Under-examined End-of-Life Option: Hastening Death by Voluntarily Stopping Eating and Drinking (VSED)

> Dying in the Americas Henderson, NV - Mar. 24, 2018

> > **Thaddeus Mason Pope**, JD, PhD Mitchell Hamline Health Law Institute

Who

am 12

l am a law

professor

Welcomes You

Who else?

Saint Paul, MN

Alta

S.F

10 JL 21 14 2000



Since

2012

Before

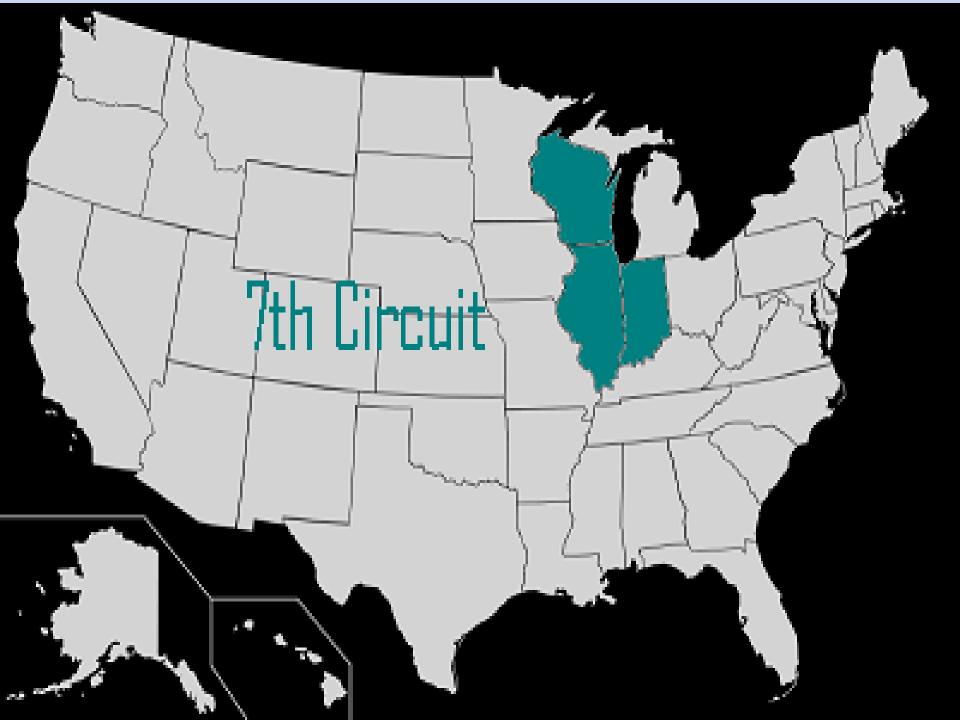
that:

Pittsburgh, PA

Georgetown bioethics

Georgetown Law

MAINARP



Los Angeles

THE UNIVERSITY OF MEMPHIS.

Philadelphia

I am a law professor.

But I often speak and write directly to clinicians



The NEW ENGLAND JOURNAL of MEDICINE



AMERICAN COLLEGE OF CHIESEOF PHYSICIANS®

VOLUME 9 | ISSUE 1 | JANUARY 25, 2018



The ASCO[®] Post

NEWS AND VIEWS FROM THE WORLD OF CLINICAL ONCOLOGY AND HEMATOLOGY



Preserving Sexual Function



Advance Directives & POLST Hastening Death – VSED Hastening Death - MAID Medical Futility Surrogate Decision Making Right to Die & UMT **Brain Death & Organ Donation Conscience Based Objections** Healthcare Ethics Committees

THE RIGHT TO DIE The Law of End-of-Life Decisionmaking

Third Edition

Alan Meisel Kathy L. Cerminara Thaddeus M. Pope

Medical Futility Blog

4 million pageviews

Introduction

More & more jurisdictions expanding **EOL** liberty

Most VISIBLE exit option

Medical aid in dying

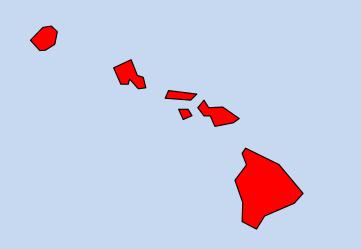
MAID legal in 7 US states



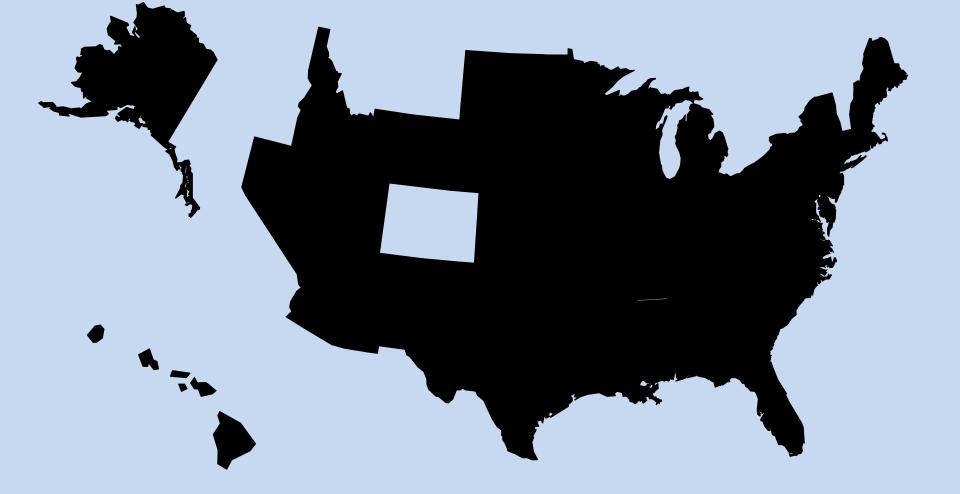


Maybe soon 9





MAID illegal in 49





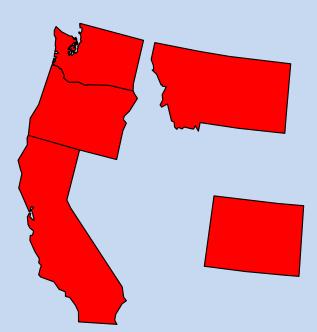
Other exit

options

Dementia challenge

raised repeatedly

Challenge <u>even</u> in these states



Cannot satisfy 2 conditions at same time



Terminal

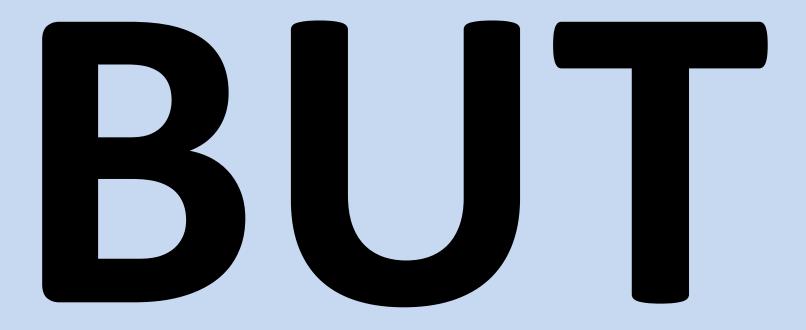
illness

"incurable and irreversible . . . condition . . . death within six months."



Capacity

"solely and directly by the individual . . **not...advance** directive"



Capacity >

not terminal

Terminal \rightarrow

no capacity



American College of Physicians Leading Internal Medicine, Improving Lives Arbitrary discrimination

Kevin Sampson S E 2001

A

R

C

A

E

S









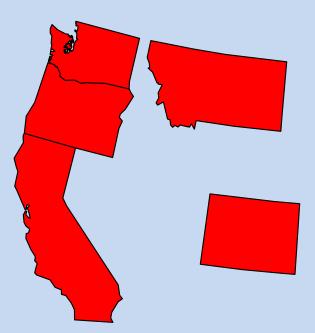
At least 10 years away



No "advance" MAID in the

Americas

No help for dementia even here









Other exit

options



Voluntarily Stopping Eating & Drinking

MAID gets

massive

attention

neglected in academic & policy circles

Define

VSED



Physiologically able to take food & fluid by mouth

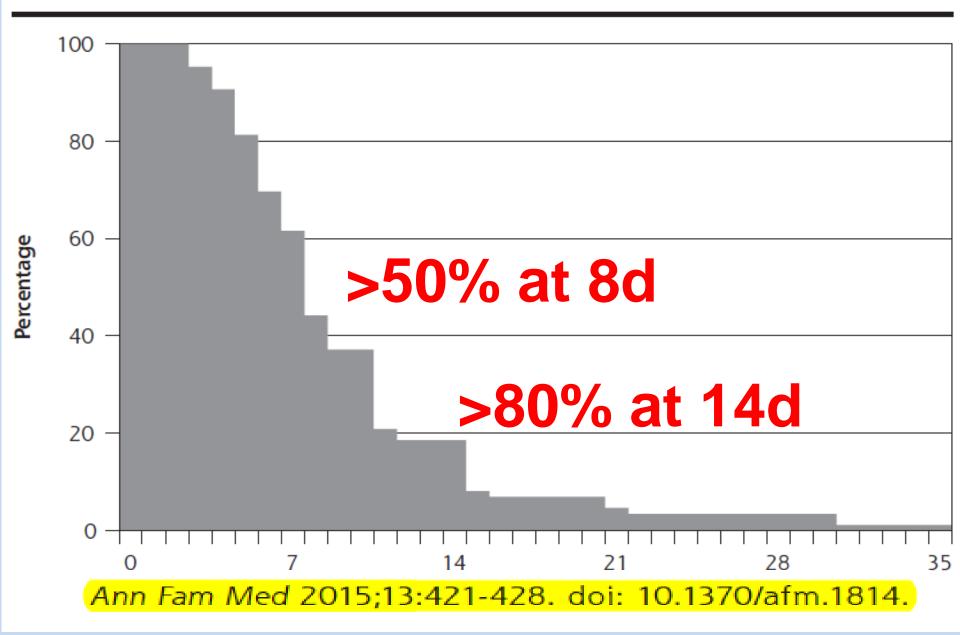
Voluntary,

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



1st person

narratives



A JOURNAL OF QUALITATIVE RESEARCH

FEATURING:

NARRATIVE SYMPOSIUM

Patient, Family, and Clinician Experiences with Voluntarily Stopping Eating And Drinking (VSED) <i>Thaddeus Mason Pope</i> , Symposium Editor	75
RESEARCH ARTICLE	
A Qualitative Study of US Clinical Ethics Services: Objectives And Outcomes Leah Mcclimans, Geah Pressgrove, and James Rhea	127
CASE STUDY	
Ethical Challenges in the Care of the Inpatient with Morbid Obesity Paul L. Schneider and Zhaoming Li	145

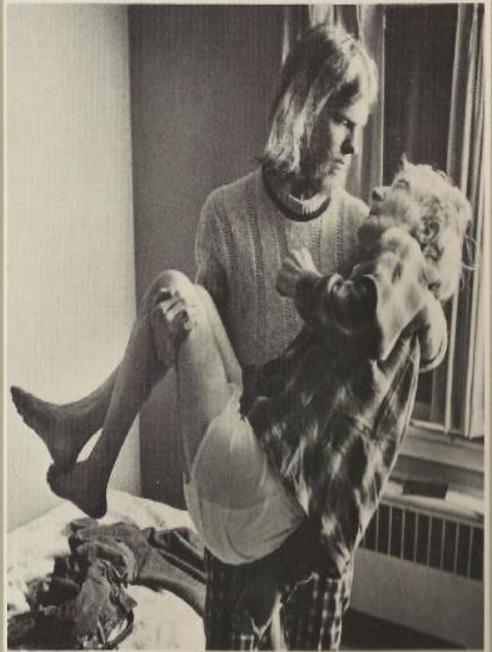
Symposium: Patient, Family, and Clinician Experiences with Voluntarily Stopping Eating And Drinking (VSED)

Volume 6 Number 2 Summer 2016

Phyllis Schacter



Frank Tugend and his grandson, Dan Jury, 1954.



Dan Jury and his grandfather, Frank Tugend, 1974.



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

NATIONAL BESTSELLER

On My Own

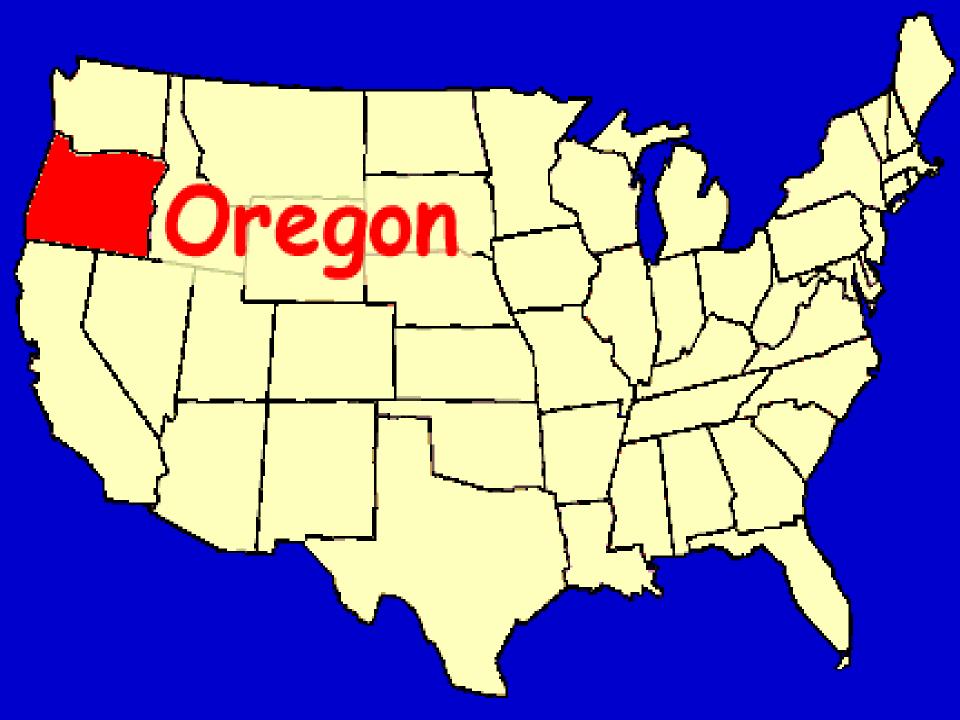
Diane Rehm

*Clear, moving and completely honeot, ... Dane Rehm has again hound her voice, and, as she has always done, she speaks purclimately and couragrounly about insues that concern us all." —The Moshington Post



Preferred

by many



Even though MAID available, "almost twice" chose VSED



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



Growing professional society endorsements

POSITION STATEMENT



Nutrition and Hydration at the End of Life

Effective Date:2017Status:Revised Position StatementWritten by:ANA Center for Ethics and Human RightsAdopted 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)

Wien Med Wochenschr https://doi.org/10.1007/s10354-018-0629-z



themenschwerpunkt



Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen

Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)

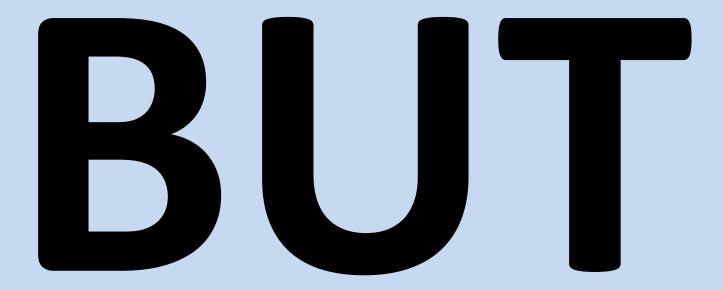
Angelika Feichtner · Dietmar Weixler · Alois Birklbauer

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



concerns

Clinician involvement very important



Uncertainty &

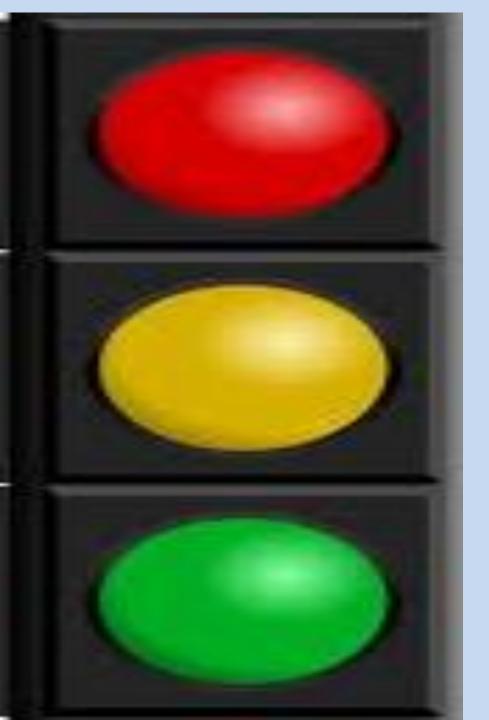
reluctance

JOURNAL OF PALLIATIVE MEDICINE Volume 15, Number 3, 2012 © Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2011.0234

Prevalence of Formal Accusations of Murder and Euthanasia against Physicians

> 600 palliative care physicians

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



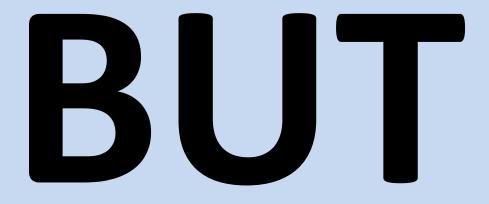
Prohibited

Unsure

Permitted

Almost never: express prohibition

No U.S. jurisdiction expressly prohibits VSED



Absence of a red light not good enough

Clinicians want express permission

No statutory

permission

No judicial precedent

No red lights No green lights

Lack of clarity & guidance

neglected in academic & policy circles





College of Physicians and Surgeons of British Columbia

300-669 Howe Street Vancouver BC V6C 0B4 www.cpsbc.ca

Telephone: 604-733-7758 Toll Free: 1-800-461-3008 (in BC) 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



Providers

ask

IS VSED

legal?

IS VSED

illegal?

Wrong

questions





Law is rarely binary

Risk

assessment

Measure

Mitigate



case types



VSED now by patient with capacity



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

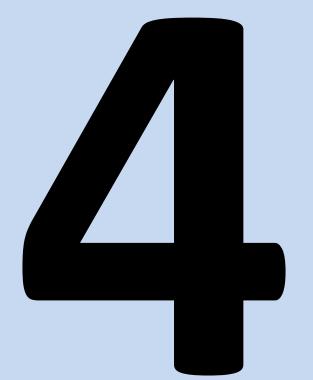
VSED now, patient with

capacity

Extremely

low risk

of sanctions - criminal, civil, regulatory



Arguments



Right to refuse

medical

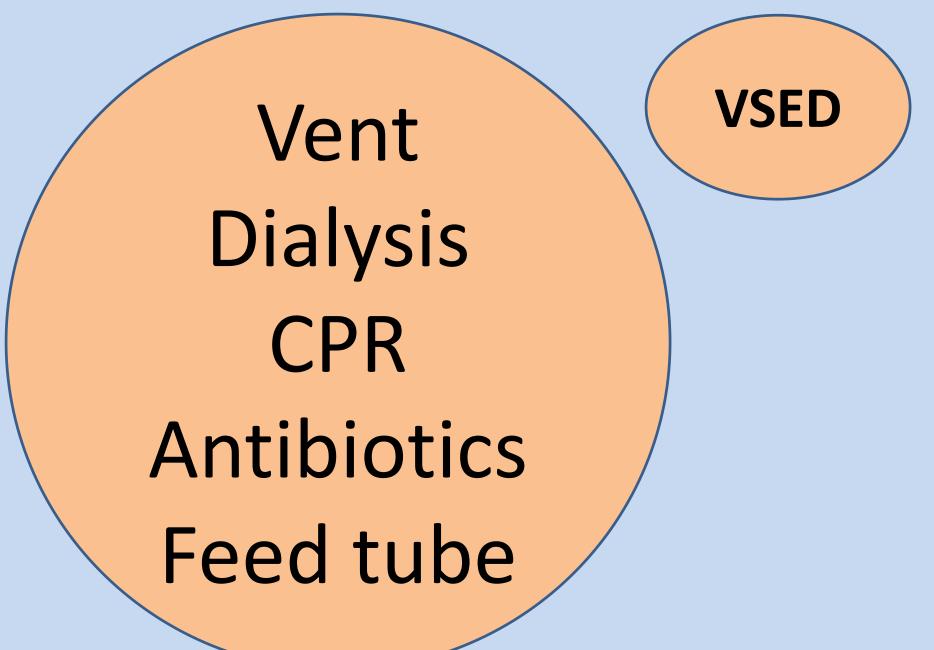
measures

Well established

> 4 decades

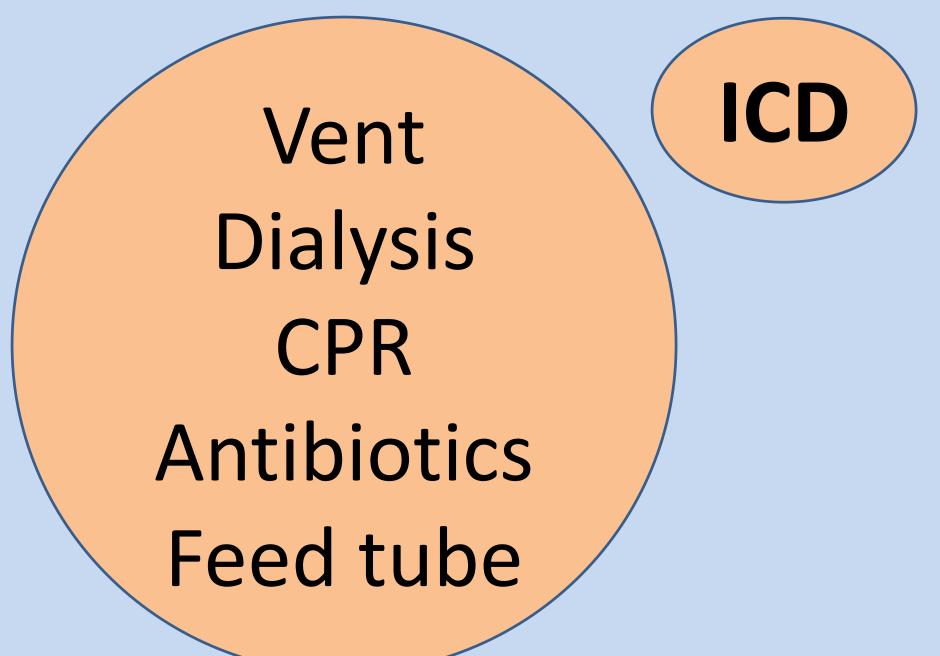
Right to refuse medical

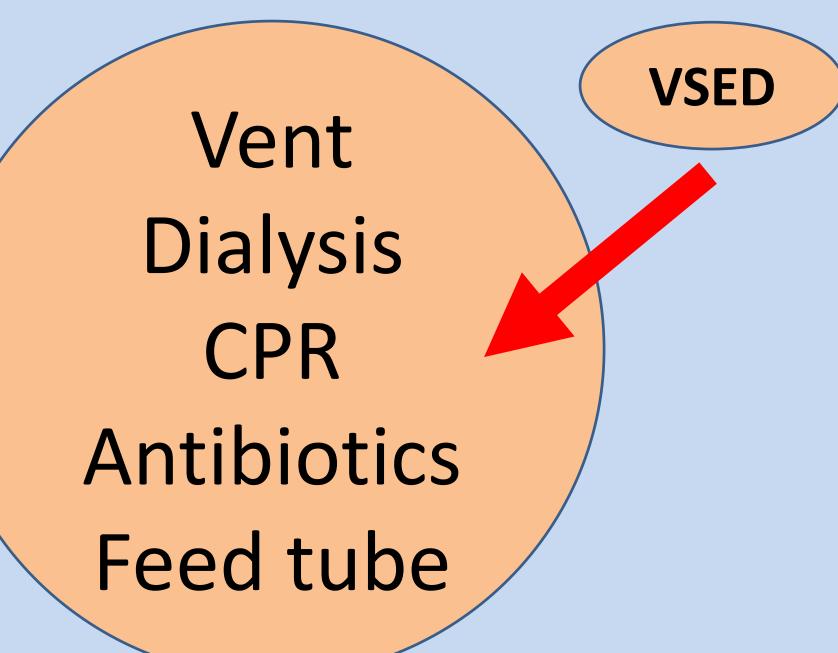
Vent Dialysis CPR Antibiotics Feed tube



Unclear







Not DIY

Part of a broader treatment plan

Supervised by licensed healthcare professionals

Harvard CEC

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



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



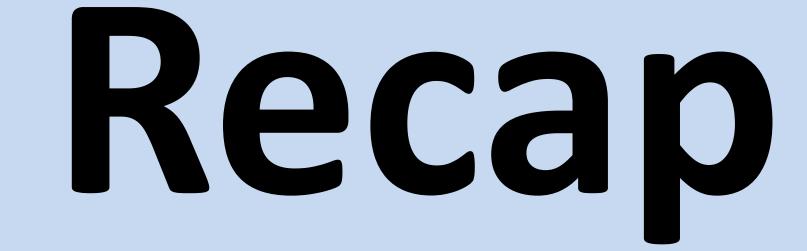
KNMG Royal Dutch Medical Association and V&VN Dutch Nurses' Association Guide

2014 EX - print Flendly edition





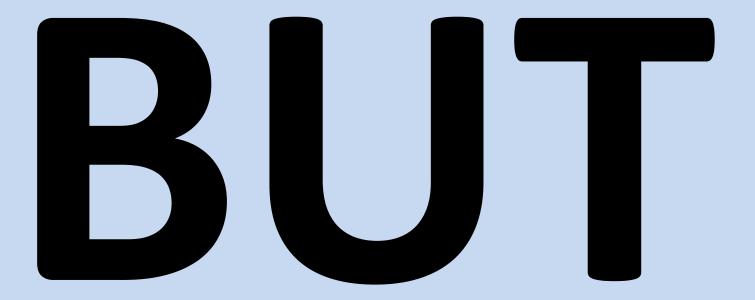




ONH =

"treatment"

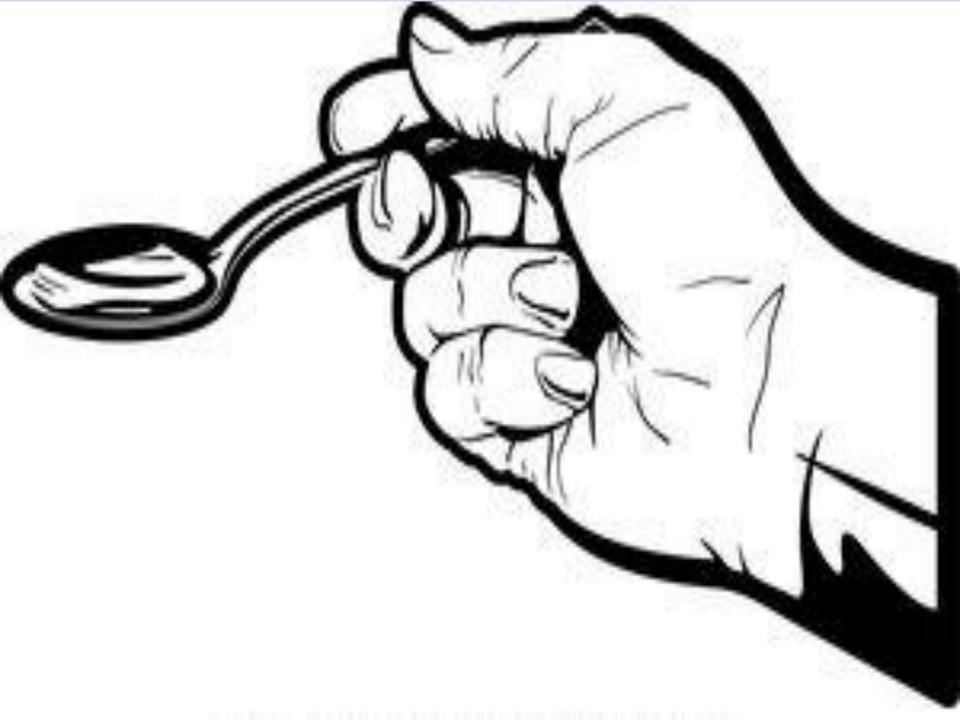
Right to VSED refuse medical



<u>Barely</u> established ANH = medical treatment

Medical b/c not "typical human"

Implies ONH is not medical



ONH ¥

"treatment"



Right to refuse medical



Right to refuse

unwanted

measures

Does not matter whether food & fluid is "medical treatment"

Right to refuse any intervention (medical or not)

Unwanted contact

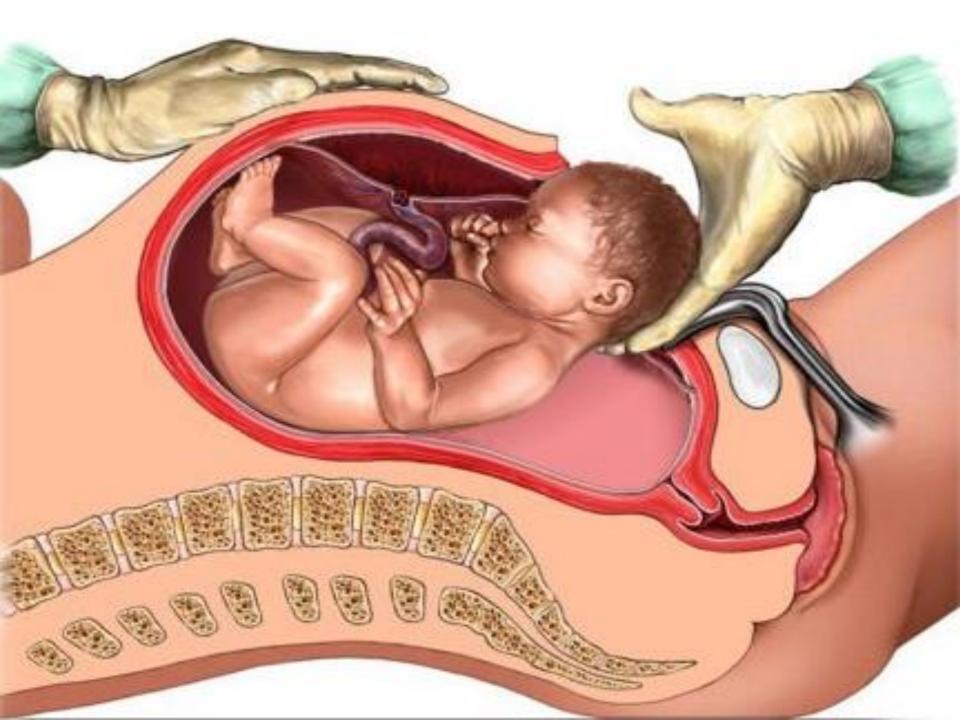
Even if clinically beneficial

Battery

Patient consented to left ear

Physician operated on right ear

Mohr v. Williams (Minn. 1905)



Force feeding is a battery



Chief Justice Rehnquist

"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



VSED is not

assisted

suicide

56 US jurisdictions

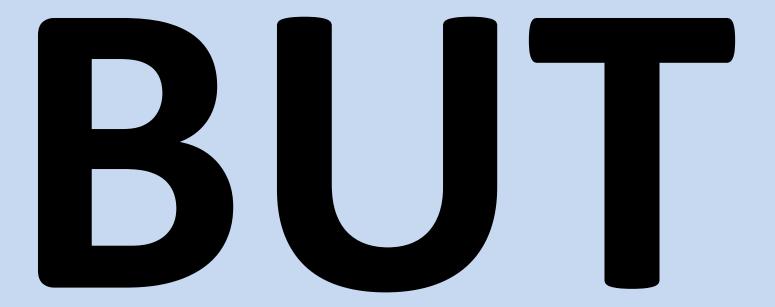
"Every person . . . aids, or

advises, or encourages

another to commit suicide,

is guilty of a **felony**."

Clinicians worry participation with VSED = assisting suicide



VSED 7



Active

Passive

AS statutes target active conduct



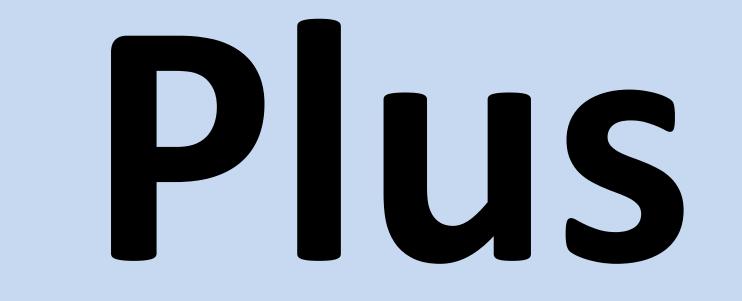




Normally:

"Providing the physical means by which the other person commits . . . suicide"

VSED entails only passive conduct



Even if otherwise within scope

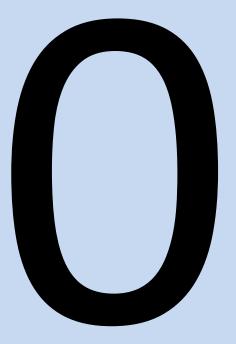
Exception

purpose of diminishing . . . pain or discomfort"

- . administering, . . .
- preclude . . . prescribing . .

"Nothing . . . prohibit or

Everything clinician does in **VSED** expressly exempted from AS statute



cases



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

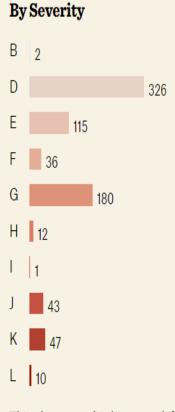
(773 Deficiencies)

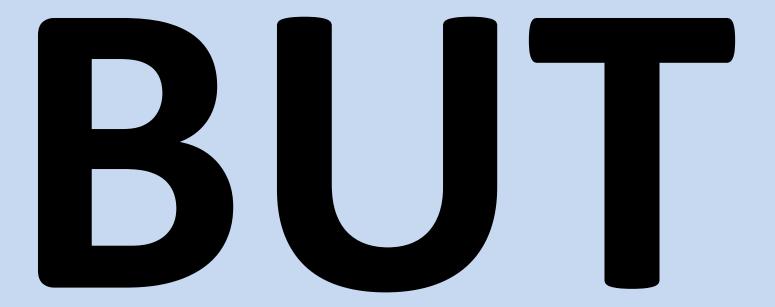
 $\leftarrow \text{Previous} \quad \textbf{1} \quad 2 \quad 3 \quad 4 \quad 5 \quad 6 \quad 7 \quad 8 \quad 9 \quad \dots \quad 15 \quad 16 \quad \text{Next} \rightarrow$

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) Home Info	The Woodlands	Tex.	2	K to L
April 28, 2015	BRIARCLIFF HEALTH CENTER (REPORT) Home Info	Tyler	Tex.	2	L
Aug. 7, 2013	KINDRED TRANSITIONAL CARE AND REHABILITATION- RIDGM (REPORT) Home Info	Fort Worth	Tex.	4	L
May 20		Mathie	Τον	3	

Deficiencies With "Dehydrate"









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

Over-treatment

just as risky as

under-treatment

Risk ~ 0









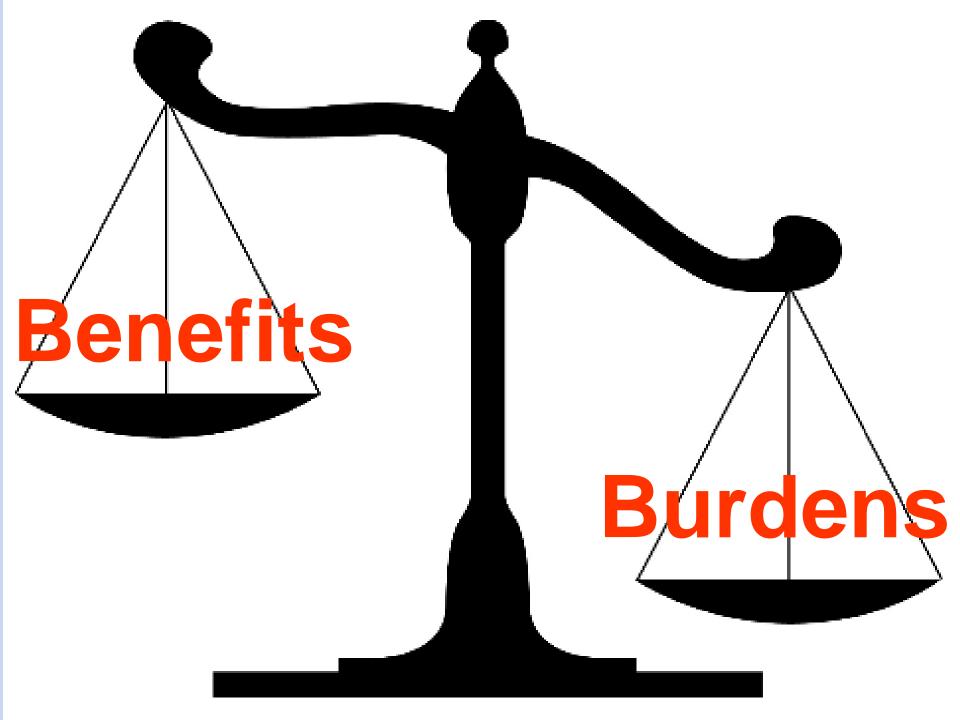
Safe Harbor[®]

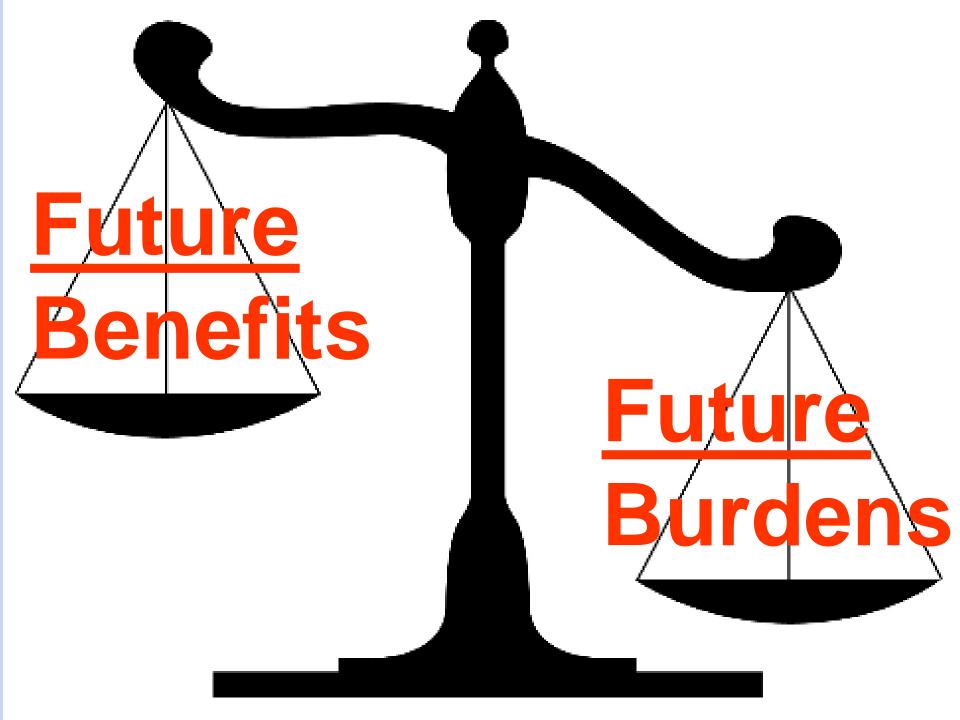
VSED now, patient with capacity

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



do it





What

is it



Complete AD, today

R1-Parent B

STREEMEN

Advance Health Care Directive



Direct VSED

in future



When reach point

that you define as intolerable



You lack capacity at that time

That is

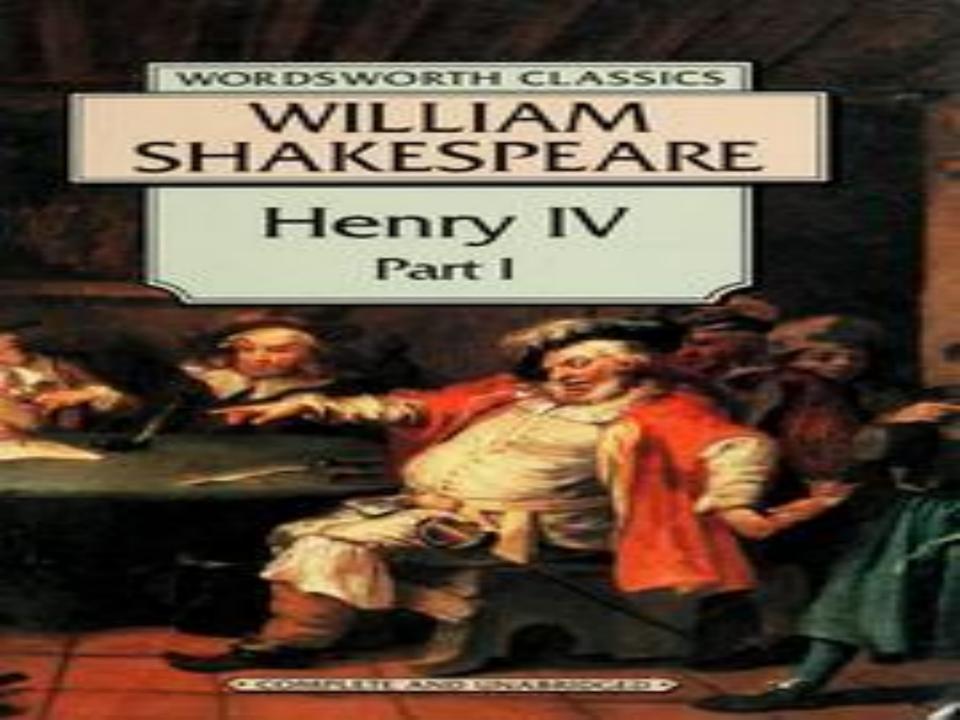
"advance

VSED"

Viable

option?

Can you leave VSED instructions in an AD?



Glendower: "I can call spirits from the vasty deep."

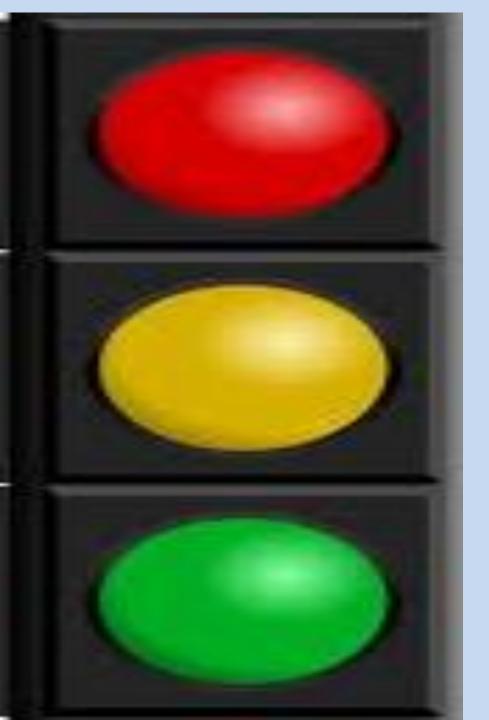
BBC

Hotspur: "Why, so can I, or so can any man; But will they come when you call for them?"

BBC

You can write anything you want in an AD

But . . . will it be honored



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 . . ."

"Providing nutrition or

hydration orally . . . is

not health care"

NY Pub Health Code 2994-a

Autonomy

Autonomy

Prospective autonomy

No green (yet)

Some red



ls advance VSED request enforceable?

2 recent

Cases





Margot Bentley

TO MY FAMILY. MY PHYSICIAN, MY LAWYER & ALL OTHERS WHOM IT MAY CONCERN

I. Marsaert A. Bentley of Million hereby declare that if the time comes when I can no longer take part in decisions for my future, I wish this statement to stand as an expression of my wishes.

IF AT SUCH A TIME THE SITUATION SHOULD ARISE THAT THERE IS NO REASONABLE EXPECTATION OF MY RECOVERY FROM EXTREME PHYSICAL OR MENTAL DISABILITY, 1 DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES".

I DO ASK THAT MEDICATION BE MERCIFULLY ADMINISTERED TO ME TO ALLEVIATE SUFFERING EVEN THOUGH THIS MAY SHORTEN MY REMAINING LIFE.

I MAKE THIS STATEMENT AFTER CAREFUL CONSIDERATION AND IS IN ACCORDANCE WITH MY CONVICTIONS AND BELIEFS.

I HEREBY ABSOLVE ALL WHO FOLLOW THESE INSTRUCTIONS TO BE FREE OF ANY LEGAL LIABILITY. IN PARTICULAR, I WOULD REQUEST THE FOLLOWING INSTRUCTIONS TO BE CARRIED OUT:

A. NO ELECTRICAL OR MECHANICAL RESUSCITATION OF MY HEART WHEN IT HAS STOPPED BEATING.

B. NO NOURISHMENT OR LIQUIDS.

NO MECHANICAL RESPIRATION WHEN I AM NO LONGER с. ABLE TO SUSTAIN MY OWN BREATHING. D. NO SURGERY.

Ε.

OTHER In the event that mental deterioration is I am unable to ecoquize the members of my as the second get I HEREBY DESIGNATE My husband John h. Blatley

OF Missimo, B.C. Canada TO SERVE AS MY PROXY FOR THE PURPOSE OF MAKING MEDICAL DECISIONS ON MY BEHALF IN THE EVENT THAT I BECOME INCOMPETENT AND UNABLE TO MAKE SUCH DECISIONS FOR MYSELF. John Blatley SHOULD BE UNABLE TO CARRY OUT MY WISHES, I HEREBY APPOINT Kathy hittles OF SPRESSION

AS AN ALTERNATE PROXY.

WITNESS WITNESS:

WOLALN & M Z ↘

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				BE KEPT Asures",
			LIQU	

Facility refuses to honor

Margot Bentley



Family loses

				BE KEPT Asures",
			LIQU	

Probably meant this

Take home

lesson

If you mean hand feeding, say "hand feeding"





Nora Harris

PART I: 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:

Me 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:

the second second

Take home

lesson

If you mean hand feeding, say "hand feeding"

Would better ADs have helped MB or NH?

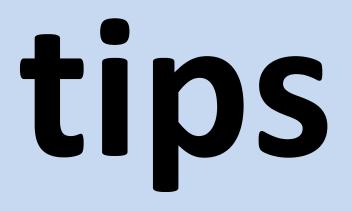
The New Hork Times | http://nyti.ms/1ujCDEh

HEALTH | THE NEW OLD AGE

Complexities of Choosing an End Game for Dementia

By PAULA SPAN JAN. 19, 2015

Practical



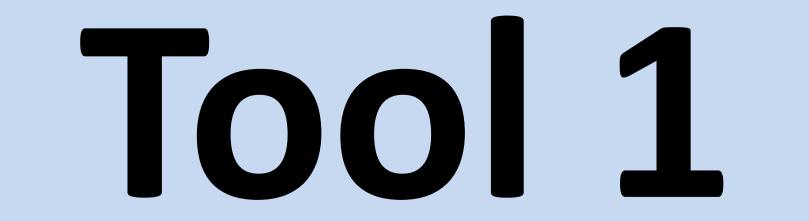
Evidence

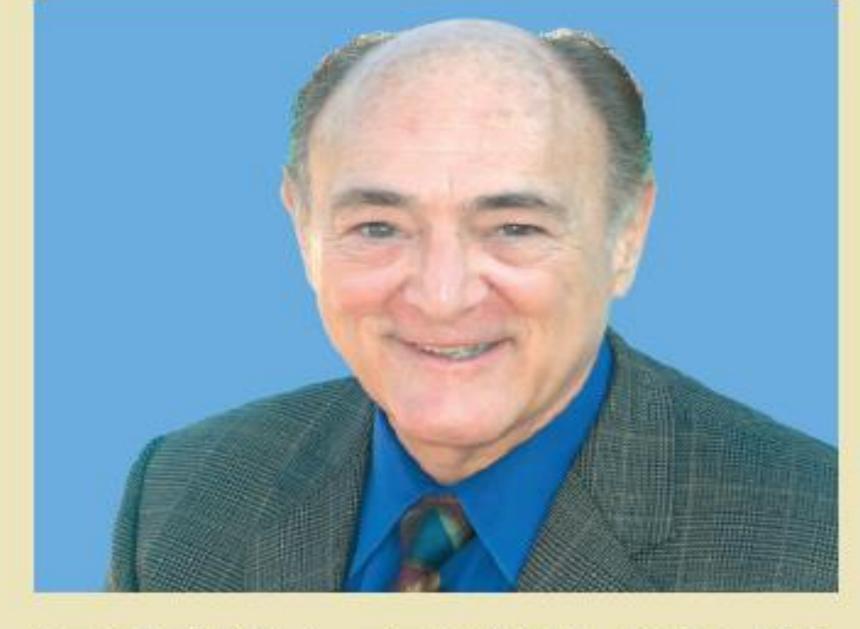
Unusual



Be very specific on the when

Be very specific on the what





STANLEY A. TERMAN, PhD, MD

for Natural DyingTM

Harias

MITA VENT

Sort them now to obtain your personal NATURAL DYING—LIVING WILL

...to let others know EXACTLY what you will want, if the time comes when you are too sick to speak for yourself.

© 2009-2011 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]



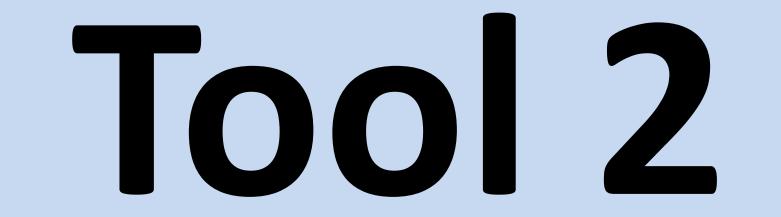
I cannot remember the important events of my life. If reminded, I don't know why they are important. [1.2]



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]

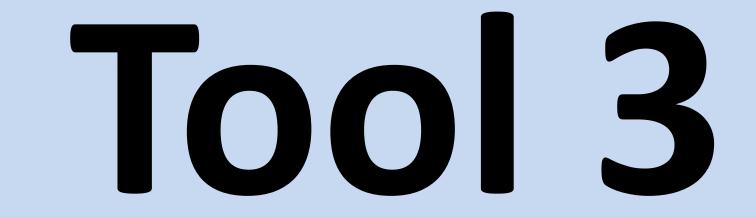


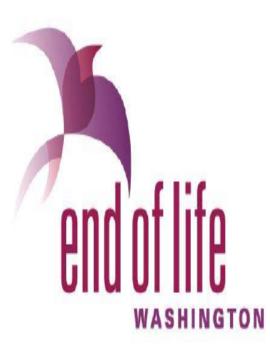


End of Life Choices NEW YORK

Advance Directive for **Receiving Oral** Food and Fluids in Dementia

Clear definitions and prompts





Your life. Your death. Your choice.

MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING

Few other

tools

Voluntarily Stopping Eating and Drinking



Conclusion

VSED is important EOL option

Need more education & planning tools

- Thaddeus Mason Pope, JD, PhD
- Director, Health Law Institute
- Mitchell Hamline School of Law
- 875 Summit Avenue
- Saint Paul, Minnesota 55105
- **T** 651-695-7661
- **C** 310-270-3618
- E Thaddeus.Pope@mitchellhamline.edu
- W www.thaddeuspope.com
- B medicalfutility.blogspot.com