . . .”

Uncommon
but not
surprising

Autonomy



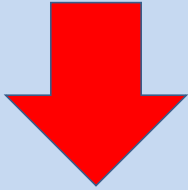
No green (yet)
Some red



Patient
Advocate

Broad
powers

Patient can



Advocate can

Mich. Comp. L. Ann. § 700.5509

“A patient advocate . . .
exercise powers
concerning . . . **care,**
custody, and medical . . .
treatment”

Unlike a Wisconsin
agent, a Michigan
patient advocate
may consent to
withholding **oral**
nutrition or hydration



BUT

2 conditions

Patient permission

VSED **not** within default scope of patient advocate authority

Mich. Comp. L. Ann. § 700.5509

“A patient advocate **may make a decision** to withhold or withdraw treatment that would allow a patient to die **only** if the patient has expressed in a **clear and convincing manner** that the patient advocate is authorized to make such a decision”

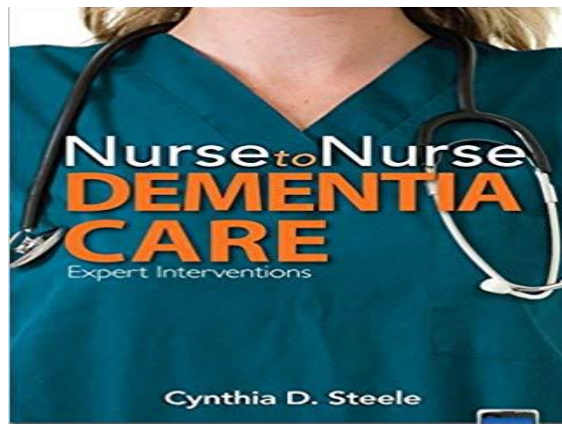
2 recent cases

Case 1

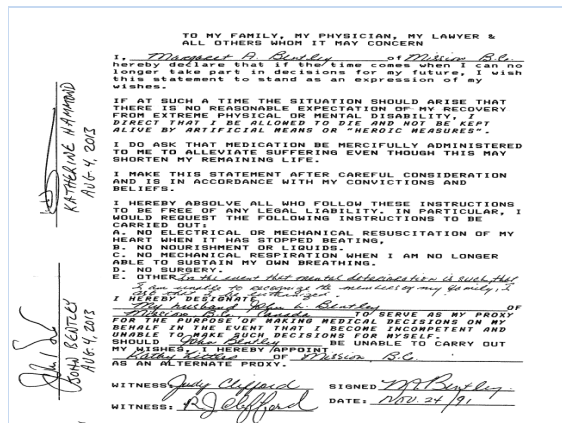




Margot Bentley



Margot - stage 7 Alzheimer's



DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES",

B. NO NOURISHMENT OR LIQUIDS.



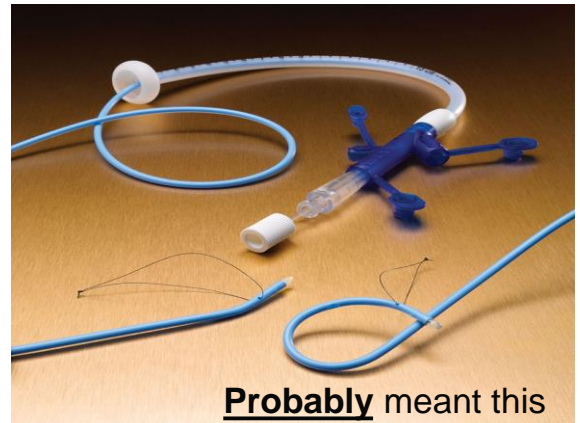
Facility refuses to honor



Family loses

DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT
ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES",

B. NO NOURISHMENT OR LIQUIDS.



Take home lesson

If you mean
hand feeding,
say "hand
feeding"

Case 2



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:

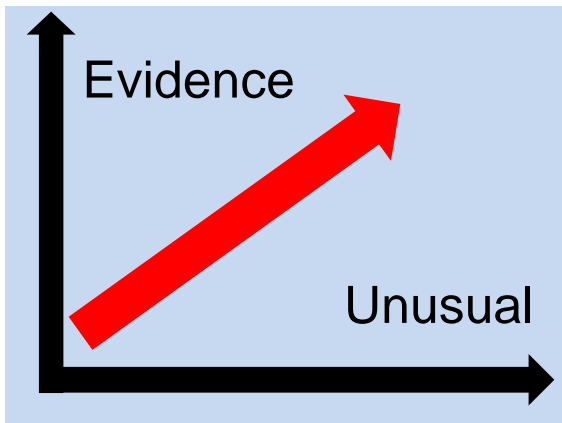
Nora a. I Choose **NOT To Prolong Life**. If I initial this line, I do not want my life to be prolonged and I do not want life-sustaining treatment to be provided or continued if any of the following conditions apply:

Take home
lesson

If you mean
hand feeding,
say "hand
feeding"

Would better
ADs have helped
MB or NH?

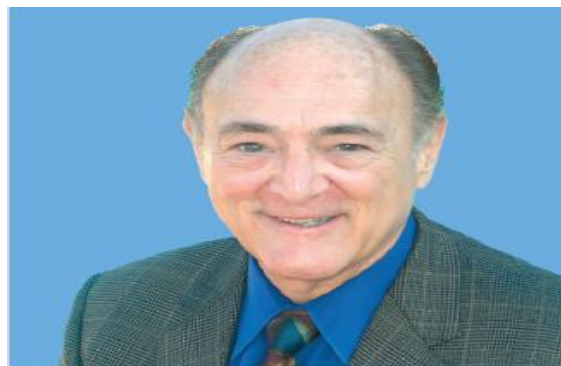
Practical tips



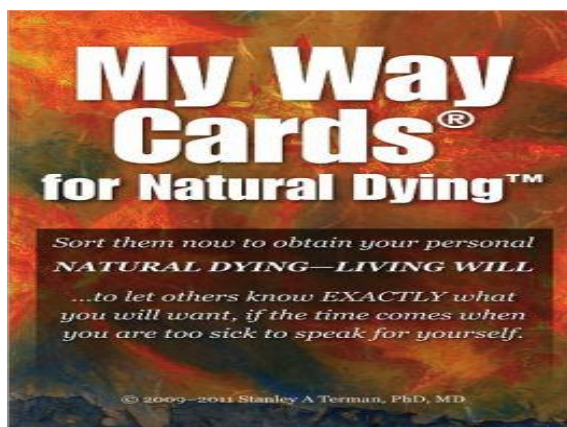
Be very
specific on
the when

Be very
specific on
the what

Tool 1



STANLEY A. TERMAN, PhD, MD



(Loss of personal identity.)

I do not seem to know it is me when I look in the mirror. I cannot tell others anything about me. [1.1]



When I see people in my close family or see my best friends, I do not know who they are.

[3.1]



(This patient is both incontinent and dependent on others to change his diapers.)

I do not use bathrooms. I let my clothes get wet and dirty. Others must change my diapers (nappies). [4.5]



(Leaving bad memories of yourself.)

The way I act now is hurtful or shameful.

I may yell insulting words or take off my clothes in front of strangers.

[4.6]



I cannot remember the important events of my life.

If reminded, I don't know why they are important. [1.2]



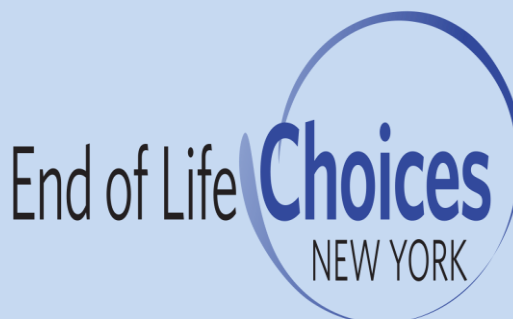
I have severe pain. But I cannot say what bothers me.

Doctors don't see my pain. They do not treat my pain.

[2.6]



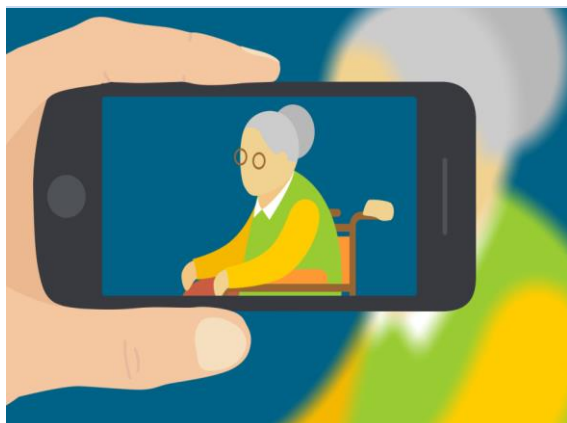
Tool 2



MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING

Advance Directive for Receiving Oral Food and Fluids in Dementia

Clear definitions & prompts



2 conditions

Patient permission

No veto

Mich. Comp. L. Ann. § 700.5511

“**Irrespective** of a previously expressed . . . desire, a **current desire** by a patient to have provided, and not withheld . . . life-extending care, custody, or . . . treatment is **binding** on the patient advocate”

“**regardless** of the then ability or inability of the patient to participate in care, custody, or medical treatment decisions or the patient's **competency.**”

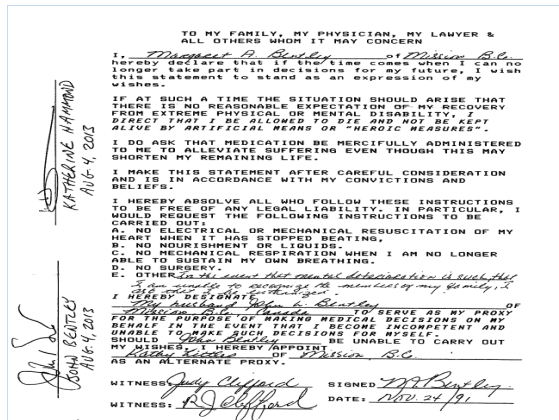
Incapacitated vetoes count

Tricky

Case 1



Margot Bentley



Assume AD
clear & valid



Swallowing = revocation

Practical
tips

Ulysses
contract
language

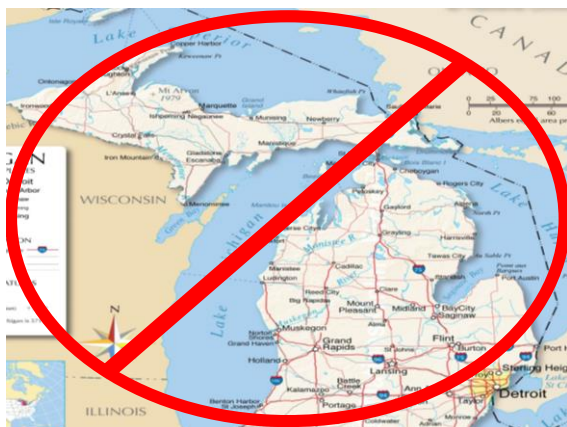


**ABOUT THE ADVANCE DIRECTIVE FOR
RECEIVING ORAL FOOD AND FLUIDS IN DEMENTIA**

“If I am suffering from advanced dementia . . . my instructions are that **I do NOT want to be fed by hand**”

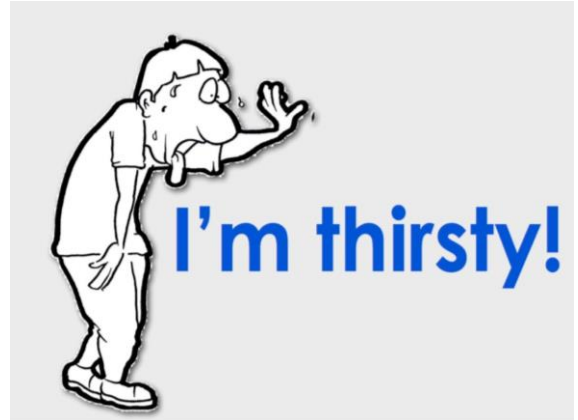
No hand feeding **even if** “appear to cooperate in being fed by opening my mouth”

Listen to my **prior** self not my current self



BUT

“current
desire”



Conclusion

VSED is
important
EOL option

Need **more**
education &
planning **tools**

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349

References

Materials from the
 cases discussed in
 this presentation
 are available at

<http://thaddeuspope.com/braindeath>

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 nearly **3 million** direct visits. Plus, it is redistributed through WestlawNext, Bioethics.net, and others.

352

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